



# STRENGTHENING EVIDENCE-BASED HIV HEALTH CARE

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Lessons for Advocacy Movements and Funders

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*The*  
**A T L A N T I C**  
*Philanthropies*

ADVOCACY AND ACTION FOR SUSTAINABLE SOCIAL CHANGE AND HEALTH EQUITY

# EXECUTIVE SUMMARY



**The Southern African HIV Clinicians Society (SAHIVCS) has played a significant role in the history of the HIV/AIDS epidemic in South Africa.** In its first decade, it grew into a substantial organisation with an important voice in the fight against AIDS in South Africa – providing expert, knowledge-based information at a time when this was seriously needed.

**South Africa has more people living with HIV than any other country in the world,** with an estimated 6.8 million HIV-infected individuals in 2014, equivalent to 18 percent of the global HIV burden. But HIV/AIDS has been politicised in South Africa and marred by ongoing controversy over the past two decades, notably AIDS denialism and official mistrust of antiretrovirals (ARVs).

**The Society was conceptualised in 1997** at a meeting of southern African clinicians in Geneva, to bring together clinicians in the field of HIV/AIDS so that it could act as a centre of expertise for the purposes of disseminating such expertise to those practising in the field. In the context of AIDS denialism, ineptitude of health leadership and delays in implementing life-saving policy, these clinical experts identified the need to develop a structure to coordinate the response to the HIV/AIDS epidemic in southern Africa and to provide relevant and up-to-date information and guidelines.

**The Society is strategically positioned to provide support with its extensive membership and reputation as a source of best-practice information.** South Africa has the largest antiretroviral treatment (ART) programme in the world, and whilst good progress has been made with regard to the development of public policy, implementation has been inconsistent and fragmented, and the number of professionals trained has not kept pace with the growing burden of disease. The Department of Health (DoH) faces significant challenges in ensuring that HIV programmes and policies are implemented in terms of the national strategic plan (NSP) goals. Health-care workers (HCWs) require significant professional training and capacity building in the adoption of new treatment guidelines.

**The Society's vision is to promote the highest-quality, cost-effective standard of health care for all persons in southern Africa infected and affected by HIV.** For almost two decades, the Society has sought to educate and empower clinicians working in the treatment and management of HIV/AIDS, especially those in the government rollout sites, through training, by offering postgraduate courses in HIV clinical management, hosting Continuing Medical Education (CME) meetings, and providing resources and bursaries to sponsor HIV clinicians to attend conferences.

**Society members are respected and influential HIV clinicians, key opinion leaders and policymakers within southern Africa.** They are routinely called upon to give advice and guidance by civil society and corporate organisations, government, and the media. At times, they have operated in difficult circumstances, often with significant opposition from government.

Over nearly two decades the Southern African HIV Clinicians Society has risen to the challenge of dealing with 6.8 million infected people, 18% of the total global HIV burden

The Society's role has been to support clinicians in managing the world's largest ART programme, overcoming many system challenges

The Society's vision is to promote the highest-quality, cost-effective standard of health care for all in southern Africa infected with HIV

Society members are respected, influential HIV clinicians, key opinion leaders and policymakers throughout southern Africa

**The Society enjoys strong relationships with partner organisations** and maintains mutually beneficial relationships with pharmaceutical companies, government, and non-governmental organisations (NGOs), as well as several private-sector organisations committed to Corporate Social Investment programmes. The Society carries out a co-coordinating and networking role with other key South African and Southern African Development Community (SADC) players in the field of HIV, and has strengthened relationships with other countries' clinicians' societies, including Zimbabwe, Botswana, and Namibia.

**The Society has made significant contributions to, and supported the widespread adoption of, HIV best-practice through a variety of activities**, including CME meetings; development of best-practice guidelines on specific aspects of HIV treatment and care; online discussion groups; and a scholarship programme for doctors and nurses. The Society has been instrumental in developing curriculum and accreditation procedures for a College of Medicine Diploma in HIV Management.

**The Society has been a voice of advocacy** for rural doctors under political pressure in South Africa, on a regional level has advocated human rights, has taken a stand against the proposed Ugandan laws affecting homosexuals, and has assisted victims of xenophobic attacks in South Africa to continue receiving ARVs.

**The Society monitors and informs** the development and implementation of national HIV policy, and advocates for policies that support the highest standard of health care. The Society's Treatment Guidelines have served as powerful advocacy tools, supporting HCWs and advocating for patients.

**The Society works in informal and formal partnerships such as the Stop Stockouts Project (SSP),<sup>1</sup>** supporting health workers, communities, government and other organisations to provide 'rapid advice' to nurse and doctor clinicians on how to manage patients in the event of stockouts. Drug stockouts have been identified as a particularly serious issue, with life-threatening consequences for people living with HIV. Inconsistent access to ARVs seriously compromises HIV and tuberculosis management. The chronic and ongoing nature of the problem, along with limited organisational resources, led the Society and the Rural Health Advocacy Project to join forces with the Treatment Action Campaign, SECTION27, Médecins Sans Frontières, and the Rural Doctors Association of South Africa to create the SSP.

**Society membership provides intangible benefits**, such as belonging to the 'brains trust' of HIV treatment and policy development in southern Africa; a strong civil society network that gives members a voice within HIV health care in the region; and a collegial network where advice and support regarding day-to-day patient care, clinical management, and HIV research are easily accessible.

<sup>1</sup> Medicine stockouts are defined as the absence of specified medication in the storage area of the health facility

The Society has consolidated its focus on adopting best HIV practice including CME, establishing clinical guidelines, providing online forums, scholarships, and course accreditation

The Society has served as a powerful human rights advocate for rural doctors and has monitored, evaluated and informed on national standards and participated in innovation

The Society has worked in partnership with advocacy groups and other organisations, in particular on the Stop Stockouts Project. It provides rapid advice to doctors and nurses dealing with the critical issue of drug stockouts

**The Society will continue to grow through the further development of branch structures**, particularly in rural areas to fill the huge vacuum of information in these areas. By marketing itself more aggressively and becoming a stronger player in the region, the Society can provide a blueprint for other countries to roll out their programmes. A huge repository of HIV knowledge and expertise lies within the Society and can be exported to other areas in the region and beyond Africa.

**The biennial Society Conference was born out of a response to members' need** for a conference with a clinical HIV focus. These conferences have become a forum to achieve everything the Society set out to do. They are hugely successful, marked by strong attendance, high-quality presentations, and terrific feedback from delegates, and are distinguished from other conferences as they focus on clinical content with skill-building sessions.

**The mainstay of the Society's activities is information/knowledge-provision** – both in terms of communicating with members and with the wider society. The Society strives to maintain a dialogue with its members via the most convenient channels: website, direct mailers, social media and text messages.

**The Society's publications** – *Southern African Journal of HIV Medicine (SAJHIVMED)*, *Transcript* and *HIV Nursing Matters* – reach thousands of HCWs every month. These publications inform on training courses, symposia, conferences, monthly branch meetings, current ARV prices, and clinical guidelines.

**SAJHIVMED is one of the most sought-after medical journals in the country** and is free online. It is distributed for free to Society members, pharmaceutical companies, academic institutions, public and private-sector organisations, national and provincial DoHs, all government ART rollout sites, public libraries, academic institutions and NGOs. The *SAJHIVMED* is distributed throughout Africa and is often the only source of up-to-date information that gets to rural areas.

**Clinical Tips are short, clinical text messages** sent to approximately 1,800 Society nurse members weekly, focusing on ART guidelines, appropriate ARVs and eligibility, side effects, prevention of mother-to-child transmission and HIV/TB treatment. The website remains the Society's most valuable marketing tool, where all the Society publications are posted. The Society has had several web-based topical discussion interest groups where specialists come together and give their input on a particular subject or case study. The Society also has a significant Facebook and Twitter following.

**Atlantic Philanthropies funding commenced in 2006, and Atlantic was the first significant donor of the Society.** This financial support enabled the Society to gain administrative and organisational capacity, secure office space, professionalise the organisation, expand its IT and website capacity, and significantly expand its programmatic activities in accordance with its objectives. These included expanding its continuing professional development-accredited branch meetings, issuing and distributing the Society's publications, the *SAJHIVMED*, *Transcript* and *HIV Nursing Matters*; developing HIV clinical management Guidelines; and financing Society conferences, including a skills-building programme and bursaries for Society members. Atlantic's requirement of matched funding has attracted additional donors, especially the pharmaceutical industry, and has facilitated the Society's efforts to draw

Society membership provides a host of intangible, but valuable, benefits

The Society will continue to grow through mechanisms such as establishment of branches, provision of a knowledge repository and hosting conferences

Biennial Society conferences provide a forum distinguishable by their focus on clinical content and skill-building

Through its publications the Society reaches thousands of HCWs every month

SMS Clinical Tips reaches 1800 Society nurse members weekly

the government into the consultation process. In 2010 Atlantic provided the Society with the impetus to conduct an external evaluation.

**The Society has undergone considerable organisational growth and development**, and addressed issues of governance, capacity and structure. It is registered as a non-profit company, with a fiscal committee dedicated to spending donor funds according to budget. The organisation has been professionalised, its capacity increased, and governance strengthened. The Society has moved from the pioneering phase into the consolidation phase, where impact and sustainability are currently areas of focus. The Society faces a challenge to secure donor funding and income from other sources due to the global economic slowdown as well as the downturn in the South African economy. The Society will not be able to achieve its intended outcomes if it is not able to secure funding. The Society's financial sustainability is critical to maintain and grow the organisation.

Atlantic  
Philanthropies  
funding enabled  
organisational  
development of the  
Society

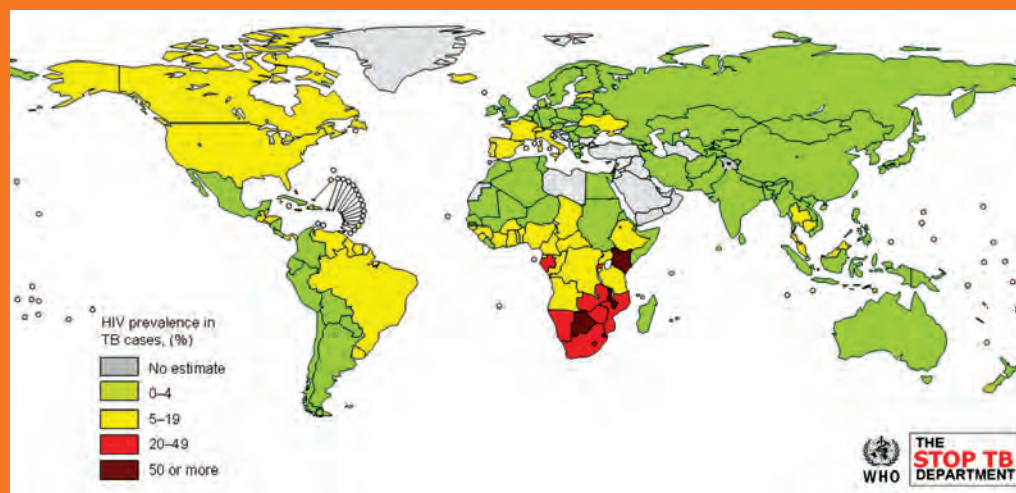
A matched funding  
approach attracted  
additional donors

### The complex clinical struggle that faced the SA HIV Clinicians Society at the time Atlantic Philanthropies commenced its funding in 2007, and which continues.

Figure 1: Illustrative HIV and AIDS data from South Africa, 2013




Figure 2: Estimated HIV prevalence in new TB cases, 2006





## ACKNOWLEDGEMENTS



I have been privileged to be a part of documenting the story of the Southern African HIV Clinicians Society. The Society's journey is a testimony to the efforts of the small staff complement and visionary board members who have left a legacy far beyond their size. I would like to acknowledge the staff and board members who so generously gave their time for interviews and assisted with data collection. In particular, Lauren Jankelowitz and Michelle Robinson were exceedingly helpful in making reports available, securing the time of board members for meetings and answering my endless questions. I would like to acknowledge Irwin Friedman for his tireless support and energy for this project and Zola Madikizela and Gail Birkbeck for involving me in this important endeavour. Thank you also to Louise Torr for her editorial support and meticulous attention to detail. Finally, this process has enabled me to reflect on the role of funders in supporting advocacy organisations, and my sincere appreciation is extended to The Atlantic Philanthropies for having the foresight and vision to invest in people and organisations in South Africa with such remarkable impact.

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July 2016

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## ACRONYMS AND ABBREVIATIONS

AHP	African Health Placements
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral treatment
ARVs	Antiretrovirals
AWACC	Annual Workshop in Advanced Clinical Care
BOD	Board of directors
CDC	U.S. Centers for Disease Control
CEO	Chief executive officer
CME	Continuing medical education
CPD	Continuing professional development
DDG	Deputy-director general
DoH	Department of Health
EDL	Essential Drugs List
FAQ	Frequently asked question
FDA	U.S. Food and Drug Administration
FDC	Fixed dose combination
FIDSSA	Federation for Infectious Diseases South Africa
FPD	Foundation for Professional Development
GP	General practitioner
HCWs	Health-care workers
HIV	Human immunodeficiency virus
HIVDR	HIV drug resistance
IAS	International AIDS Society
MCC	Medicines Control Council
MEC	Member of the executive committee
MOI	Memorandum of incorporation
MOU	Memorandum of understanding
MSF	Médecins Sans Frontières
MSH	Management Sciences for Health
MTN	Mobile Telephone Network (South African cellular service provider)
NGO	Non-governmental organisation
NHLS	National Health Laboratory Services
NIMART	Nurse initiated management of antiretroviral treatment
NPC	Non-profit company
NSP	National strategic plan

PDG	Paediatric discussion group
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-exposure prophylaxis
RHAP	Rural Health Advocacy Project
RuDASA	Rural Doctors Association of South Africa
SA	South Africa
SADC	Southern African Development Community
SAHIVCS	Southern African HIV Clinicians Society
SAJHIVMED	Southern African Journal of HIV Medicine
SAJM	South African Journal of Medicine
SAMA	South African Medical Association
SAMEA	South African Monitoring and Evaluation Association
SANAC	South African National AIDS Council
SANDF	South Africa National Defence Force
SEAD	Strategic Evaluation, Advising and Development Consulting
SSP	Stop Stockouts Project
TB	Tuberculosis
TAC	Treatment Action Campaign
UNHCR	United Nations High Commission for Refugees
WHO	World Health Organization



## INTRODUCTION

Since its inception in 2004-05, The Atlantic Philanthropies' Population Health Programme in South Africa has awarded more than 100 grants, totalling more than ZAR 1 billion, with a collective goal of improving access to quality health care for all and to reducing health inequities across South Africa.

As Atlantic exits the funding stage, the focus of attention has moved to evaluation, with a commitment to capture the learnings through a variety of means, including high-level evaluations, individual reviews, case studies, and targeted assessments of individual grantees, all with a view to locating outputs of long-term value to the field.

## PURPOSE OF THE REPORT

As part of its commitment to giving voice to the underprivileged and marginalised, Atlantic funded key advocacy, primary health care, and human resources programmes within the Population Health Programme. One of the beneficiaries was the Southern African HIV Clinicians Society (hereinafter referred to as 'the Society'), funded from 2009 to 2014.

Atlantic has commissioned a series of individual case studies aimed to showcase the impact of grants to its beneficiaries. The Society case study sought to address the following major questions:

1. Was the Society's strategic approach, as funded by Atlantic, appropriate and effective?
2. What can be learned from this strategic approach and programme achievements?
3. What is the likelihood of the Society's sustainability beyond Atlantic funding?
4. What challenges, barriers, and opportunities are there in making further progress?

## METHODOLOGY

This case study was developed using a mixed-method approach drawing from theoretical frameworks including outcomes harvesting. A range of methods was employed including document review, observation, questionnaires, secondary quantitative data analysis, focus group discussions, and key informant interviews.

1. Document review of available materials related to the Atlantic grants and the Society's activities and achievements;
2. Administering a questionnaire to the Society's senior leadership to ascertain information on operations, structure, finances, capacity building, advocacy activities, key successes, challenges, and opportunities;
3. Secondary quantitative analysis of data that had been collected by the organisation to demonstrate outcomes;
4. Key informant interviews from senior managers, board members, and staff of the organisation; and
5. Focus group discussions with senior leaders of the organisation.

Data from document reviews and interviews were analysed and key information extracted on objectives, implementation experience, challenges, and success factors.

Key lessons from the case study were presented at the following conferences in 2015:

- Public Health Association of South Africa: panel discussion '**Advocacy to strengthen health systems**'.
- South African Monitoring and Evaluation Association: panel discussion '**Lessons learnt by civil society and government from citizen-based monitoring of medicine stockouts**'.

The material was also used to prepare a publication for a journal targeting lessons for funders:

- *The Foundation Review*, '**Enhancing funders' and advocates' effectiveness: the processes shaping collaborative advocacy for health system accountability in South Africa**'.

The material may be adapted for other journal publications, opinion pieces, advocacy briefs, etc. It is also intended that the recipients of Atlantic grants will be brought together in thematic groupings to explore learnings from their common experience that can shape further advocacy work. This will be facilitated by the case study researchers.

# THE STORY OF THE SOCIETY

## THE HIV LANDSCAPE

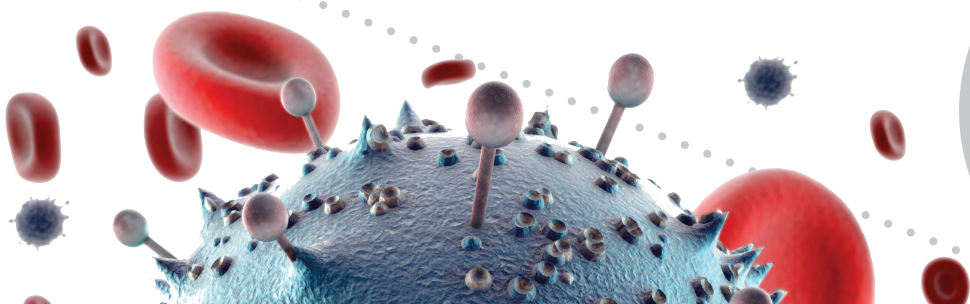
South Africa has more people living with HIV than any other country, with an estimated 6.8 million HIV-infected individuals in 2014, equivalent to 18 percent of the global HIV burden. The 2012 antenatal sentinel survey demonstrated an overall antenatal prevalence of 29.5 percent among women 15 to 49 years of age. Although it appears that the HIV epidemic curve in the antenatal population has plateaued, with no increase over the last seven years, it has stabilised at a high prevalence level, creating great demand for care and treatment.

HIV/AIDS has been largely politicised in South Africa and, as a result, has been marred by ongoing controversy over the past two decades. The previous health minister, Manto Tshabalala-Msimang, in particular, came under international criticism for her vocal mistrust of antiretrovirals and her support of nutrition as sole therapy.

The Treatment Action Campaign (TAC) was crucial in providing a civil society response, standing up and challenging 'quackery' and fighting for the right to access to ARVs. In 2001 the Pretoria High Court ordered the government to provide Nevirapine to all pregnant women for prevention of mother-to-child transmission (PMTCT). In 2002 the Constitutional Court denied the government appeal. In 2003 Cabinet committed to creating a comprehensive treatment plan. These court and parliamentary actions were followed by the development and adoption of the National Treatment Plan 2007-2011, the 2008 PMTCT Policy, and the update of guidelines in 2009. The latest antiretroviral treatment (ART) guidelines of 2016 allow for early initiation of ART irrespective of CD4 count or World Health Organization (WHO) staging.

South Africa has the largest ART programme in the world, and it is expected to rapidly expand in the coming years as the government has introduced more aggressive ART guidelines and promotes provider-initiated HIV counselling and testing. The 2015 UNAIDS report indicated that a cumulative total of more than 3.2 million people had been initiated on the treatment. While significant, the coverage still falls short of the total number of people eligible to receive treatment. In 2013, an estimated 82 percent of adults and 63 percent of children who were eligible were on treatment.

Whilst good progress has been made with regard to the development of public policy, implementation has been inconsistent and fragmented. Fewer doctors and nurses are available in the public sector presently than in the mid-1990s. The number of professionals trained has not kept pace with population growth, the growing burden of disease, or attrition. It is generally recognised that civil society and government need to work together to achieve the national strategic plan (NSP) targets. HIV prevention, diagnosis, care, treatment, and support services should be accessible to all people in South Africa, and the global and national NSP target of 90 percent HIV treatment coverage will not be reached if strategic and innovative approaches to delivering HIV primary care service are not considered.



**South Africa has more people living with HIV than any other country in the world, with an estimated 6.8 million HIV-infected individuals in 2014, equivalent to 18% of the global HIV burden**



## ORIGINS OF THE CLINICIANS SOCIETY

In the context of AIDS denialism, ineptitude of health leadership, and delays in implementing life-saving policy, clinical experts in South Africa identified the need to develop a structure to coordinate the response to the HIV/AIDS epidemic and to provide relevant and up-to-date information and guidelines.

*In the late 1990s Des Martin and a group of private doctors were starting to see HIV-positive patients. At the time, there were no guidelines and there was no treatment available, but they were hearing about treatment. ... They started attending overseas conferences such as the International AIDS Society to access information to bring back. They contributed to early clinical studies, linking with pharma to access medicines. (Society CEO)*

The Society was conceptualised in 1997 at a meeting of southern African clinicians in Geneva, to bring together clinicians in the country in the field of HIV/AIDS so that it could act as a source and centre of expertise for the purposes of disseminating such expertise to all those practising in the field. The Society aimed to promote the highest standard of health care for people living with HIV in southern Africa and to provide support and guidance to health-care practitioners in the field of HIV, providing knowledge-based leadership to clinicians at a time when the government institutions were not doing so.

The Society's vision was to ***promote the highest quality, cost-effective standard of health care for all persons in southern Africa infected and affected by HIV***. For almost two decades, the Society has sought to develop the capacity of health-care workers (HCWs) and unite the profession through a coordinated, scientific response to the HIV epidemic.

At its inception, the Society received minimal seed funding from a pharmaceutical company to set up its structure. The Society was established as an affiliate of the South African Medical Association (SAMA), run by an elected president and executive committee. It was constituted as a Clinicians Society (and not a broad stakeholder group) and was registered in 1998 as a Section 21 company.

Upon being formally constituted, the Society had 250 members, representing some of the most respected and influential HIV clinicians, academics, and policymakers in the region. The Society's membership experienced a noteworthy growth to a peak of just under 14,000 members by 2008. The Society was considered the largest HIV interest group in the world. The member database showed more than 90 different specialisations represented in the Society membership. In addition, while membership is predominantly South African, there are Society members from 45 countries, mostly in the southern African region but also members from other African countries and indeed beyond Africa.

The organisation was first located in a back office at Toga laboratories in Johannesburg, Gauteng Province (a private laboratory dedicated to HIV/AIDS monitoring and support activities) as the Toga leadership was instrumental in setting up the Society. The relocation of the Society's offices in August 2007, to be based in the same premises as Soul City and the Rural Doctors Association of South Africa (RuDASA), enabled the Society to establish improved links and working relationships, including joint initiatives and projects with other organisations working in the field of HIV. In March 2013, it again relocated to its present offices in Norwood.

The Society faced many challenges as a fledgling membership-based organisation.

*I contributed to developing guidelines, but was at the time not on the board or any structures. I got elected as president and inherited a structure I knew nothing about; I never worked on a board ... none of us had grant-writing skills. The Society was putting out its journal to huge numbers, on paper was a huge organisation with a large membership*

*The Society's vision is to promote the highest-quality, cost-effective standard of health care for all persons in southern Africa infected and affected by HIV*

*database ... but was barely making salaries. Funding came from membership fees and advertising, while drug companies sponsored meetings, which were well attended by 80 to 100 people. ... The turning point was running into Zola [Madikizela] — it sounded like Atlantic had money. The first thing I did when I arrived was write the Atlantic grant proposal for core funding of organisational processes and to fund specifically the Society's journal and guidelines. (Past President)*

## FUNDERS

The Society derived income from the following sources:

- Development grants;
- Membership fees;
- Journal income/advertising;
- Sponsorships;
- Conference sponsorships;
- Advertising;
- Foundation for Professional Development (FPD) collaboration; and
- Branch meetings sponsorships.

Early sponsors included pharmaceutical companies such as Abbvie, Activo, Aspen Pharmacare, Cipla Medpro, MSD, Mylan, and Sanofi. In 2006, the Society received its first grant from Atlantic totalling ZAR 9.4 million. Its purpose was to strengthen the institutional capacity of the Society to support the public sector Comprehensive HIV/AIDS policy rollout by developing guidelines and advocating for best care of HIV patients. Atlantic's funding was reported to constitute approximately 65% of the total income received by the Society from 2006 - 2008. Atlantic's second grant of ZAR 9 million in 2011 was intended to enable the Society to provide support to health workers and the DoH in their effort to achieve the NSP goals. The focus was on public policy and advocacy and professional development of health workers through training and information dissemination. Atlantic's funding was reported to constitute approximately 30% of the total income received by the Society from 2011 - 2013.

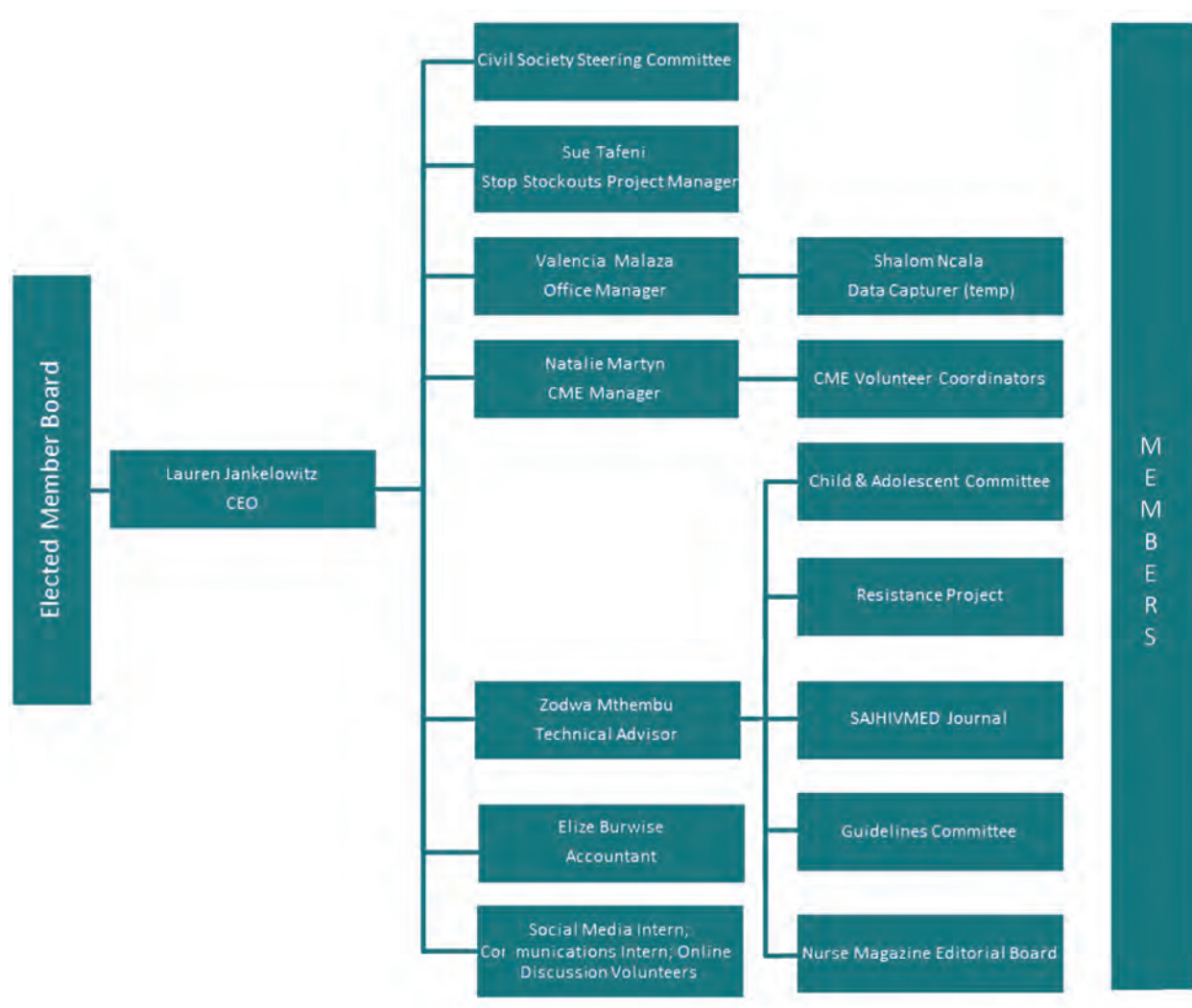
Table 1: Description of Society funders, 1997-2015

Funder	Year	Purpose
Pharmaceutical companies	1997	Seed grant
Foundation for Professional Development (FPD)	2010	Training partnership, Society provides scientific expertise on FPD's HIV courses and in return FPD sponsors a free year of Society membership to HIV course attendees
Atlantic grant 1	2006-2009	Core funding, journal, guidelines
Pharmaceutical companies	2009	Support 65 CPD-accredited branch meetings across South Africa
Pharmaceutical companies	2009	Advertising to support the publication of the SAJHIVMED
Sainsbury Family Charitable Trust Momentum Trust	2009 2010 2013	Support publication and dissemination of the Society's magazine for nurses working in HIV; contributes to the Society's CPD-accredited branch meetings, the SAJHIVMED, Transcript
MTN Foundation	2009-2011	Partially support skills-building workshops at AIDS Conferences
Atlantic grant 2	2011-2014	Public policy and advocacy; professional development of health workers through training and information dissemination
AIDS Funds	2013	Develop an HIV drug resistance (HIVDR) prevention and management educational programme

## STAFFING AND GOVERNANCE

The Society has maintained a lean organisational structure, employing at various times a manager who coordinated the work of technical staff working on the journal and a small complement of administrative and support staff. In addition, the Society has benefited from the contribution of a number of interns over the years.

Figure 3: Clinicians Society organogram



There was no formal oversight committee at its inception, and the Society relied on a group of respected HIV clinicians who served as an executive committee on a voluntary basis. When the Society put measures in place to professionalise the organisation and established a registered non-profit company, a board of directors was appointed. The board serves the role of providing oversight and strategic direction to the Society. Since its inception, the Society has benefited from having leading HIV clinicians on the board. The following individuals currently serve as board members: Dr Francesca Conradie (president), Dr Natasha Davies, Dr Ashraf Grimwood, Dr Moeketsi Tsepo Mathe, Dr Michelle Moorhouse, Prof Yunus Moosa, Dr Tim Tucker, and Prof Francois Venter.

# PRIORITIES AND OUTCOMES

In 2015, following a strategic planning process, the Society updated and refined its mission, objectives and values.

## MISSION

The Society's Mission is to:

- Strengthen and support quality comprehensive, evidence-based HIV health care in southern Africa

## OBJECTIVES

The Society's Objectives are to:

- Partner with governments, private sector, and civil society to implement optimal HIV programmes and policies;
- Foster evidence-based HIV-related education for health-care workers (HCWs);
- Produce evidence-based guidelines;
- Facilitate interactions amongst HIV HCWs to optimise patient care;
- Expand access to Society activities including HCWs without HIV management experience or those within less-resourced regions;
- Advocate for the best possible HIV treatment, care, and prevention;
- Empower and encourage members to promote Society values and objectives; and
- Improve TB diagnosis, care, and prevention within the context of the HIV epidemic.

## VALUES

- Guardianship: We strive for clinical excellence through promoting respect for humanity, equality, ethical, and evidence-based practice.
- Responsibility: We seek to enhance the credibility of southern African health care by adhering to the principles of good governance, accountability, and transparency.
- Selflessness and co-operation: We aim to enhance health-care access and build health-care providers' capacity by establishing supportive, inclusive, and empathetic relationships within the health-care community.
- Pioneering work and self-empowerment: Through mutual empowerment, independent, and courageous advocacy — and the pioneering of new discoveries — the Society endeavours to do great things to advance quality HIV/TB care in southern Africa.

## EVOLUTION OF THE SOCIETY'S PRIORITIES AND PLANNED OUTCOMES

At inception in 1997, the Society aimed to strengthen the capacity of HCWs to provide HIV prevention, care, and treatment services, and to support the implementation of South Africa's national strategic plan (NSP) for HIV/AIDS and sexually transmitted infections. This involved:

1. Development of appropriate local HIV guidelines using local experts;
2. Direct support to hospital and clinics through the distribution of expert educational materials;
3. Support of clinical best-practice and advocacy for best care amongst key influence groups;
4. Increasing access to appropriate local information on HIV/AIDS to HCWs;
5. Increasing support to rural sites; and
6. Improving sustainability of the Society to ensure that this support can continue to strengthen public-sector responses to the HIV epidemic.

In 2006, the Society described its intended short-term (18-month) outcomes as follows:

1. Construction of guidelines relating to critical topics that will positively influence HIV care in the public sector;
2. Identification and framing of discussion documents on key HIV issues facing the country;
3. Expansion of distribution of the *SAJHIVMED* and the newsletter *Transcript* within the public sector to disseminate more broadly emerging trends and evidence-based approaches in HIV care;
4. Expansion of the number of Society branches to support those seeking to improve and deliver quality HIV care; and
5. Strengthening key relationships with the Department of Health and civil society to gain acceptance for appropriate HIV care initiatives.

The long-term outcomes included:

1. A strong, evidence-based HIV programme run by well-trained HCWs;
2. High standards of HIV health care throughout the private and public sectors;
3. A deeper respect for, and understanding by HCWs of, the ethics and human rights issues pertaining to HIV; and
4. A Society that has expanded influence, sustainability, and independence, and that plays an active role in strengthening civil society.

In 2008, the Society described its short-term (18-month) intended outcomes as follows:

- Updated HIV/AIDS treatment policy guidelines and protocols for children, drug users, and sex workers;
- Provision of clinical and moral support to health professionals, especially those in the government's ARV roll-out sites; and
- A stable and appropriately staffed Society that provides leadership on HIV/AIDS issues in the country.

The medium-term (three-year) intended outcomes were:

- A system to facilitate collaboration between private and public-sector health professionals involved in the ARV roll-out programme;
- Documentation of best-practice models for providing ARVs to a huge population in resource-constrained areas and under a weak health system; and
- A sustainable, independent Society that enjoys high international regard.

By 2011, the Society had consolidated its programme into three core components: education, links to training programmes, and information dissemination; public policy and advocacy; and information management systems. The specific project objectives included:

1. **Education, links to training programmes, and information dissemination** to:
  - Increase HCWs' knowledge and understanding of the best possible HIV care and treatment through the use of quality, critical and peer-reviewed materials;
  - Build the capacity of HIV HCWs to manage HIV and TB by providing professional development activities; and
  - Provide resources, technical support, and accessible referral networks to the public, HCWs, and other service providers in the field of HIV.
2. **Public policy and advocacy** to:
  - Inform the development of national HIV/TB public policy and monitor its implementation;
  - Advocate for public policies that will support the highest standard of health care for all people living with HIV; and
  - Stimulate debate within the HIV medical community on topical issues relating to HIV.
3. **Information management systems** to strengthen the Society's systems used to disseminate and communicate valuable resources and information

In response to the growing concern of HIV and TB co-infection, in 2012 the Society added to its objectives: improve TB diagnosis, care, and prevention within the context of the HIV epidemic.



## PROGRESS AND ACHIEVEMENTS

### EDUCATION, LINKS TO TRAINING PROGRAMMES, AND INFORMATION DISSEMINATION

The Society's objectives focused on education, links to training programmes, and information dissemination were aimed to:

- Increase HCWs' knowledge and understanding of the best possible HIV care and treatment through the use of quality, critical, and peer-reviewed materials;
- Build the capacity of HIV HCWs to manage HIV and TB by providing professional development activities; and
- Provide resources, technical support, and accessible referral networks to the public, HCWs, and other service providers in the field of HIV.

One of the critical functions and objectives of the Society has always been to educate and empower clinicians working in the treatment and management of HIV/AIDS. Support is provided to health-care professionals, especially those in the government ARV roll-out sites through training, offering postgraduate courses in HIV clinical management, hosting continuing medical education (CME) meetings at branch level, provision of its publications, distribution of posters, etc. Resources and bursaries are also provided by the Society to allow the sponsorship of HIV clinicians to attend conferences and relevant courses.

The Society is a continuing professional development (CPD) accreditor for all its initiatives. Membership of the Society provides members with CPD points for participating in Society activities, including:

- Attendance and speaking at Branch meetings, conferences and HIV CME meetings;
- Submission of completed journal questionnaires; and
- Authorship and co-authorship of articles published in the Society's journal, the *SAJHIVMED*.

**A critical function of the Society is to educate and empower clinicians working in the treatment and management of HIV/AIDS**

### Branch CME meetings

During the Atlantic grant period, the Society has had 19 active branches in South Africa, including Bloemfontein, Bo-Karoo, Cape Town, Durban, East London, Johannesburg, Lichtenburg, Mafikeng, Nelspruit, Paarl, Port Elizabeth, Pretoria, Rustenburg, and West Rand.

Forming relationships with clinicians, scientists, activists, expert speakers, the national Department of Health (DoH), pharmaceutical companies, Society members, and other HCWs has been an important part of CPD. In the past, the Society had been successful in obtaining partial sponsorship of meetings by pharmaceutical companies. However, in the last few years, pharmaceutical sponsorship of meetings has decreased, impacting the Society's ability to convene regular meetings. Many of the branch meetings were unsponsored and ran at a small to substantial loss. In addition, pharma, the main sponsor of these meetings, was more likely to fund urban than rural meetings, and in the absence of other funding, rural meetings were no longer being held. Yet there was still a big demand in rural areas. For example, even without funding, a Society meeting was attended by more than 80 people in one rural area.



The branch structure faced further challenges: Being coordinated by volunteers who were busy clinicians was unsustainable.



The Society, in conversation with pharma, embarked on a restructuring of the branch meetings and developed the model of one-day CMEs. The new one-day CMEs were designed to have a mini-conference format. They were held on Saturdays from 08h00 to 16h00 in venues that were fully or partially sponsored. Regional CME meetings were held in Eastern Cape, Gauteng, KwaZulu-Natal, North West, and Western Cape. The South African Medical Association (SAMA) negotiated Level 2 accreditation through which members received 18 points for attending the structured one-day CME. The Society, which had been organizing evening CMEs, continued to do so but on a much smaller scale.

CME topics cover all aspects of HIV management, including clinical and ethical issues. The Society, in partnership with local branch coordinators, identifies relevant topics and expert speakers, and makes all the logistical arrangements for the meetings. Topics range from clinical discussions regarding HIV management, managing co-infections and co-morbidities; information regarding changing drug regimens; and social and ethical issues such as disability, informed consent, intimate partner violence, and medico-legal implications of disclosure.

Pharma is allowed to play a role in selecting topics (though not directing content), to ensure return on investment and its continued interest and support. In 2015, pharma sponsored seven one-day CMEs and a few evening CMEs. Some funding that covered CMEs was specific to the grant focus and limited the scope of that CME. For example, the Society was funded through a grant specific to pre-exposure prophylaxis (PrEP) to run one-day CMEs focused on PrEP, starting in 2016.

Most speaker presentations are uploaded onto the website for anyone to download, and the CME meeting calendar is online. All sites are coordinated by a local HCW, without whom these meetings could not function. The meeting platform provides HCWs with an opportunity to expand their knowledge around the complexities of HIV management in the context of the South African health-care system.

The new format of CME meetings was well received and attracted the maximum number of delegates that could be accommodated per venue. The pilot meetings in 2015 recorded the following attendance: Eastern Cape, 140; Gauteng, 93; KwaZulu-Natal, 97; and Western Cape, 100. The CME meetings have been a great success, due largely to their emphasis on both research and networking. Branch meetings act as important gatherings to discuss topical issues and hear the presentations of experts. HIV best-practice changes rapidly, and Society members rely on branch meetings to stay informed of developments. At a Johannesburg meeting on the HIV treatment guidelines, 82 percent of the 73 participants described themselves as 'knowledgeable' or 'very knowledgeable' about the guidelines post talk, compared with 45 percent before the talk. The ultimate goal of this activity is to build the capacity of HCWs to provide best-practice services in HIV prevention, testing, care, and treatment.

These branch meetings are attended by a range of health-care professionals, including nurses, medical doctors, physiotherapists, psychologists, specialist clinicians, pharmacists, researchers, dieticians, surgeons, paediatricians, medical students, general practitioners, and lab scientists. The high turnout at these meetings is a positive indication that the Society is filling a critical gap in the region.

Figure 4: Number of Society branches in South Africa, 2007-2014

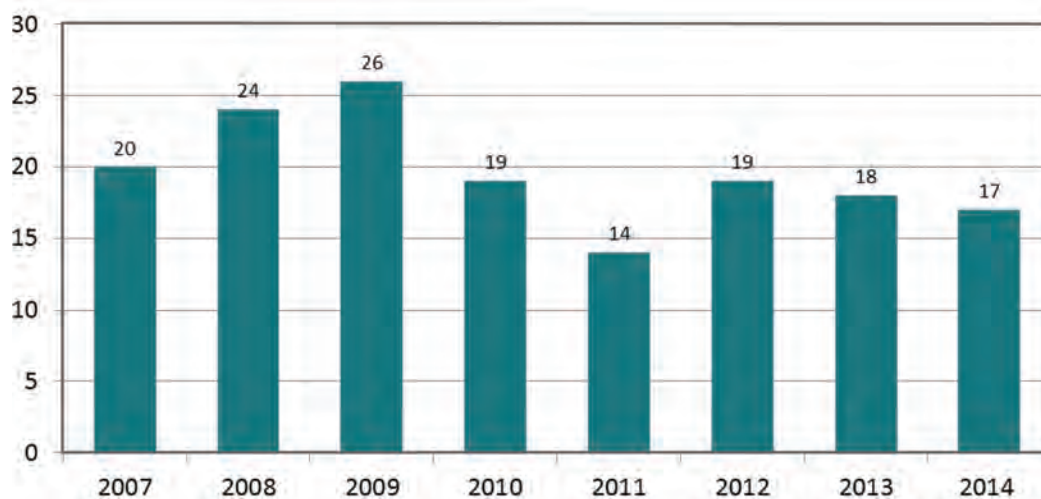


Figure 5: Number of branch CME meetings held, 2010-2014

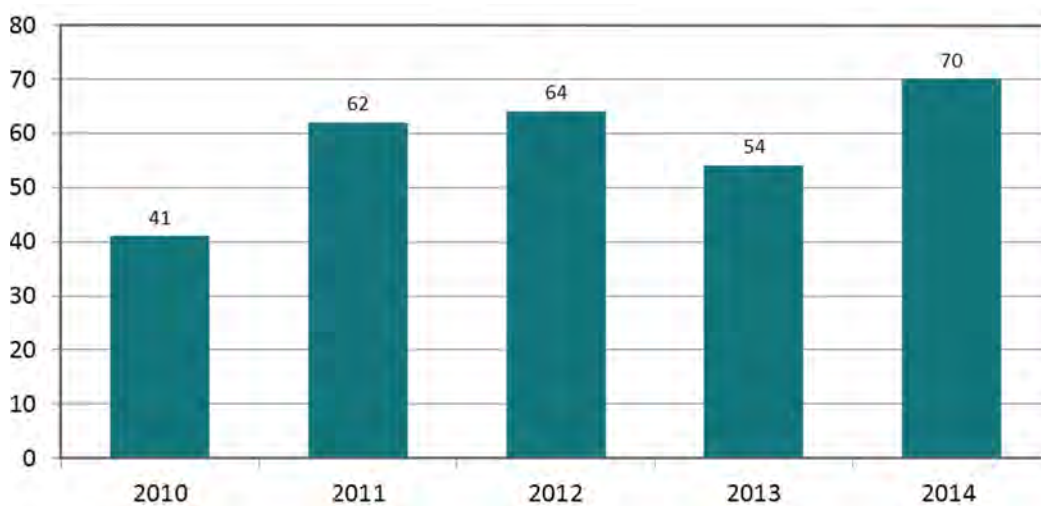
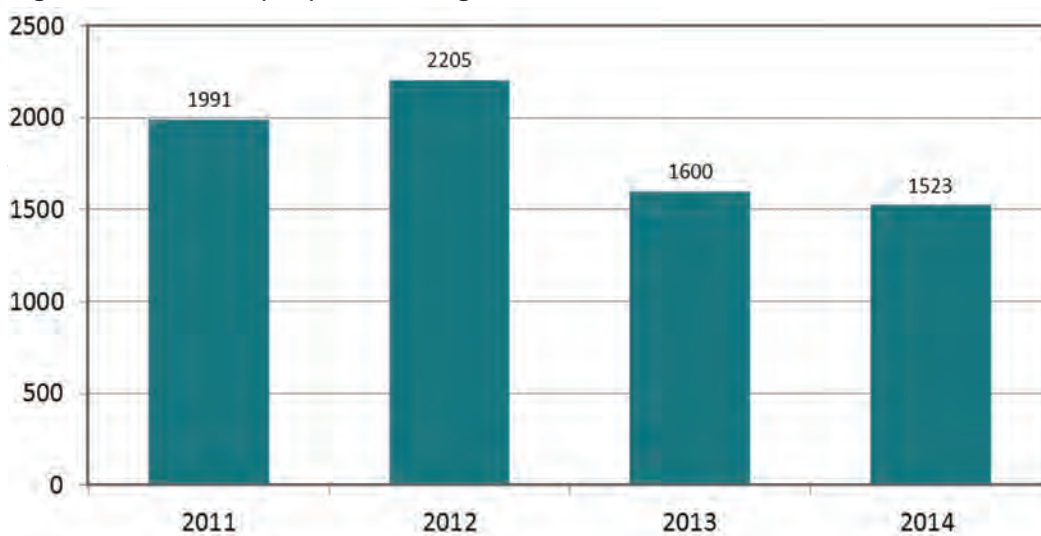


Figure 6: Number of people attending CMEs, 2011-2014



## Rural branches



The Society's support of rural doctors has increased. The Society increased the number of branches in deprived, rural areas both in South Africa and within the SADC region, and provided bursary and institutional support to the Rural Doctors Association of South Africa (RuDASA). This has ensured that comprehensive, evidence-based information on HIV reached the areas hard hit by the pandemic.

The Society tried to expand the number of branches and have a greater penetration in rural areas. However, this proved difficult, despite significant efforts. The logistics of such meetings were complicated, travel to the rural areas was time-consuming, and the appetite of the small pool of experts to go to these hard-to-reach areas was limited.

Attendance at and frequency of monthly branch meetings varied significantly between urban and rural areas, with an average of 130-plus attending meetings in Johannesburg, approximately 90 in Pretoria, and 50 to 60 in other areas.

Interestingly, in some settings, rural meetings were the most enthusiastically attended, with clinicians and other HCWs travelling up to three hours by public transport to attend a two-hour lecture. Weekend workshops have been fully embraced, demonstrating how appreciated they are in under-resourced areas.

The Society encourages pharmaceutical companies to commit more resources to support rural branches. Sponsors of popular urban sites have been asked to co-sponsor a rural site. Well-established branches such as those in Johannesburg and Pretoria, are encouraged to adopt a rural branch and assist in its establishment.

The Society considered alternative strategies to ensure that the benefits of regular branch meetings were made available to clinicians in under-resourced areas. The Society continues to explore every opportunity to secure good speakers to visit the branches and introduced honorariums to these speakers to compensate them for their time away from work while addressing meetings in rural areas. The Society also explored ways to increase rural involvement by offering nurses and lay HCWs extended training alongside doctor-focused short branch meetings.

The Society attempted to find new branch leaders in rural areas. While a few were found, it became evident that speakers found the travelling to extreme rural sites so demanding that it was difficult to run regular meetings. The number of clinicians in these rural areas was also found to be limited, and therefore a decision was made not to continue with this strategy. The new strategy resulted in meetings being held in 'draining areas', where large towns or cities hosted clinicians from the surrounding rural areas. This has been more successful. Members are supported financially to travel to and from branch meetings in bigger centres.

The Society has strong relationships with rural organisations, including the RuDASA, the Rural Health Advocacy Project (RHAP) and African Health Placements (AHP). In partnership with the RuDASA, RHAP and Médecins Sans Frontières, the Society piloted a CPD-accredited advocacy training programme for rural HCWs this year. This initiative provided greater insight into how the Society can best support rural areas.

South African branch meetings were previously filmed and aired on the learning channel MindSet to increase access to the discussions and learnings. Funding has been lost, so this service ended in 2014.

The Society is also working on a plan to conduct a road show in the more rural areas of the region to increase awareness of its work. The Society still does not have a presence in significant parts of the country.

## Regional branches

The Society is a regional body, and other southern African countries could benefit tremendously from the establishment of more branches. Society branches were established outside of South Africa, with five still functional in Botswana (Francistown and Gaborone), Namibia (Windhoek), and Zimbabwe (Harare and Mutare). Due to limited regional funding and support, the Society used opportunities when key opinion leaders travelled to other events in these countries to present at regional CMEs.

*The regional branches are in the position the Society was 15 years ago, limping along without staff and funding, and attempting to develop a presence through volunteers. The Society is committed to supporting them either through providing them with resources where possible or linking them to pharmaceutical companies who are willing to sponsor meetings. (CEO)*

In 2015, the Society was awarded a sub-grant for regional work, which began in June 2016, from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). It is intended to strengthen branches, recruit members, and establish a membership base in two more southern African countries, Mozambique and Zambia. This will include providing regional branches with materials, setting up a page on the Society website with translated materials and sharing the Society database system. The Namibian and Zimbabwean branches have also expressed a need for similar support, but as yet there is no funding for this.

Branches in other countries in the region tend to operate more autonomously. The Botswana and Namibian branches in particular were described as almost being subsections of the Society, and the fees collected by them go into their own coffers, allowing them substantial autonomy.

## Postgraduate courses

The Society has partnered with various institutions to provide important up-to-date courses. The Society, previously the largest special interest group within the South African Medical Association (SAMA), worked in conjunction with the association's education arm — the Foundation for Professional Development (FPD) — to provide ongoing professional development and necessary accreditation for doctors working in the field of HIV. This strategic alliance was an important milestone that facilitated huge organisational growth. In terms of this collaboration, the Society contributed to the creation of HIV/AIDS-related training materials (and continues to contribute to the updating of these). In return, the FPD paid the Society a royalty for every person trained at FPD in an HIV-related course and every trained FPD participant (in an HIV-related course) received automatic Society membership. FPD, together with the Society, has trained thousands of doctors in the last decade.

The Society continues to offer the diploma in HIV medicine through the South African Colleges of Medicine. The Society also awards the SA HIV Clinicians Society Medal to the most successful candidates of the annual HIV diploma courses. This prestigious medal has been awarded since 2008.

## Nurse programme

In 2009, the Society created a programme for support to nurses working in the field of HIV/AIDS. The ethos behind this initiative was that the success of the South African Government's NSP would depend on a strong nurse-based programme within the health-care sector. Nurses have indicated that they require more support, training, and development to support the NSP. The Society realised it was ideally positioned to provide this support since approximately 40 percent of its members were nurses. In 2012, the Society established a relationship with a public health-care clinic in Hammanskraal to pilot the Nurse Leadership Hub project. It also provided TB workshops together with The Aurum Institute as part



of branch meetings and capacity-building meetings for nurses in new areas. In 2014 and 2015, the Society ran nurse capacity-building workshops in North West.

The flagship of the nursing programme was the journal dedicated to nurses, *HIV Nursing Matters* and the weekly *SMS Clinical Tips*. Monument Trust specifically funded the nursing programme in an effort to strengthen nurse initiated management of antiretroviral treatment (NIMART). There was increasing support provided to nurses, targeting CMEs at nurses specifically and providing educational opportunities and bursaries for them to attend conferences. The Society provides complimentary conference registration to more than 50 nurses each year. In the second grant period, the Society provided further capacity building, training, case-study workshops, and set up leadership hubs for nurses. There were also peripheral programmes such as a support programme for HIV-positive nurses. A WhatsApp group was formed, but this did not really gain any traction. The *SMS Clinical Tips* has taken off massively, and anecdotally the Society has learned from nurses that it has been useful and informative. As many as 2,000 people have received the *SMS Clinical Tips* weekly. Government has also recognised the value of the platform for reaching nurses: When the country shifted to fixed dose combination (FDC), the Society was asked by government to send a series of tips to sensitise and inform nurses about the change.



*HIV Nursing Matters* is a journal dedicated to supporting nurses in the management of NIMART.

Since the Monument grant ended in mid-2015, the Society has not been able to access additional funding, despite investing time in soliciting funding. The nursing programme has been shut down, the programme manager retrenched, and all other activities were stopped. The Society has a small nurse-focused grant from Anglo American Chairman's Fund, which sustains *SMS Clinical Tips* and *HIV Nursing Matters*. The journal is published three times per year instead of four, with a reduced-quality print, and a lower-cost printer has been sourced to save costs.

*In 2015 we submitted one funding proposal per week. I am surprised that we haven't been successful in finding a funder for the nursing programme. It seems there has been a move in the funding environment. The kinds of donors who would have funded the nurse programme are now funding human-rights-oriented citizen democracy, and the nursing programme doesn't fit with those kinds of grants. But I honestly feel the nursing programme is just on hold and it will be restarted when funding is secured. (CEO)*

## Committees and think tanks

The Society's child and adolescent committee is responsible for developing guidelines on the management of HIV in paediatric populations and providing technical expertise to the DoH on behalf of the Society. The sub-committee works closely with Society staff and the executive committee to ensure that the Society's core programmes (e.g., branch meetings, guidelines, publications) include a focus on paediatric issues. The steering committee of five members meets monthly and provides guidance and direction to all Society paediatric- and adolescent-related activities.

The committee informed the development of paediatric targets and implementation strategies in the NSP. Their involvement helped ensure that the NSP was informed on the best available scientific evidence in paediatric HIV and reflects the realities of implementation in the field.

The committee is working closely with the DoH and the South African National AIDS Council's (SANAC) technical task team for treatment, care and support on the development of clinical practice guidelines and other policy issues. To this end, the Society:

- Was actively involved in the development of the new antiretroviral treatment (ART) guidelines for the paediatric and adolescent population;
- Successfully advocated for stand-alone adolescent ART guidelines for the first time ever;
- Finalised a recommendation on the use of second- and third-line ARVs;
- Released a statement on the U.S. Food and Drug Administration (FDA) approval of Tenofovir from age 2;
- Conducted a survey assessing antiretroviral use and practices in paediatric patients via the paediatric discussion group (PDG);
- Provided comments and input into the hospital and clinic-level paediatric standard treatment guidelines published by the Essential Drugs List (EDL);
- Revised the 2012 antiretroviral dosing chart to include new medicine formulations licensed by the Medicines Control Council (MCC);
- Released a statement on the functional cure of a child as presented at the Conference on Retroviruses and Opportunistic Infections;
- Lobbied the government for supplementary tenders to provide salvage treatment for children; and
- Rewrote the guidelines and the training material for the DoH new FDC roll-out.

The Society also established or contributed to the following national expert think tanks:

- Opt-out testing;
- Over-the-counter testing;
- Responses to inappropriate guidelines;
- Blood donation screening;
- TB and HIV integration; and
- Paediatric care.

## Guidelines

The Society also introduced best-practice guidelines, which have proved to be one of the Society's most important and useful activities. Clinical guidelines produced by the Society are evidence-based, widely circulated, and accepted as the standard for the clinical management of HIV-related issues within the region. An overwhelming majority of Society members report using the guidelines in their clinical practice.

***The best-practice guidelines are one of the Society's most important activities and are widely used to inform health care***

The Society provides support and administrative expertise to rapidly bring experts together, establish consensus, and then consult and finally collate each guideline. There appears a good procedural basis to the generation of the guidelines, with conflicts of interests being formally declared, and the pharmaceutical sector having only observer status in the discussions, if present at all. The draft guidelines are formally peer reviewed, and published only after sign-off by the chair of that guideline development group and the Society's president.

The turnaround time for guidelines is approximately six to nine months since these are reviewed both locally and internationally. Once completed, guidelines are published in the Society's journal and distributed to the members nationally and internationally. The guidelines are also sent to the South African provincial and national DoHs and other health non-governmental organisations (NGOs).



*The DoH is increasingly contacting us to get inputs from the Society, as they realise that we can put together an expert committee and produce niche guidelines quickly, whereas the DoH can't especially if they are in a massive hurry. The Society can put together a really good consensus statement from HIV experts in a matter of days. (CEO)*

The Society's guidelines have considerable local credibility and are widely used to inform health care. The guidelines concerning the care of HIV-infected adults and children are used by the managed-care (medical aid) industry as the reference point in awarding medical benefits to HIV-infected people and have been adopted by the DoH for the Comprehensive Plan for the Treatment and Prevention of HIV/AIDS.

## Engaging the Department of Health

Historically, Society guidelines filled a gap that the national DoH did not have the capacity to fill. Today, Society members and DoH work in partnership to issue evidence-based HIV guidelines appropriate for public health. The challenge is to define a clear process for engagement with the national DoH to reduce the redundancy in guideline development processes. The Society is presently working with both the DoH and SANAC to develop a clear process for how the Society can contribute to the DoH's existing process for guideline development.



The goal is to have a memorandum of understanding (MOU) with the DoH outlining roles in guideline development. The Society worked hard to formalise its participation in national guideline development with the DoH, but despite initial interest, at the end of 2013 it became clear that DoH would not endorse an official partnership. Meetings were held to discuss whether a formal MOU could be established with the DoH with regard to guidelines, however, its leaders were not keen and believed the Society's guidelines to be in competition with theirs. Although disappointing, DoH's position forced the Society to examine its role in developing and advocating for evidence-based HIV medicine. Making a decision to proceed with guideline development has given the Society greater focus and clarity for this activity.

Despite the constrained resources to continue this activity, the Society board members overwhelmingly thought that there was still a role for the Society to pursue guideline writing. First, it was clear that the development of 'niche' guidelines — i.e., guidelines that address either complicated issues in HIV medicine (e.g., diagnosis and treatment of neonates) or issues that are not priorities for public health (e.g., fertility for the HIV-affected couple) — firmly remain part of the organisation's mandate. Niche issues in HIV are beyond the scope of DoH and must be addressed by experts; achieving expert consensus in these areas is important to promote equitable and quality care across the country. On complicated technical issues, the DoH has indicated that it looks to the Society to provide guidance, and it is clear that funding is needed to continue this activity.

DoH guidelines provide little explanation of the rationale driving the decisions made, while the Society's guidelines elucidate the decision-making process. This is a recognised value of Society guidelines and supports the organisation's objectives to educate HCWs.

*The process for developing the DoH antiretroviral treatment guidelines is chaotic and frustrating. For example, Society members are often asked to make critical decisions on ART monitoring or regimens in a very short time frame with no notice, which allows for little to no peer-to-peer debate and discussion. The lack of a technically strong expert at the national DoH also complicates the process; e.g., when there are controversial issues DoH is unable to assess differing opinions and evidence and manage the process to resolution, which often stalls the guideline's development. (Society report)*

Given that it is unlikely that DoH's management of the process will improve in the near term, board members thought that the Society should continue to develop guidelines and recommendations on antiretroviral therapy. This will require at minimum twice-yearly discussions among a small group of experts to assess new data or other HIV policy changes, for example WHO policy, and revisions of the existing Society adult, paediatric and PMTCT guidelines when necessary.

Developing and writing guidelines allows the organisation to maintain its autonomy. While the Society and DoH may agree on HIV policy now, there is no assurance that this will continue. To drop this core function, the organisation risks losing the capacity and institutional memory to support this activity.

Regular committee meetings will ensure that experts have both a forum and adequate time to assess and debate emerging data. It is hoped that this process will facilitate consensus and enable the experts to speak with one voice when DoH queries arise.

## Guideline development process

The Society considered appointing a scientific committee to oversee the development of all Society guidelines and speeding up the development of guidelines by contracting in scientific writers. The board however decided that a committee for this role was unnecessary, and that the Society's adult and child and adolescent committees would be responsible for overseeing guideline development in their issue areas. Standard operating procedures guide the work of the committees.

The board members comprise a large part of the committees, and every guideline decision is taken by the board on the basis of scientific merit. The committees still monitor emerging issues, make recommendations on guideline topics and appoint individuals for the development of each new identified guideline. The committees also review existing guidelines and advise whether the guidelines need to be updated or can remain unchanged. The respective teams set up to draw up the guidelines normally comprise a broad spectrum of interested parties, which allows broader social and political considerations to also be factored in. The Society is also asked to put together slides, audios, and films to be used in master training.

Bringing key opinion leaders from each population group (i.e. paediatric, adult, prevention of mother-to-child transmission) together for the Society's guideline committee has the unanticipated benefit of promoting cross-disciplinary debate. The Society had been following DoH's lead and separating experts by population — for example, adult or paediatric — while HIV medicine has become increasingly harmonised across age cohorts. Bringing HIV clinicians together from different specialities to discuss and debate HIV medicine brought new perspectives and ideas to the table. The guideline committee will continue to foster this inter-disciplinary collaboration.

It was also recognised that engaging up-and-coming leaders in guideline discussions is critically important to facilitate leadership development in the next generation of HIV clinicians. The Society's recent review/update of the adult ART guidelines found that by involving some of the 'less usual' participants, the process was greatly enriched. The committee meeting included six to eight key opinion leaders and six to eight young infectious-disease physicians. The younger group greatly valued the opportunity to interact with the more established HIV scientists; the established group appreciated the opportunity to teach and hear different perspectives. The meeting facilitated a level of peer-to-peer engagement on technical issues, which doesn't happen in the field or outside of academia. It was clear that providing opportunities such as these to up-and-coming clinicians is important to help build and develop future leaders; where possible, all future antiretroviral guideline meetings will utilise this approach.

## Guidelines completed

The following are a few examples of guidelines that the Society has developed.

- 1 In response to a request from DoH, the Society developed an interim advice document on how to manage patients in the context of Tenofovir and Abacavir drug shortages. This document has proved to be one of the most important and useful set of guidelines written by the Society. The Society's Child and Adolescent committee also published advice on the use of Tenofovir in children, in response to the approval by the U.S. Food and Drug Administration of its use in children.
- 2 The deputy minister of correctional services was involved in developing a guideline for prisoners, in terms of looking at testing, prevention, and treatment within the prison context. Although this guideline is not formally recognised by government, it does in effect provide a 'gold standard', and many in government recognise its value.
- 3 In conjunction with the United Nations High Commission for Refugees (UNHCR), the Society produced Clinical Guidelines on the Management of ART for Displaced Populations. These guidelines were launched at a media briefing in 2007 and attracted extensive media attention. They were widely distributed, together with posters summarising the guidelines, to national (in all Southern African Development Community [SADC] countries) and South African provincial health departments, NGOs and to the WHO. They were updated in 2014. The guidelines are particularly powerful, as clinicians from several SADC countries were involved in their drafting, and the committee was co-chaired by the head of the UNHCR. The WHO is using these guidelines to guide its own process aimed at producing clinical guidance on displaced people internationally. These guidelines have also been developed into a booklet which has been made available in English and French to cater to the needs of the refugee communities in South Africa.
- 4 A meeting of the clinical working group on cryptococcal meningitis was held in May 2007 and attended by 15 national and internationally recognised experts in the field. The guidelines on cryptococcal screening and treatment were published in 2008 with an accompanying poster and updated in 2012.



Table 2: Best-practice guidelines

Year	Guidelines produced
2007-2010	<ul style="list-style-type: none"> <li>Guidelines for displaced persons</li> <li>Adult ARV guidelines</li> <li>Guidelines for prisoners</li> <li>Nutrition guidelines</li> <li>Transplant guidelines</li> <li>Guidelines for treating sexual assault patients</li> <li>Cryptococcal meningitis management</li> <li>Renal replacement</li> <li>Post-exposure prophylaxis</li> <li>Symptomatic hyperlactataemia and lactic acid</li> <li>Pre-ART guidelines</li> <li>Childhood TB guidelines, in collaboration with the South Africa Society for Paediatric Infectious Diseases</li> <li>Guidelines for drug users and sex workers</li> </ul>
2011	<ul style="list-style-type: none"> <li>Guideline on safer conception in fertile HIV-Infected individuals and couples</li> <li>Management of HIV-hepatitis B co-infection</li> <li>Isoniazid preventive therapy in HIV-infected South African children</li> <li>Blood transfusion</li> </ul>
2012	<ul style="list-style-type: none"> <li>An update to the 2008 guidelines for antiretroviral treatment therapy in adults</li> <li>An update to the 2010 ARV dosing chart for children and adolescents</li> <li>Resistance testing guidelines</li> <li>A review of the use of blood and blood products in HIV-infected patients</li> <li>Guidelines for the use of pre-exposure prophylaxis in men who have sex with men who are at risk for HIV infection</li> <li>HIV post-exposure prophylaxis guidelines</li> </ul>
2013	<ul style="list-style-type: none"> <li>Guidelines for the prevention, diagnosis, and management of cryptococcal meningitis in HIV-infected persons, 2013 update</li> <li>Antiretroviral drug dosing chart for children and adolescents, 2013</li> <li>Management of drug-induced liver injury in HIV-positive patients treated for TB</li> <li>Management of mental health disorders in HIV-positive patients</li> </ul>
2014	<ul style="list-style-type: none"> <li>Management of HIV infection in adolescents</li> <li>Management of mental health disorders in children</li> <li>Neonatal diagnosis and treatment</li> <li>Review of adult antiretroviral treatment guidelines</li> <li>HIV testing, mental health, and tuberculosis guidelines</li> </ul>

## Outcome of guidelines

The development of important guidelines by the Society has been highly successful and pertinent, filling a critical gap in the availability of relevant information for HCWs dealing with HIV management. A crucial strength of the Society is that the applicability and validity of these guidelines are not questioned by government or experts in the field, which in effect, endorses them to a certain extent.

*The Strategic Evaluation, Advising and Development Consulting (SEAD) evaluation team was particularly impressed with the area of guideline development. It is the area where there is perhaps some justification in thinking that the Society actually represents the HIV-positive patients as well as doctors. The guidelines act as a powerful advocacy tool, distilling what is known as 'best-practice' in the developed world, and modifying these into guidelines that are appropriate for the southern African region. The guidelines appear to walk the difficult line of being applicable to both the private and public sectors. (External evaluation, 2010)*



## Conferences

The Society and its individual members representing the Society attended numerous local, national, and international conferences where they have presented up-to-date, evidence-based initiatives and practical advice/expertise. The Society's inputs are well received by doctors, clinicians, politicians, and key policymakers in the field of HIV.

The Society has attended and presented at all major local, regional, and international HIV conferences including:

- International AIDS Conference
- Regional HIV Conference
- South African AIDS Conference
- South African TB Conference
- Federation for Infectious Diseases South Africa
- Conference on Retroviruses and Opportunistic Infections
- RuDASA Conference

Senior members of the Society present at these meetings each year and actively participate in dissemination of the proceedings through branch meetings. The Society was also profiled at these events and sought to increase its membership using these opportunities. The Society is highly respected and is always welcomed at conferences to exhibit as well as to participate in the conference programmes — particularly in relation to skills-building sessions.

*Society members disseminate conference proceedings through branch meetings, and seek to increase membership, and build skills*

## Skills building and support for existing conferences

The Society is responsible for planning and implementing the skill-building programme at the Southern African AIDS and TB Conferences. The workshops provide a practical rather than academic component at the conferences and equip attendees with skills to better manage HIV and TB in their health-care facilities. A Society committee meets to determine the topics, based on the need in the field, and then identifies speakers who can facilitate the workshops. The Society covers the speakers' registration and travel expenses. The workshops are well attended and highly regarded by participants. The Society has a successful track record of obtaining pharmaceutical and other corporate sponsorship to partially support these workshops.



The following examples are the types of conferences the Society has participated in and the range of activities it contributed to.

At the third **AIDS Conference** (Durban, June 2007), eight keynote sessions were chaired and addressed by members of the Society. The conference organisers requested that the Society organise the skills-building sessions:

- Adult ART case studies (Linda Gail Bekker)
- HIV science for the non-scientist (Nathan Geffen)
- Paediatric ART case studies (Francesca Conradie)
- How to do a nutritional assessment (Dave Spencer)
- Should we have a mass circumcision programme? (Francois Venter)
- How to write a donor proposal (Holly Fee/Helen Struthers)
- Setting standards for HIV care and how to run a large HIV clinic (Winnie Moleko)
- Getting youth tested for HIV (Thulani Grenville-Grey)

An average of 100-plus delegates attended each of the sessions, and more than 1,300 attended those organised/addressed by the Society. The Society arranged a major public debate during the session 'Should

we have a mass circumcision programme?' Approximately 250 delegates attended and contributed to the debate, which received wide national and international media coverage.

Furthermore, the Society leveraged additional sponsor funds to provide bursaries for 20 rural doctors to attend the conference.

The **TB Conference** (Durban, July 2008) hosted 1,700 delegates over four days. The Society hosted 16 skills-building workshops attended by 667 delegates in total. These workshops helped disseminate information, offered practical skills to attendees, and afforded attendees the opportunity to engage with experienced clinicians/adult/child on complicated patient issues.

In addition, 2,000 copies of the *Southern African Journal of HIV Medicine* (SAJHIVMED) were distributed to conference delegates; the latest *Prisoner Guidelines* poster was inserted into each copy. Promotional materials including lanyards, mouse pads and T-shirts were handed out to increase the profile of the Society. The Society provided bursaries to 16 doctors and other HCWs from rural areas to attend the conference.

The **International HIV Conference** (Botswana, September 2008) was attended by 1,000 delegates. The Society hosted four skills-building workshops, attended by 391 people in total. Executive committee members also presented and facilitated sessions at the conference. Approximately 1,000 copies of SAJHIVMED were distributed to conference delegates, as well as a large number of promotional items. Some 500 copies of the *Prisoner Guidelines* poster were handed out to conference delegates and members of the media.

The Society offered bursaries to six participants to attend the conference from Malawi, Mozambique, Namibia, and Zimbabwe. The Society secured funding for 10 additional doctors and other HCWs, particularly from rural and other under-resourced areas/regions, to attend the conference.

At the **RuDASA Conference** (Beaufort West, September 2008), the Society presented its annual Rural Doctor of the Year Award. It distributed SAJHIVMED and other educational material to conference participants. The Society provided bursaries that allowed eight HCWs from rural and under-resourced areas to attend the conference. The Society also provided bursaries to 10 medical students from the University of Pretoria who are members of a university rural health interest group. The bursaries covered the conference registration costs in full and also provided bursary holders with a contribution towards their travel and accommodation costs. Several of the students and HCWs who received bursaries from the Society also presented papers and posters at the conference.

The **4th Southern African AIDS Conference** (Durban, April 2009) was attended by 4,500 delegates. The Society secured funds from MTN SA Foundation to host 12 skills-building sessions and exhibit at the conference. The Society president, members of the executive committee and staff were part of the conference planning committee and presented and chaired a number of plenary sessions.

The workshops were extremely popular: A total of 1,080 delegates attended, and some rooms were filled to capacity. These workshops are a valuable investment in ensuring that medical professionals receive the most up-to-date information and education, thus enabling them to offer a better service to people infected and affected by HIV/AIDS and other opportunistic infections.

The Society also had an exhibition stand at the conference and used this opportunity to disseminate information as well as recruit new members. The stall was one of the busiest at the conference, with over 3,000 copies of SAJHIVMED distributed, as well as a range of promotional materials.

A total of 20 bursaries were awarded to doctors and other HCWs from rural areas to attend the conference.



At the **National AIDS Conference** (Durban, June 2011), the Society organised 14 skills-building sessions. Topics were largely clinical case studies, including:

- How to implement a male circumcision programme;
- Management of opportunistic infections in HIV patients;
- How to do the perfect fine needle aspirate;
- Managing paediatric ART resistance; and
- Nursing and the ART of comprehensive HIV/TB care.

Feedback was positive, and the Society secured sponsorship from MTN and Abbott. The Society provided 30 bursaries to members to attend. Bursary recipients also received a small stipend to support travel and accommodation costs.

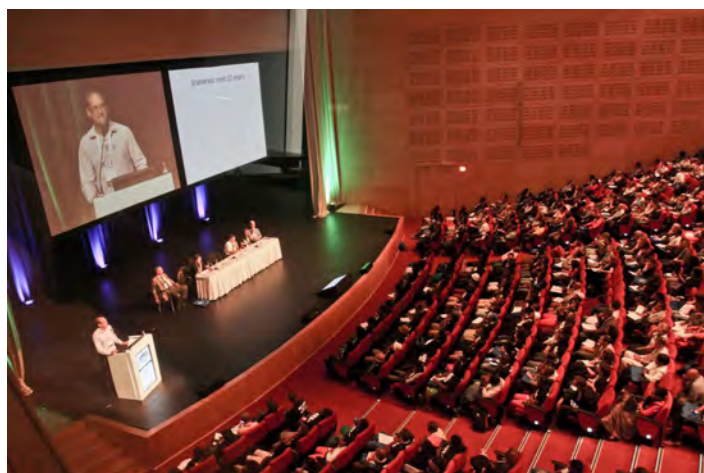
At the **National TB Conference** (Durban, June 2012), the Society utilised 30 regional bursaries awarded by another partner and held six skills-building workshops and two roundtable sessions, funded by Atlantic.

At the **annual Workshop in Advanced Clinical Care** (Durban, October 2012), the Society provided clinical workshops, roundtable discussions, and case-study workshops. In addition, 10 bursaries were provided for attendance at this conference.

## The HIV Clinicians Conferences

The Society's conference support activities have changed from providing capacity-building support at existing conferences to focus more heavily on the Society's own biennial conference. The Society's conference focuses on HIV/AIDS clinical content, setting it apart from other conferences held to date in South Africa. The conferences have been an amazing success with strong attendance, high-quality presentations, and positive feedback from delegates.

The **South Africa HIV Clinicians Conference** (Cape Town, 2012) was the inaugural conference of the Society. The theme was 'Striving for Clinical Excellence'. The first conference programme was diverse and included six international speakers and 118 local speakers. The total number of delegates was 985, of which 220 were sponsored to attend. Atlantic sponsored the registration for 100 people, mostly rural doctors and nurse initiated management of antiretroviral treatment (NIMART) nurses. There were 90 poster presentations and 11 abstracts chosen for oral presentations, all of which were of good quality and representative of the excellent work being done in the field.



Prof Francois Venter at the Society's conference, Cape Town, 24-27 September 2014

The Society's second conference, South Africa HIV Clinicians Conference (Cape Town, 2014), had the theme 'Excelling in Clinical Care' and was attended by 950 delegates. It included six international and 88 local speakers. There were 92 poster presentations and eight oral presentations.

The Society's third conference, South Africa HIV Clinicians Conference (Johannesburg, 2016), had the theme 'Our Issues. Our Drugs. Our Patients'. A total of 916 delegates attended and there were seven international and 108 local speakers. The conference accepted 24 oral and 50 poster presentations. The social events included a cocktail party attended by more than 480 people and a dinner attended by 246 people.

*The Society's conference has been an amazing success.*

*Focusing on clinical content and skill-building sessions, it is marked by strong attendance, high-quality presentations and terrific feedback from delegates*

# The Society's third conference *Our Issues. Our Drugs. Our Patients* Johannesburg April 2016

Keynote speakers, from left to right:

Dr Joe Eron, Professor of Medicine in the Division of Infectious Diseases at the University of North Carolina at Chapel Hill.

Prof Yunus Moosa, Associate Professor, Chief Specialist and Head of the Department of Infectious Diseases at the University of KwaZulu-Natal

Dr David Spencer, Head of the Adult Antiretroviral Programme, Right to Care

Prof Ebrahim Variava, Adjunct Professor of Internal Medicine at WITS

Prof Gary Maartens, head of the Division of Clinical Pharmacology and chief specialist physician and professor at Groote Schuur hospital and University of Cape Town.



The Society's third conference held in Johannesburg in April 2016 was well attended.

The conferences have hosted skills-building sessions for nurses and doctors in a series of parallel sessions, chaired by local experts. There were also a number of open sessions and debates, challenging cases presented and research findings disseminated. Topics were diverse and comprehensive, covering issues from managing HIV complications, clinical laboratory sciences, fertility choices, nutrition, ethics, TB, health economics, drug choices and drug resistance, new diagnostics and mental health. Atlantic has in the past provided bursaries primarily to nurse clinicians to attend the conferences. The conferences also included social functions allowing delegates to meet and network. Various aspects of the conference were sponsored by a wide range of sponsors and exhibitors. The conferences are fully accredited for continuing professional development.

## Bursaries and scholarships

### Conference bursaries



The Society provides bursaries to HCWs to attend the annual RuDASA conference, the Southern African AIDS Conference or the Southern African TB Conference (held in alternating years), and other regional conferences (e.g., the Botswana HIV Conference). In selecting bursary recipients, the Society prioritises HCWs providing HIV or TB services in rural or other under-resourced areas. Bursaries cover conference registration and contribute towards recipients' travel and accommodation expenses. Between 2008 and 2012, 112 bursaries were awarded for external conferences.

The bursary programme allows HCWs the opportunity to attend a national or regional conference to improve their knowledge of HIV and TB management. Bursary recipients are required to provide feedback to their colleagues, thereby benefitting the entire health-care facility, not just the individual.

*From RuDASA we would like to express our thanks for the SA HIV Clinicians Society's bursaries that were made available specifically for Rural Doctors. I have had very positive feedback from the doctors that did attend and being able to attend has certainly been appreciated. It also facilitated that some of the rural doctors were able to share more of their experiences and place their practice into a larger context of what is being done elsewhere. (Bernhard Gaede, RuDASA)*

Society members promote opportunities for professional development. When the Society advertised bursaries for nurses to attend the South Africa TB Conference, more than 500 enquiries were received; it was possible to issue only 10 bursaries each to nurses and doctors. Conference bursaries remain an important perk of membership, yet the Society has struggled to receive an adequate number of applications from nurse members, despite advertising in *HIV Nursing Matters*. The Society will utilise its branches to increase awareness of available bursaries and galvanise doctor members to nominate nurses.

In the past, the Society has been successful in securing partial corporate sponsorship for its conference support activities to supplement the sponsorship from Atlantic. MTN Foundation and Aspen Pharmacare have contributed to the bursary programme. The Society continues to request funding from corporate sponsors to support this activity.

### Scholarship programme

The Society developed a scholarship programme to support continuing education for both doctors and nurses and to increase the number of HCWs with advanced HIV management training. Based on the availability of funds, the programme provided scholarships for up to five doctors and five nurses per year, in order to complete the Colleges of Medicine HIV management diploma and Stellenbosch University's Certificate Programme in Clinical Competency in Antiretroviral and Tuberculosis Treatment, respectively. An expert committee comprised of nurse educators and professors of HIV medicine was appointed to advise on the selection criteria for recipients and to assess the applications received. The availability of scholarships is advertised to all members through the Society's nursing magazine, *SAJHIVMED* and the Society newsletter, *Transcript*. Scholarships cover the course fees and provide a contribution towards other expenses.



## PUBLIC POLICY AND ADVOCACY

The Society's strategic objectives focused on public policy and advocacy, and aimed to:

- Inform the development of national HIV/TB public policy and monitor its implementation;
- Advocate for public policies that support the highest standard of health care for all people living with HIV; and
- Stimulate debate within the HIV medical community on topical issues relating to HIV.

Advocacy is a key strategy to achieve policy change, and the Society participates in advocacy activities on an ongoing basis as issues of importance arise. The Society continues to work closely with the South African National AIDS Council (SANAC) and the DoH to advance evidence

### Support for rural clinicians

The Society has advocated for improved management of doctors, and particularly for rural doctors. The Society's collaboration with RuDASA has been positive, often being an advocacy voice for rural doctors who were under political pressure. The very strong support given to two doctors mired in political controversy - Drs Colin Pfaff and Mark Blaylock in KwaZulu-Natal (KZN) - will go down as significant acts of advocacy for all doctors.

*The Society  
has been a voice  
of advocacy for  
rural doctors under  
political pressure*

### CHALLENGING DISCIPLINARY ACTION AGAINST MANGUZI DOCTOR

From 'The ghost of AIDS denialism: Manguzi Hospital and dual loyalty' by Marlise Richter and Donna Knapp van Bogaert, *SA Journal of HIV Medicine*, 2008

'In July 2006, the World Health Organization (WHO) released its new guidelines on Prevention of Mother-To-Child Transmission (PMTCT), which recommended the use of dual therapy where indicated. Despite advocacy efforts to urge the national DoH to revise its PMTCT guidelines in line with WHO recommendations, the 2002 guidelines remained in force. In the public sector, scores of pregnant women with HIV/AIDS therefore received the less efficacious monotherapy.

[Dr Colin] Pfaff, Chief Medical Officer of Manguzi Hospital, as well as other concerned doctors in the province, investigated national and international PMTCT programmes, noting that in KZN 23% of women with HIV/AIDS on the existing single-therapy PMTCT programme transmitted HIV to their infants. This was in contrast to, for example, a less than 5% transmission rate in the Western Cape province where dual therapy had been in use since August 2004. Gravely concerned, in May 2007 Pfaff and his colleagues wrote to the KZN DoH requesting permission to start rolling out dual therapy in the Manguzi PMTCT programme: "We cannot sit in silence any longer."

When the provincial DoH failed to keep its promises concerning dual therapy implementation, Pfaff and his colleagues took the initiative and raised funds from an international donor in order to purchase dual therapy. In August 2007, Pfaff began to implement the 2006 WHO dual-therapy programme at Manguzi Hospital. Six months later, on 25 January 2008, the national DoH released its new PMTCT guidelines.

During the same month as the revised PMTCT guidelines were announced, Pfaff was threatened with suspension. Disciplinary action was taken against him in January 2008 because, as it was stated, he had 'allegedly acted beyond his authority in accepting a donation and implemented a (PMTCT) dual therapy to pregnant mothers and new-born babies without prior permission of his superiors."

*'Pfaff was sent a letter from the Manguzi Hospital CEO asking him to respond to the charge that he 'wilfully and unlawfully without prior permission of (his) superiors rolled out [PMTCT] dual therapy to the pregnant mothers and new-borns. Pfaff has contravened policy. We are not against dual therapy treatment for HIV-positive babies, but it is not something that has been implemented yet. We have not yet budgeted for it and we do not have the capacity yet for it.' He was disciplined by the then KZN Member of the Executive Committee (MEC) for Health.*

*In a statement, the Southern African HIV Clinicians Society said that 'the institution of disciplinary action against (the doctor) for providing better therapy than that advised by the Department is symptomatic of the lack of initiative and crude politicking that still seems to plague our country's response to HIV'.*

*The Society, along with the Treatment Action Campaign (TAC), RHAP, Section 27, Wits Centre for Rural Health, RuDASA and others provided vocal support and worked together to challenge his unfair suspension. The TAC issued the following statement on disciplinary action against Dr Colin Pfaff, on 18 February 2008:*

*"Dr Colin Pfaff and other medical doctors working in Manguzi Hospital have put patients before the process. The AZT he used was donated by Manguzi Mission Fund, so the provincial hospital incurred no cost for the HIV infections prevented by Dr Pfaff.*

*Ms Nkonyeni's statements contradict government policy, particularly the HIV & AIDS and STI Strategic Plan for South Africa 2007-2011, National Strategic Plan (NSP), which explicitly provides for the implementation of dual antiretroviral prophylaxis for PMTCT. We demand that the Manager of Manguzi Hospital and the KZN DoH withdraw disciplinary action against Dr Pfaff. We also demand that Ms Nkonyeni apologise for her inflammatory statements. We call for the speedy implementation of dual antiretroviral prophylaxis."*

*As a result of the public outcry and media reporting on the matter, the Department withdrew charges against Pfaff.*

*The Society, [South African Medical Association] and RuDASA have also shown support to Dr Mark Blaylock, who was suspended for throwing a photograph of [Member of the Executive Committee] Neliswa Nkonyeni in the dustbin, due to his frustration with the never-ending political tension between the MEC and clinicians.*

## Regional advocacy for human rights

**The Society has taken a stand against laws affecting homosexuals in the region, and assisting victims of xenophobic attacks**

The Society's willingness to operate as an advocacy agency for human rights in the region is demonstrated in its letter to the Speaker of the Uganda Parliament, raising concern that the proposed Anti-Homosexuality Bill of 2009 included the introduction of the death penalty for people living with HIV who engage in same-sex sexual activities. The letter strongly stated the Society's belief that the Bill would have a profound negative impact on Uganda's efforts to combat HIV, and it called on Members of Parliament to ensure that this Bill is not passed into law.

The Society was also involved in assisting victims of xenophobic attacks in South Africa to continue receiving ARVs and, where necessary, ensure that they resumed treatment.

## Technical support to advocacy organisations



The Society supports advocacy organisations and processes, by adding the voice of science and fact to the different debates. It provides to other advocacy groups, such as TAC and Section 27, evidence-based information on global and local HIV/AIDS trends. The Society also played a role in other important advocacy initiatives such as the revived Civil Society Coordinating and Monitoring Forum. The Society has played an active and positive role in giving technical, clinical and scientific advice to several other organisations on key issues including:

- Treatment for prisoners — The Society executive provided affidavits to facilitate treatment in the Durban Westville prisoners' case, in the action between the AIDS Law Project and the Department of Correctional Facilities, which has been ordered to provide care to prisoners.
- Testing of the South Africa National Defence Force (SANDF) applicants and personnel — Affidavits were provided by the Society executive in an action brought by the AIDS Law Project against the SANDF, which practised discriminatory HIV testing. This case attracted much media attention and was finalised, in favour of the AIDS Law Project, with Society support.
- Unregistered medicines/treatment — The Society has been involved in actions, together with TAC, against the Rath Foundation, which promoted unscientific and dangerous medical remedies.

## Treatment guidelines

The Society plays an important patient advocacy role through the publishing of treatment guidelines, which have to be seen as being one of the most powerful advocacy tools. These have allowed for rational decision-making in the face of massive historical pressure from government forces. In most countries, guidance documents are hotly debated but are not typically advocacy tools, as they were in South Africa in the face of denialism. In South Africa, where there was a formal process of undermining scientific evidence relating to HIV, these guidelines stand out as a bold set of statements supporting HCWs and advocating for patients.

*Treatment guidelines have served as powerful advocacy tools, supporting HCWs and advocating for patients*

*The need for advocacy became far more acute following 2008. The new dispensation saw a chaotic production of guidelines and choices of treatment. AZT was chosen as first line rather than TDF, which would have had profound implications for the country. The Society weighed in and harnessed every single senior clinician to motivate for TDF. (Past President)*

## National Strategic Plan (NSP)

The Society monitors and informs the development and implementation of national HIV policy, and advocates for policies that support the highest standard of health care. The Society was one of the key organisations that provided technical assistance in the development of the NSP for HIV/AIDS and sexually transmitted infections (2012-2016), which is the guiding document for HIV policy in South Africa. The Society provided direct technical support to the drafting process, as well as dissemination of the targets set by the NSP, in the *SAJHIVMED*. The Society set up an NSP committee, consisting of key Society members from the executive committee, the paediatric sub-committee and the nurse advisory board. The purpose of the committee was to develop recommendations for realistic targets and monitoring strategies for the treatment, care and support portion of the NSP. The Society's then-president, Prof Francois Venter, played an integral role in writing the plan, and the members were routinely updated on its progress.



The Society partnered with other civil society organisations through the Civil Society Coordinating and Monitoring Forum to ensure that civil society had a voice in the development of the plan. The Society worked closely with the DoH and SANAC on the plan through its participation on the council's technical task teams. The Society also facilitated member input into the development of the plan. In addition, the Society provides continued support to the DoH in updating existing treatment guidelines.

## Monitoring NSP and other HIV policies

The Society supports the government in its implementation of the NSP. It monitors and reports, through its network of health workers, NSP implementation problems such as ARV drug stockouts (unavailability of ARVs at the health facility), budget shortfalls and drug resistance.

The Society continues to monitor implementation of the NSP through its member committees, board, and partner organisations, and to engage the membership when challenges arise. The Society, through its network of HIV HCWs, is able to provide critical information on implementation of the HIV programme on the ground. The Society utilises this network proactively to gather evidence to inform its positions on proposed policy and legislation, and to respond to implementation problems as they arise (e.g., the Society contacts members in specific areas of the country to collect information on ARV drug stockouts, human resource problems, budgetary shortfalls, etc.). The Society also routinely monitors key aspects of implementation through the use of short surveys to its membership and/or online polls included in *Transcript*.

***The Society monitors and informs national HIV policy, and advocates for policies that support the highest standard of health care***

The Society supports board and guideline committee members' travel and time to attend national technical meetings, including meetings held by SANAC and the Essential Drugs Programme.

These activities provide evidence-based information to assist the DoH in assessing the implementation of its HIV policies and programmes, and provide a mechanism for Society members to bring serious problems that affect health service delivery to the attention of the DoH. The information collected also informs the Society's policy positions and advocacy initiatives.

The Society's president and other senior members of the executive committee have advocated for the successful implementation of the NSP and where necessary intervened to ensure that scientific, evidence-based information guides the implementation thereof. Examples include:

- Motivation to the DoH for Stavudine to be replaced with Tenofovir as first-line therapy for the national programme. The Society recommended a key change to the national adult treatment guidelines that was agreed to and adopted;
- Formally complained about delayed switching of antiretrovirals in KwaZulu-Natal after complaints were received about the onerous bureaucracy required of clinicians when switching drugs for toxicity or due to resistance;
- Raised the issue of the delay in registration of critical ARVs by the Medicines Control Council (MCC) in South Africa; and
- Advocacy for accelerated access to more effective national ART and PMTCT regimens — the Society formally requested an explanation from SANAC for the delay in implementation. SANAC managed to have the local updated guidelines released in early 2008.

## Roundtable discussions on emerging issues



The Society raised awareness and encouraged debate and discussion on important emerging or controversial issues that impact HIV policy and management by holding a series of roundtable discussions involving key stakeholders. It capitalised on the existing CME meeting infrastructure to hold these discussions. Discussion papers from the meetings were developed and disseminated to all Society members and stakeholders (DoH, MCC, SANAC, the media, partner organisations, etc.). Besides raising awareness and encouraging open debate, the Society believes that these meetings and the subsequent discussion papers influence long-term public health policy development.

In October 2011, the Society held a debate on the government's new policy on infant feeding, and more than 150 people attended to hear the pros and cons. Participants were able to provide input through hand-held voting sets.

At the end of March 2012, the Society held its second debate on whether homoeopathy should be used in the treatment of HIV patients. More than 90 people attended.

In October 2012, the Society held another debate on science and conspiracy in HIV, focusing on recent challenges to such proven HIV prevention methods as circumcision, TB drug-induced liver injury, whether informed consent was necessary in clinical care, and when to start antiretroviral treatment.

During the Society's conferences, several roundtable debates have been held, ranging from the use of Stavudine to adherence, the Child Care Act, sexual violence, ethics of testing, etc.

## Media exposure

The Society continues to play an influential role within the media in relation to HIV/AIDS clinical issues. The Society's marketing strategy has been a key element in raising its successful and influential media profile. The Society president and executive committee members have given extensive interviews to a range of medical journalists from the print, radio and television spheres.

The issues that have been discussed include:

- The NSP;
- ARV rollout programme;
- HIV testing and counselling;
- ARV prices;
- Prevention of mother-to-child transmission programme;
- HIV and ageing;
- Tuberculosis and extensively drug-resistant tuberculosis;
- Circumcision;
- Rural doctors and treatment of HIV/AIDS in rural areas; and
- Guides for clinicians and patients during the public-sector strike.

Advocacy opportunities are sought with media, religious groups, unions, education groups, business leaders, the military, the police, and 'non-health' strategic government ministries, such as Departments of Trade and Industry, the Treasury, Foreign Affairs and Arts and Culture, including breakfast meetings for the media with key commentators.

The Society has issued the following press releases, letters to the media and publications:

***The Society continues to play an influential role within the media with regard to HIV/AIDS and related issues***

- Delay in Registration of Antiretrovirals by Medicines Control Council (March 2010);
- Dysfunctional MCC Under Legal Threat; Chris Batemann *South African Journal of Medicine* (May 2010);
- Delay in Registration of ARVs by MCC; *Plus News* (March 2010);
- MCC Blocking Access to Lifesaving Meds – HIV Clinicians; Anso Thom (March 2010);
- Open Letter to Parliament of the Republic of Uganda Regarding the Anti-Homosexuality Bill 2009 (January 2010); and
- Various articles on tuberculosis, HIV counselling and testing in schools, HIV-positive child care, urban legends, lipodystrophy.

The Society has written letters on a number of issues that have impacted patient care, including:

- The shutdown of services by the National Health Laboratory Services (NHLS) due to lack of payment by provinces;
- The need for a unique patient identifier;
- Drug shortages and stockouts;
- Overcharging and/or denying care to foreign patients at Gauteng hospitals;
- The Ugandan anti-homosexuality bill;
- The change in the pharmacy bylaws allowing self-testing HIV kits to be purchased legally;
- 'Fake' products that lack science and promise HIV cure; and
- Poor media reporting on drug side effects such as lipodystrophy.

## Essential Medicine Stockouts

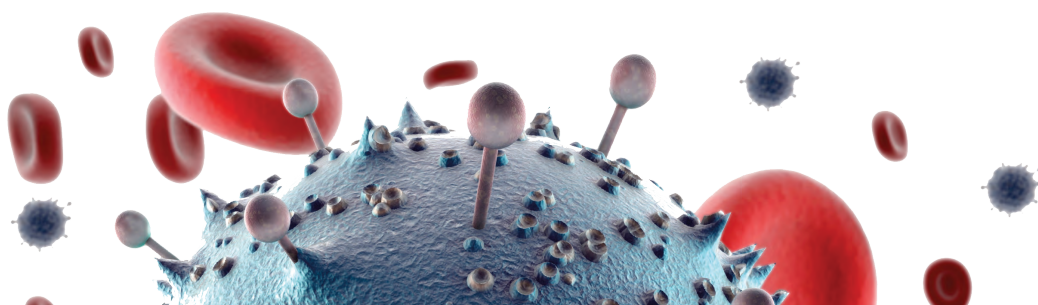
Drug stockouts have been identified as a particularly serious issue with life-threatening consequences for people living with HIV.<sup>2</sup> The reasons for stockouts are varied and persistent, including problems with the supply chain, procurement, communication between clinics and depots, and accurate forecasting. The DoH is well aware of the issue and has been working with partners on strengthening pharmaceutical systems. Despite the awareness and technical assistance, the situation is not improving, and inconsistent access to ARVs seriously compromises HIV and TB management.

The Society has worked in informal and formal partnerships with health workers, communities, government and other organisations to address the challenges related to access to medicines.

The Society's role, when alerted to stockouts by health providers, was to provide rapid advice to nurse and doctor clinicians on how to manage patients in the event of stockouts.

Initially the Society had been involved only at the point of emergency, i.e., providing guidelines to

<sup>2</sup> Stockouts are defined as the unavailability of specified medicines from the health facility stores.



## PROVIDING RAPID ADVICE

HIV-infected people need an uninterrupted medical supply; missed doses of their drugs may have devastating consequences.

In June 2011, faced with a shortage of Amphotericin B, the Society sent a letter to the manufacturer to gain more information on the crisis, and sent an all-member email outlining how to manage patients in the absence of the drug. Similarly, in August the Society's Child and Adolescent Committee worked with SANAC's technical task team to provide guidance on the use of Tenofovir in children 16 years and younger in light of Abacavir tablet shortages.

During 2012, the Society responded to reports of Tenofovir shortages and developed guidance for clinicians on how to manage patients. There have since been 3TC, EFV, Lamivudine, Tenofovir and Abacavir shortages, as well as Moxiflox. The Society has dealt with them on a case-by-case basis, as they worked with the civil society partnership to try and raise funds to address the stockouts issue more methodically.

clinicians experiencing drug shortages. The Society continued this role, but the board of directors raised the imperative to intervene with the DoH at the systems level. The Society began working with both SANAC and the DoH more closely on how to resolve stockouts.

Rural health workers had been highlighting problems and raising attention to the challenges of drug stockouts in Eastern Cape. In 2013 Médecins Sans Frontières (MSF) and Treatment Action Campaign (TAC) were involved in the Mthatha depot intervention. It was in this context of increasing awareness of system failure that the Society formed partnerships to jointly address the growing problem of drug stockouts.

## SENTINEL SURVEILLANCE

The Society partnered with Section 27 and the RHAP to develop a system to collect routine information on drug stockouts. The goal of the programme was to develop 'sentinel surveillance sites' at key hospitals and clinics in largely rural provinces and to monitor drug and medical supply stocks and any shortages that arise. The Society encouraged members to report stockouts when they happen, and several health workers have registered to serve as 'sentinel surveyors', which means they indicate whether any essential medicines (based on a predefined list) have been out of stock in the previous month. These data have helped provide a picture of medicine stocks at sentinel clinics and hospitals across the country.

The Society and partners conducted a needs assessment to determine the main reasons for drug shortages and to define a list of drugs/medical supplies to routinely monitor. Results were shared with key stakeholders, including the DoH, SANAC and Management Sciences for Health (MSH), an NGO which provides technical assistance to DoH on pharmaceutical systems.

This assessment of existing drug and medical supply shortages not only provided additional information on problems affecting the implementation of the NSP but allowed urgent interventions to prevent and address drug stockouts. They shaped the language of 'stockouts' as a shorthand that would capture public and political attention for the broader health crisis — a standardisation of language that is a sign of a network consolidating itself.

The Society's stockouts project, a partnership with the RHAP, regularly collected HCW-reported medicine stockouts and liaised with the DoH to help resolve the issue. However, the chronic and ongoing nature of the problem, along with limited organisational resources, led the Society and RHAP to join forces with TAC, SECTION27, MSF, and RuDASA to create the Stop Stockouts Project (SSP).

## COALITION TO MONITOR AND ADDRESS DRUG STOCKOUTS: THE STOP STOCKOUTS PROJECT (SSP)

In 2013 the Society, in partnership with RHAP, RuDASA, MSF, TAC and Section 27 formed a consortium organisation – the Stop Stockouts Project (SSP). The goal of the collaboration is to help ensure reliable availability and access to medicines and medical supplies in South Africa by monitoring and reporting medicine shortages and stockouts when they occur.

By pooling resources, the consortium was able to hire project staff and engage in a full-time effort. The project is funded and supported by all five organisations; each organisation is represented on the SSP board and the Society provides in-kind support of office space to the project manager, administrator, and mobile health (m-health) advisor. Interestingly Atlantic has funded five of the six consortium partners in SSP although their decision to collaborate was not related to the fact that they were fellow grantees of Atlantic.

The project's focus is on monitoring and reporting medicine stockouts across the country. It has two processes of surveillance. The first reaches out through all its member organisations to health providers and community service users — including to the formal clinic committees where community members have representatives — providing a system for them to alert the SSP of a stockout. Any patient or health-care worker can report a stockout of a medicine via telephone, email, [text message] or WhatsApp. Once alerted, SSP staff will investigate the report with the clinic, depot, and provincial and national health departments, if necessary, escalating their queries upwards until they are resolved. These individual alerts provide early warning of potential national stockouts resulting from supplier problems.

The second surveillance system is a national telephonic questionnaire survey asking facility respondents (head nurse or pharmacist) whether the facility had experienced a stockout or shortage of a medicine, and probing for more information if they had. This enabled the SSP to identify the magnitude of drug stockouts and produce a report on the number of public health facilities that had reported a stockout or shortage of ARVs and/or TB medicine in the preceding three months.

*The Society is the clinical partner in the consortium. We can look at the issue from the perspective of the impact on the patient. (CEO)*

The first SSP survey was conducted in 2013. Of 3,846 clinics, 2,432 (61 percent) were contacted and only 9 percent of those refused to participate in the survey. Of the 2,139 facilities that did provide information, 1 in 4 faced a stockout or shortage of ARV or TB medication within the three months prior to being contacted. Approximately 1 in 10 facilities experienced problems with vaccine supplies. Half of these supply issues were ongoing at the time of contact.

One in five facilities reported that patients were referred elsewhere and/or sent away without their medications. Other consequences of stockouts such as changing the patient's regimen and giving the patients less than a month's supply were also noted.

In late 2013, the SSP shared the findings of the first survey with the DoH and provincial heads of pharmacy, and released its report on which *Health-e* reported as did other media. An article entitled



'Widespread stock outs of HIV, TB meds "a national crisis"' by Health-e,<sup>3</sup> published 29 November 2013 , stated that:

*More than ten percent of all health centres in the country have experienced stock outs of HIV and tuberculosis (TB) medicines in the last three months, jeopardising the health of millions of South African [sic]. The findings are part of a new report released 28 November by a civil society coalition ... under the banner of The Stop Stockouts Campaign. Between October and September 2013, the campaign interviewed about half of all health facilities in the country. One-in-five health centres surveyed reported shortages of HIV and TB medicines in the last three months. The Free State was the worst affected province, with more than half of facilities surveyed reporting stock-outs.*

The project established a working relationship with the Essential Drugs Programme at the DoH and works in partnership with national and provincial staff to resolve stockouts. Historically, the Society has recognised DoH for its acceptance of the problem and its commitment to addressing and resolving many of the reasons behind stock shortages. DoH, however, was deeply unhappy with SSP for publishing its survey and releasing it to the media. The first survey was met with hostility by the minister of health, who addressed press conferences and issued statements denying the extent of the crisis, attacking TAC for dishonesty, and placing blame on manufacturers. SSP, however, found that only 20 percent of stockouts reported during the survey were manufacturing related and that poor planning, management, and coordination were behind the bulk of stockouts. The handling of the release of the first survey report unfortunately caused a rift between the Society and senior DoH staff, and the Society has worked to repair the relationship.

The SSP learnt from this experience. Partners further tightened the methodology of the second survey while also working hard at building relationships with the DoH. They negotiated an 'escalation protocol' that gives the DoH two days to respond to a stockout query from SSP at each level (clinic, district, or province). If the problem is not addressed, SSP goes to the media.

*It didn't start on a good footing, but when we set up the escalation protocol, it worked better. It is benefiting government because it is working closely with the very patients we serve — we have a shared interest and we appreciate that. Going forward we need to understand what society is saying and how they think the process can be improved, instead of a top-down approach. (Director, Medical Supplies Depot)*

SSP has also developed more constructive engagement with provinces on the findings of the survey. The Head of Department (HoD) and member of the executive committee of Gauteng DoH sent out a circular to facilities to cooperate with SSP. There has been some engagement with Limpopo, Mpumalanga, and North West, but the relationship with Free State has been fraught. SSP maintains a delicate balancing exercise between continued positive engagement with those provinces that submitted action plans to reduce stockouts and the political engagement with the minister around his denial of the problems.

*In the first SSP report of 2013/2014, we did not pay sufficient attention to the rigour of the methods, the quality of the data, and the interpretation of the findings. Some involved don't have the same rigour in critically appraising evidence, e.g., a case study was included in the report of someone who ran out of medicines, but we didn't review the report critically enough as clinicians to comment that this particular drug shortage would not necessarily have affected this particular patient. The DoH took particular objection to the Society because of its clinical expertise role in the consortium. While this was a valid piece of work, it needed to be re-done with a far more hands-on approach, evaluating critically what was really important in the report. For the subsequent report, the Society has been more involved with the content, and SSP has put together a good report. Whereas the first report was seen*

3 <http://www.health-e.org.za/2013/11/29/widespread-stock-outs-hiv-tb-meds-national-crisis/>



*to be critical of government, the subsequent report provided greater rigour in describing the methods and the interpretation of results. SSP has held meetings with key DoH managers of the national HIV and pharmacy programmes who now see the SSP as one measure the DoH can use to determine what's happening on the ground. It has become a much more collaborative process. (Board President)*

## INFORMATION MANAGEMENT SYSTEMS

**'Communication is the mainstay of the Society's activities' for its members and wider society**

The Society's objective focused on information management aimed to strengthen the Society systems used to disseminate and communicate valuable resources and information.

The Society uses a number of platforms to communicate with members — website, direct mailers, social media and text messages — so that they are able to hear about news, events, and publications, as well as submit feedback via various channels. They strive to find the most convenient ways to engage with and maintain a dialogue with members. Since 2013, the Society has been assisted by a dedicated social media and communications intern who is responsible for maintaining the website and social media forums while also responding to queries.

The Society appears to have appropriate links to other organisations and has established itself as a credible and respected voice in HIV/AIDS communication — an honest broker — in the country.

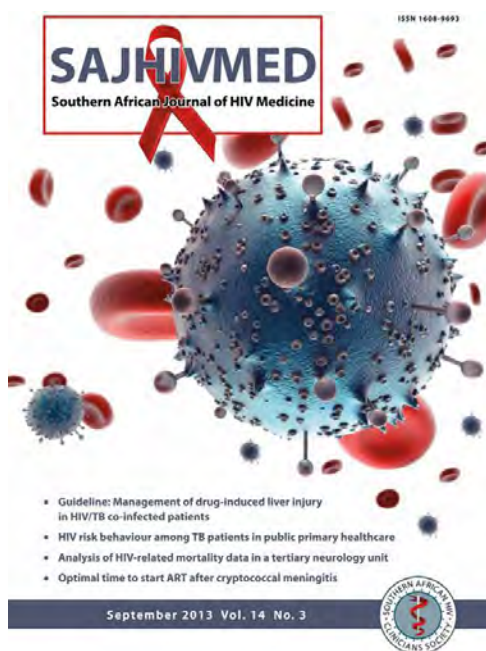
*As an information/knowledge-provision organisation, communication is obviously the mainstay of the Society's activities — both in terms of communicating with members and communicating to the wider society. The SAJHIVMED, Transcript, HIV Nursing Matters, Internet discussion forums and the website are all appropriate and well-received and appreciated communications products, and the Society should be congratulated for keeping them going and being successful. (External evaluation, 2010)*

## Publications

Through the Society's publications — the *SAJHIVMED*, *Transcript* and *HIV Nursing Matters* — the organisation reaches thousands of HCWs every month. The Society's key strengths are the wide reach and coverage through its publications, which supply information on training courses, symposia, conferences, monthly branch meetings, current ARV prices, and clinical guidelines.

### *The Southern African Journal of HIV Medicine (SAJHIVMED)*

The Society's flagship publication, the *SAJHIVMED*, publishes original research, case reports, commentary, and reviews on a quarterly basis. First published in 2000, this Society journal serves as a vehicle for providing up-to-date, evidence-based information on HIV management to HCWs in Southern Africa, and is one of the Society's most popular programmes. It is an important resource and ensures that members have access to information that is both in line with international best-practice standards and specifically relevant to the Southern African context.



The *SAJHIVMED* is one of the most-sought-after medical journals in the country, and the Society has consistently printed up to 4,000 copies of each edition, also accessed by more than 10,000 people online where it is freely available.

All Society guidelines are published within the *SAJHIVMED*. The journal is also a major vehicle to distribute posters on clinical management issues that are well received by doctors and HCWs, and it includes a questionnaire for which four continuing professional development (CPD) points are awarded to the member for each completed and correct questionnaire returned.

The *SAJHIVMED* is now published online with articles published on a rolling basis throughout the year. The current editor-in-chief is Michelle Moorhouse, with the following editorial board members: Linda-Gail Bekker, Ameena Ebrahim Goga, Anneke Hesselning, James McIntyre, Koleka Mlisana, Keymanthri Moodley, and Francois Venter.

### Distribution

The *SAJHIVMED* is circulated to Society members, pharmaceutical companies, academic institutions and public and private-sector organisations. It is also distributed to, amongst others, national and provincial DoHs, all government ART roll-out sites, public libraries, academic institutions, and NGOs free of charge. The *SAJHIVMED* is distributed throughout Africa, and is the only source of up-to-date information that actually gets through to rural areas. Archives are available to view online. In the past, hard copies were posted out, but the journal has since become completely online, due to a shortage of funding to cover printing and dissemination. The Society intends to publish an annual “bumper” edition, to include important topics from the journals of that year, should funds allow.

### Funding

Although pharmaceutical companies contributed greatly to offset the annual cost of the *SAJHIVMED* in the past by purchasing advertising, this supported only a small proportion of the annual cost to produce and disseminate it. The Society also obtained funding from Atlantic to professionalise the journal, which was thought would attract additional donors. Editorial and reviewing support remains voluntary. The decision to change to an online journal was informed by cost and necessitated a change in 2015 to a publisher that was experienced with online journals.

### Professionalisation of the *SAJHIVMED*

In the past, there appeared to be limited editorial board involvement, with the editorial board acting more as reviewers within their speciality areas rather than playing an active role in planning issues; members of the Board also reviewed articles. The majority of decisions relating to the journal were made by the editor.

The Society faces numerous challenges in ensuring adequate and appropriate copy in a timely fashion including the fact that the editor works on a volunteer basis and has limited time to devote to the day-to-day management of the *SAJHIVMED*. A memorandum of understanding is now in place between the editor and the Society to ensure that the roles and responsibilities of the editor are formalised. If the Society were to hire a dedicated managing editor, this would make publication more sustainable in the long term, but in the current context this is not affordable.

The Society embarked on a number of activities including establishing an editorial committee, developing a standard operating procedure, developing a plan to increase the number of original research articles submitted, and developing a budget to fully fund the *SAJHIVMED*, including an accreditation plan.

There appear to be sufficient procedures in place, such as a conflict-of-interest rule, peer review, a formal guideline for authors document, a free-access policy (via the web), and a variety of other formal processes that regulate the *SAJHIVMED*. The Society journal underwent a marketing, rebranding, and redesign process.

The Society previously outsourced the advertising for its journal to its publisher. However, in 2013, the Society brought this task back into the secretariat as part of the *SAJHIVMED* sustainability plan. The Society conducted due diligence of the steps and activities required to publish in-house. The Society held discussions with the International AIDS Society (IAS) to learn more about publishing an online, in-house journal, and IAS committed to provide technical support. Publishing in-house is a significant undertaking, and it is not yet clear whether this will be a cost saving to the organisation. When the contract ends at the end of 2016, the Society intends to move the journal publication in-house.

## Accreditation

The *SAJHIVMED* has been accredited by the Department of Education, which is an incentive for researchers to submit articles.

The *SAJHIVMED* has been CPD accredited and has a formal impact rating. The Society began the accreditation process with PubMed in February 2014. It was believed that once the *SAJHIVMED* received PubMed accreditation, which is a formal recognition of academic merit, more researchers would submit articles — thereby ensuring sufficient quality advanced copy. Ensuring quality content without accreditation remains a significant challenge.

The Society continues to struggle to publish enough original research to increase its impact factor; accreditation will simply make the *SAJHIVMED* a more attractive place to publish. The key to sustaining the journal over the long term lies in achieving accreditation.

## Value of the *SAJHIVMED*

The majority of members surveyed in a programme evaluation stated that the *SAJHIVMED* is an invaluable resource in their clinical practice. The journal appears to be well appreciated by its target audience and fills a gap for credible, peer-reviewed, expert information on the HIV epidemic in the country.

*The SAJHIVMED editorial and operational staff need to be congratulated for this publication. It is a tribute to the Society that this can be done with a volunteer editor and with the ongoing quality that is achieved. The Society journal is very well received within its recipient community. There is room for more primary research to be published in the Journal (as opposed to requested review articles), over time. (External evaluation, 2010)*

The Society's journal is highly valued and a prized source of information around the region. Stakeholders commented that the *SAJHIVMED* is critical as an insightful medical reference and is the best read in Southern Africa, providing up-to-date information on cutting edge issues for doctors in both the public and private sectors. The journal is said to be practical and solution-oriented for the target groups. Charts and guidelines provided in the *SAJHIVMED* are reproduced and observed at clinics around the country.

*I happened to have a copy of the SAJHIVMED with me when I visited a public hospital in Dar es Salaam. When my colleagues there saw it, they immediately read it from cover to cover. It was the first up-to-date, reliable information they had received in over a year. You guys don't know how lucky you are. (Society member)*

*Whatever you do, do not discontinue the SAJHIVMED. That's how important it is! (Society member)*



## Transcript

The Society publishes and disseminates its newsletter *Transcript* bi-monthly. *Transcript* is newsy, focusing on issues of current interest. *Transcript* provides members with the latest information on educational resources such as CPD meetings, upcoming training sessions, branch meetings, conferences, job openings and bursaries, ARV drug prices, new publications, and support services available to HCWs.

The newsletter also allows the Society to raise topical and emerging issues, for example highlighting health service delivery problems that developed in the wake of the xenophobic attacks in South Africa in 2008. It has contained hard-hitting information on the Society's position on xenophobia, displaced people and other matters of importance to the country's clinicians. *Transcript* also contains information relevant to drug prices and pharmaceutical companies.



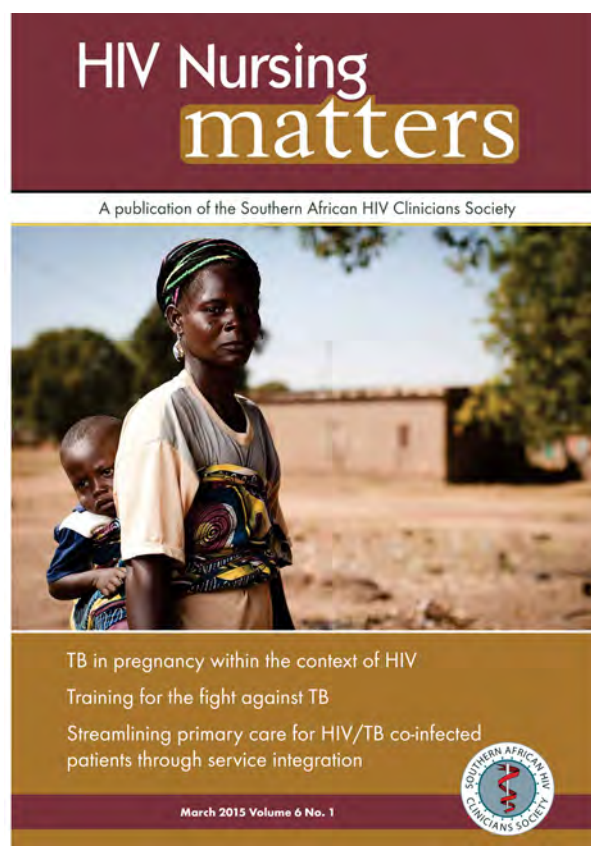
The purpose of the newsletter is to report back to the membership on Society activities and share information of potential interest. *Transcript* seems to play a useful role in maintaining communication with the Society's membership, and acts as a good marketing tool. It is often the primary source of information on available resources for members who do not have access to e-mails and the Internet.

*Transcript* has been redesigned and is now available in a more attractive format. *Transcript* was initially published quarterly, to coincide with the *SAHIVMED*, but, due to demand, publication was increased to bi-monthly issues. A more frequent publication schedule allowed for more timely information on resources of use to members. Since 2012 the Society no longer posts hard copies of *Transcript* to members (it did in the past, particularly to rural doctors who did not have regular internet access, but due to funding constraints this has been stopped). The newsletter is available to download from the website and is now online-only. It is also emailed to the membership. *Transcript* is self-funded.

## HIV Nursing Matters

The centrepiece of the Society's nurse programme is its magazine *HIV Nursing Matters*, first published in 2010. The magazine is targeted at nurses administering or managing ARVs in the public sector and features clinical, programmatic, and policy articles, and updates. The magazine serves as a resource for nurses providing HIV services, including the initiation and management of antiretroviral treatment. Its format is less academic and more reader-friendly.

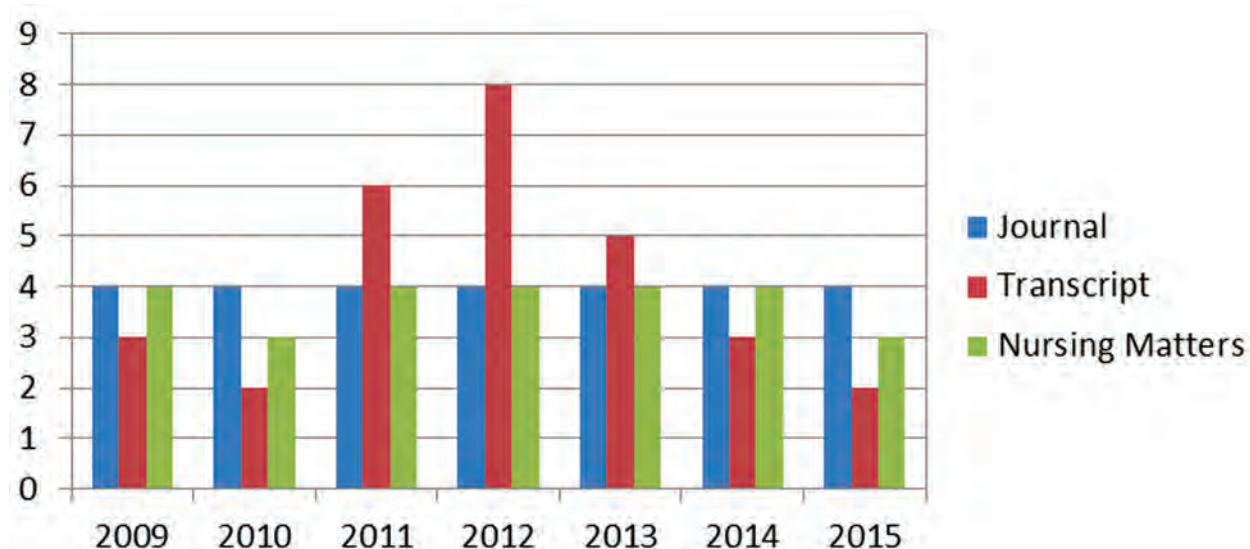
The magazine is published quarterly; the editor is supported by a four-member editorial committee



consisting of doctors and nurses, who provide strategic advice and recommendations on the content and focus of the magazine.

In 2012, the Society refined the magazine's dissemination strategy and established partnerships with HIV training organisations. These adjustments have enabled the Society to more effectively target nurses involved in nurse-initiated management of antiretroviral treatment and to provide additional resources and information with the magazine.

Figure 7: Number of HIV publication issues, 2009-2015



## Website

The website for the Society ([www.sahivsoc.org](http://www.sahivsoc.org)) underwent a significant overhaul in 2007, allowing viewers to easily access electronic copies of previous editions of the *SAJHIVMED*, upcoming branch meetings and events, the latest ARV drug prices, as well as updated treatment guidelines and current news and statements released by the Society. The website includes new programmes such as clinical case studies and the e-newsletter, *Transcript*, as well as online CME (branch meeting) programmes. All of the Society's publications are posted on its website, and the site is perceived as a valuable resource by the membership. The website also allows a quick link to joining the Society as a member.

In 2010, the website had 1,200 unique visitors per month. The Society envisioned its website as a hub for all Society resources and information. The most-visited pages in descending order are:

- Statements;
- The electronic version of the *SAJHIVMED*;
- Clinical guidelines; and
- Contact pages.

In 2011 the Society realised that though the website had been adequate to support all of the Society's programmes to date, it had been developed with a basic technology that was incompatible with the new database under development. The Society launched a redesigned website and worked with a database developer to develop a customised, web-based membership database that has automated many of the membership activities (e.g., invoicing, mass emailing) that were previously done manually. The website was also upgraded to allow for a linkage between the two; members can now log in to the website to view (and update) their contact details; download invoices; and download CPD certificates received for branch meeting attendance or online clinical case studies. The new database has made member services considerably more efficient.

The upgrade improved the look and feel of the website, but the back end was not user-friendly. It is now run using software that allows for updating to be done by a member of Society staff in the office. This ensures for faster, more efficient, and more accurate updating of information. The website is now up to date and fully functional with a capacity to hold more information. As the Society continues to grow, so the website becomes more interactive and technically advanced.

With the new database/website capabilities, members of the public are now able to go to the Society's website and search for an HIV provider based on location. The online HIV provider directory uses information from the database.

An improved design, and the addition of the member profile and provider directory, resulted in more members using the website on a regular basis to access Society resources and publications. The Society believes that this enhanced functionality is perceived as a benefit of membership and anticipates that over time the organisation would offer member-only online resources.

The Society also has a significant Facebook and Twitter following. The latter half of 2012 saw the Society start to focus on developing social media in the form of Facebook, YouTube and Twitter. During 2013, the Society also launched a blog. The Society's Facebook following has grown from 200 in 2013 to 2,800 in 2016. Twitter followers have increased from 50 in 2013 to 982 in 2016.

## Karabo

In the absence of other reliable and up-to-date sources, the Society in the early years received approximately 100 requests per month — from members and non-members — for information and contact details of HIV clinics, in specific locations and geographical areas. This service was provided on a reactive basis by the Society's database manager accessing information from the membership database. The Society was able to provide the public, HCWs, and other HIV organisations with referral lists of doctors in specific geographical areas who had training in HIV management and who were available for patient referrals, but the system was cumbersome and did not allow for real-time referrals. The Society realised there was a huge unmet need in the South African community, amongst the public, patients, clinicians, help lines, and corporations, for access to accurate and reliable information regarding clinical services.

The Society set out to develop a web-based, searchable directory of HIV clinicians for patient referrals that would be accessible to the public through the Society's website. An online provider directory would allow the Society to better serve its members and the public, to facilitate patient referrals, and to link people living with HIV with appropriately qualified clinicians. It also had the potential to draw new funders who are interested in accessing HIV clinicians.

The Society, in partnership with Soul City and LifeLine embarked on an ambitious project to create an easily accessible website ([www.karabo.org](http://www.karabo.org)) that would give access to all public and private clinics/premises and service providers in South Africa. The site provided a countrywide summary of HIV services, provided health-care professionals with relevant information to assist them in referring patients for treatment and other services, enabled the public to identify local HIV services providers, and provided information on location, services available, contact details, opening hours, etc. Additionally, the website provided basic information to users on a wide range of HIV-related issues, e.g., individuals rights, 'What is HIV?', prevention, counselling, and treatment, web links, etc.

The vision of the website was to increase the number of people who know their HIV status and enable users to locate their nearest counselling, testing, and treatment sites through a national database. This information was



provided on the website through a comprehensive series of maps and an up-to-date database that allowed users to find relevant counselling, testing, and treatment sites in different cities and towns. Once a hospital or clinic was selected, the website provided names of relevant HCWs at each facility, the address, landline and sometimes cell phone numbers, the related services provided at the clinic, and languages spoken. This website was also user-friendly and provided information including general information on counselling, testing, treatment, nutrition, antiretrovirals, and myths on HIV/AIDS and TB. Statistics of the disease in South Africa were provided as were links to other useful sites. A further link allowed other counselling, testing, and treatment sites to upload their details. Similarly, a short message service (SMS) was also attached to the website, allowing users to access similar information over their cell phones.

Karabo was completed in September 2007 and remained the Society's major source of information on HIV testing and treatment sites in South Africa. In November 2007, Levi's 'Red for Life' temporarily donated an SMS that allowed the user of any cell phone to obtain information directly from the site by sending a text message. The system responded with the names and contact details of three testing or treatment sites in that person's vicinity. Karabo continued to be a valued source of information for the LifeLine call centre operators and received 20,000 to 30,000 hits per month.

The updating of the database on the Karabo HIV Information website was later managed by the Foundation for Professional Development (FPD). The Compass Project and HIV-911 produced print directories that listed a number of HIV services in every province. Their core business was to have the most up-to-date and accurate information on where HIV-infected and affected people may receive support. These details were easily transferable onto the Karabo mainframe via technology held by FPD. FPD managed this process and handled the hosting of the Karabo website whilst the Society still owned the rights to the name and any design-related changes. In 2011 this was handed over due to lack of funding and has not been operational for many years. The DoH now has a mobile app with the clinics geo-mapped, which has replaced the need for the website while drawing from the model and purposes Karabo was initially intended for.

## Online groups

The Society has also had a number of web-based topical discussion groups that have proved useful in bringing together a large number of specialists. These are essentially interest groups where people come together and give their input on a particular subject and on case studies. This has proved to be highly successful for the development of guidelines.

***The Society maintains a dialogue with its members via convenient ways – website, direct mailers, social media and SMS***

### Paediatric Discussion Group (Manager/Moderator - Dr Leon Levin)

The Society's paediatric discussion group (PDG) has been in existence for at least five years. There are currently 1,800 subscribers who come from South Africa, and also Angola, Botswana, Kenya, Malawi, Namibia, Rwanda, Zambia, and Zimbabwe. Subscribers are predominantly doctors but include nurses, pharmacists, and counsellors. In this discussion group, a case is sent out on email, discussants are then free to reply, and responses are sent out to the whole group. At the end of each case, expert opinions are brought from overseas or locally, and a denouement of the case is given. The discussion group is currently completing case Number 47. Cases discussed are real and are chosen to include controversial or little-known issues in paediatric HIV. Patient details are removed to ensure confidentiality. Ethical issues have also been discussed. Feedback from subscribers has been phenomenal.

### Policy and Ethics issues in HIV Group (Manager/Moderator- Ms Mary Carmen)

The HIV Ethics and Policy Discussion Forum was launched in October 2006 and has 315 members. In the past, the discussion took the format of a case study that was sent out to the members via email. Members were invited to submit comments that were sent out to the discussion group as a whole. After various inputs and opinions had been received, a member was invited to write a conclusion taking into account the various ethical and policy debates raised by the respondents. Eleven case studies have been discussed and have included topics such as HIV in the military, HIV testing, dual loyalty, PEPFAR funding requirements, the ethical implications of HCW strikes, medical parole and prisoners with HIV/AIDS, prevention resource allocation for men who have sex with men in an African context, and the role of the criminal law in HIV/AIDS issues. A number of the case studies have been written up as articles for the *SAJHIVMED*. The group has now transitioned into information posting rather than a discussion group.

### Resistance Discussion Group (Moderator – Dr Jeremy Nel)

A list serve was started, as well as an online discussion group for resistance cases. This group started in 2015 and has been building slowly.

### Adult HIV Discussion Group (Manager/Moderator - Dr Francesca Conradie)

This discussion group ran for a brief period and had a subscription of 450 members. The members were from many countries, notably Botswana, Namibia, South Africa, and Zimbabwe. There were also members from France and the United States. They were from diverse backgrounds, including physicians, general practitioners, case managers for medical aids and other managed-care programmes, nurses, and counsellors. A new case was sent out every six weeks. The cases were changed once all the topics had been discussed. Depending on the case, there were usually between 40 and 70 replies. One major challenge was appealing to such a wide audience. In dealing with this, the moderator tried to pitch different cases to involve different levels of expertise, knowledge, and resources. The poll sent out at the end of 2007 noted that cases on toxicities and opportunistic infection were most in demand.

The discussion group moderators are paid a small honorarium. The Society has had discussions with funders about potential support for the paediatric discussion forum. There is interest in clinical forums, and the Society will work to publicise and promote these discussion forums more broadly to potential funders. The Society aims to increase the number of case studies dealt with by the existing discussion groups and increase the number of members subscribing to this service.

A successful discussion group requires both the right facilitator and well-defined goals and objectives. There are different levels of participation in discussion forums — largely related to interest in the topic and the degree of involvement and passion by moderators. It is challenging to review cases in depth via this forum, which lends itself more to short overviews of cases that facilitate discussion.

### Online clinical case studies and *SMS Clinical Tips*

To meet the goal of providing case study learning opportunities, the Society implemented an online, CPD-accredited clinical case study programme in 2011. The Society's online clinical case study programme provides high-quality CPD-accredited HIV education via the Society's website. This e-learning programme enables clinicians to further their education at their own pace and in their own time.

Cases are written by experienced HIV specialists and can range from management of general adult HIV/TB to specialist paediatric cases to related infectious diseases encountered when managing patients with HIV. The user must answer a series of questions correctly to be eligible to receive four CPD points. The Society currently has seven cases online, and the library is growing. The Society intends to add more cases to its clinical case study library and further develop interactive, web-based case learning through its website. To date, nearly 200 members have completed at least one of the case studies.

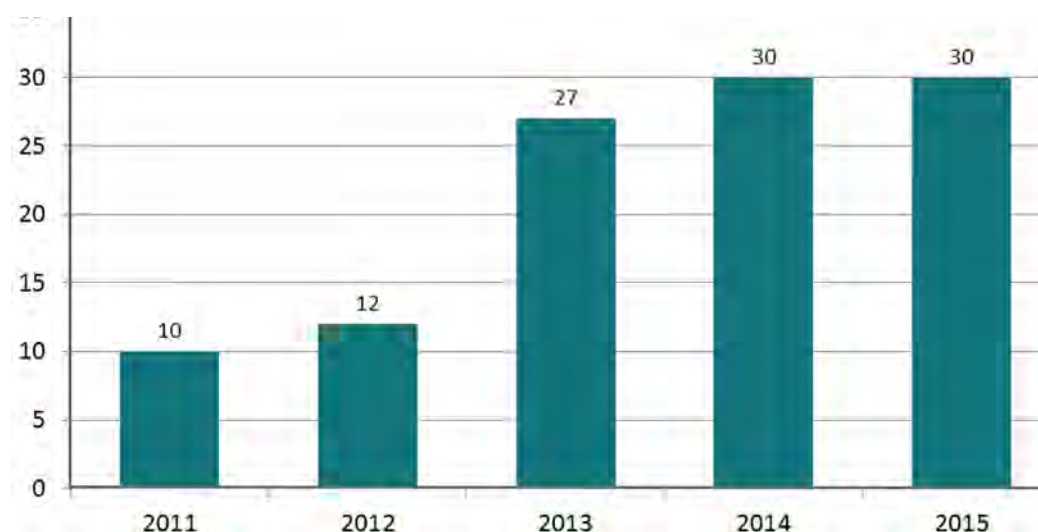
*SMS Clinical Tips* are short, clinical messages sent weekly to approximately 1,800 Society nurse members. Tips focus on ART guidelines, including appropriate ARVs and eligibility, side effects, prevention of mother-to-child transmission, and HIV/TB treatment.

*SMS Clinical Tips are short, clinical messages sent on a weekly basis, focusing on ART guidelines*

Table 3: Case studies

Year	No of people completing case studies	Clinical case study topics
2012	136	Early infant diagnosis First line failure Ethics – User Fees Management of Hepatitis B Medium term complications of d4T and how to manage
2013	223	Drug-resistant TB – diagnosis and management Virological failure and genotypic resistance on second-line ART
2014	52	Mental health and HIV
2015	101	New ART Guidelines Cryptococcal screen & treat HIV-associated fungal infections in outpatient practice Epidemiology of HIV in KwaZulu-Natal New ART guidelines and feedback from Conference on Retroviruses and Opportunistic Infections (CROI) Clinical management of common opportunistic infections ARVs: Where are we and where are we going? AIDS conference feedback Approach to an adult/child with virological failure Dimorphic fungal infections in HIV

Figure 8: Number of *SMS Clinical Tips* sent out



## SUSTAINABLE, INDEPENDENT, HIGHLY REGARDED ORGANISATION

*The Society has been a phenomenal success story — both in terms of growth of membership and in terms of the quality of its outputs. In just over a decade of existence it has grown into a substantial organisation and an important voice in the AIDS epidemic in South Africa — providing expert, knowledge-based information at a time when this was seriously needed and not coming from political and government sources. ... This outstanding success has largely been as a result of passionate and committed volunteers who saw the need for such a Society and have fulfilled its mandate admirably. Employees have also contributed substantially. It is not possible to be too overenthusiastic in praise of what has been achieved thus far. (External evaluation, 2010)*

The Society has supported the widespread adoption of HIV best-practices through a variety of activities, including CPD meetings; development of best-practice guidelines on specific aspects of HIV treatment and care; online discussion groups; and a scholarship programme for doctors and nurses. The Society's publications — the SAJHIVMED and Transcript — are widely referenced and considered credible sources of information amongst health workers. The Society has been instrumental in developing curriculum and accreditation procedures for a college diploma in HIV management.

The Society has been an active participant in the drafting of the South African Government's national strategic plan (NSP). A series of critical updated HIV/AIDS treatment policy guidelines have been put in place. Support to health-care professionals, in both the government and private sector, has also been the core of the Society's work. This takes place through a series of highly commended trainings, publications, meetings, and provision of posters to sites.

The Society has made significant strides in its organisational development and is now fully staffed, providing a credible voice of reason and leadership within the highly politicised field of HIV/AIDS.

*The Society has made tremendous progress from a small group of clinicians working from a backroom at Toga Laboratories to a vibrant and exciting group with a membership of more than 16,000. Its success has largely been the result of the work and commitment of passionate, energetic, and committed individuals, mostly working on a voluntary basis. At a time when there was no state leadership on the HIV/AIDS epidemic, the Society (alone and in partnership with many other NGOs) provided substantial intellectual, ethical, knowledge-based direction to clinicians and other health-care workers struggling to make an impact on their patients' lives and on the epidemic as a whole. This contribution — as well as the contribution by Atlantic to help make this possible — should not be underestimated. (External evaluation, 2010)*

***'The Society has been a phenomenal success story.  
.... It has grown into a substantial organisation and an important  
voice in the AIDS epidemic in South Africa — providing expert,  
knowledge-based information at a time  
when this was seriously needed'***

## Organisational growth

On recommendation from Atlantic, the Society commissioned an external review by Strategic Evaluation, Advising and Development Consulting (SEAD) in 2010. The review found that programmatically the Society lay between 'maturity prime' and 'stable', yet organisationally it lagged behind around 'adolescence'. The Society focused on programmatic activities and not on organisational development. Programmes were largely strong but not strategic, and there was no monitoring and evaluation system in place. Membership was poorly defined, and there was limited interaction and engagement with members. The governance structures were weak and ill-defined. Budgeting had been incredibly difficult due to the lack of financial policies and procedures, and historical data were missing or otherwise unavailable.

The Society was incorporated as a Section 21 company in 1998. The Society's Constitution described the Society as an official group of South African Medical Association (SAMA), which created a lot of confusion and potential legal challenges. The Society had an executive committee (also referred to in the Constitution as a management committee) of nine members but did not have a formal board as required by the Companies Act.

Limited structures, systems, and operational capacity required the Society to professionalise the organisation. Whilst the organisation had made a considerable amount of progress in professionalising since inception, the external evaluation of the Society by SEAD identified some remaining weaknesses. As discussed with Atlantic, SEAD advised the Society to implement a number of organisational and operational changes to strengthen its fitness and ensure sustainability. During the subsequent strategic planning in April 2010, key decisions were taken. The Society committed to remaining a membership organisation. It was also agreed that governance and professionalising the secretariat was a high priority.

The Society began addressing key recommendations made by the SEAD evaluation, which included the following:

- Professionalising the day-to-day running of the organisation, which involved putting policies and procedures in place;
- Identifying and strengthening assets;
- Developing a new board under the new Companies Act;
- Managing staff, funds, and resources;
- Continuing and extending programme work; and
- Raising funds.

The Society spent much of 2011 clarifying and updating the organisation's governance and legal status to ensure compliance with the new Companies Act. A legal consultant was commissioned to conduct legal due diligence of the Society and to update and amend all Society legal documents. The Society was registered as a non-profit company (NPC). The mission statement, aims, and objectives of the Society were changed to reflect the updated organisation.

An interim board of directors (BOD), elected in March 2011, revised the Society's Constitution to a memorandum of incorporation (MOI), per Companies Act requirements, and led the adoption of the MOI and the election of a new BOD at the Society's annual general meeting in December. Three executive committee members were nominated and elected to serve as an interim BOD (Eric Hefer, Tim Tucker and Francois Venter). The composition of the executive committee was amended to include representatives from nursing and other health professions, as well as individuals with financial and legal expertise. The new board was more representative of South Africa's demographics and included black, female, and gay members. The executive committee, which was not a legal entity, was dissolved and re-purposed as a strategic advisory group. The interim BOD also approved key changes at the secretariat, most notably the restructuring of financial operations and the hiring of a chief executive officer (CEO).



In January 2012, the Society's first CEO, Lauren Jankelowitz, took the helm of the organisation, and a new board of directors with eight members began their two-year tenure.

The interim BOD endorsed a policy whereby membership was defined as being up to date in the payment of membership fees. Members in arrears for six months are now routinely removed from the Society's membership database, no longer receive member benefits, and are not included in membership statistics. The executive committee approved full membership and voting rights to all members and not just doctors.

The Society has much better financial systems and policies in place, including the board's fiscal committee, to make high-level financial decisions. The Society is therefore better able to spend donor funds, according to budget.

The Society has implemented SEAD's recommendations, which have strengthened the organisation's systems and addressed many of the risks identified. The changes served to improve the strategic organisation of the Society's administration and support structure. Standard operating procedures and contracts were updated and put in place. Systems were established for asset registry and procurement arrangements. All Society hard-copy documents are now filed at the Society office. Important electronic documents are located on the Society server, which is housed at the Society office. Re-organisation of administrative arrangements included the contracting of an accounting firm to do the finances. A brand and marketing consultant was contracted for a six-month period to assist the Society in refining its brand and target markets, and ways of utilising the brand more effectively. A new information technology service provider was hired.

The Society was commended by external evaluators for the strong volunteer ethic within the executive committee, the editors and reviewers of the *SAJHIVMED*, the convenors of the branch meetings, the expert members who developed guidelines — a cast of unpaid volunteers. However, a human capital management review, resulted in the Society reconsidering its approach to volunteerism (at least, to pure volunteerism). The Society staffing structure was reviewed by the executive committee. Job contracts, job descriptions, and a performance management system were implemented with staff. It was found that there was a lack of programmatic capacity and more staff needed to be hired to address this. The Society also placed emphasis on training, development, and mentoring of staff.

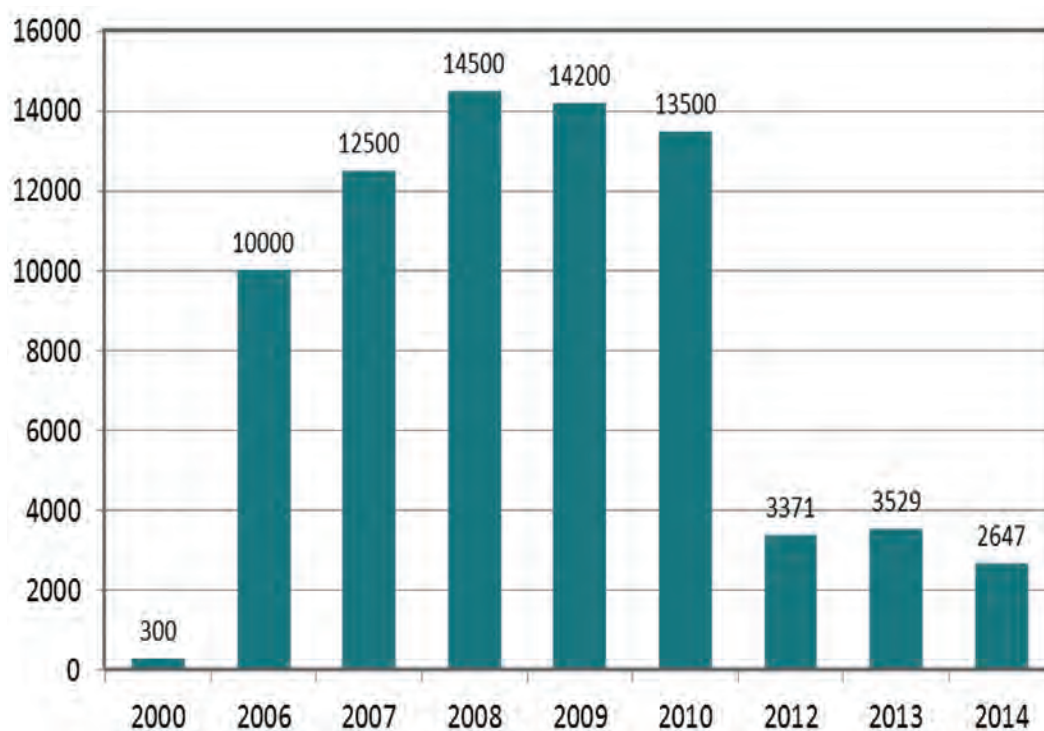
## Membership

The Society's members and its elected executive are amongst the most respected HIV clinicians and policymakers in the region, and hold prestigious posts within academic, government, and private organisations involved in HIV/AIDS care in southern Africa. The society's experts are firmly grounded in a scientific background.

The Society's membership has grown rapidly and was reported to be around 14,000 in 2008. A clean-up of the member database revealed only about 3,500 paid active members. The Society now provides benefits only to paid-up members. However, it also maintains a parallel database containing all people who have had contact with the Society in the past. This large database is important for credibility and legitimacy: The Society can say to pharma or other potential donors that it can connect to 8,000 clinicians.

*An analysis of membership trends is interesting. There was membership well over 10,000 for a few years. Then the database was cleaned and we were shocked to find the membership numbers as low as 3,000. High membership numbers are important for advocacy — having 12,000 members is sufficient leverage to beat government over the head. But even the revised membership of around 3,000 is significant. Other than SAMA, the Society is probably the biggest clinical membership organisation in SA. (Past President)*

Figure 9: Society membership trend, 2000-2014



Currently the Society has a membership of more than 3,000 HIV HCWs, including regionally and internationally respected figures in the fight against HIV/AIDS. Snapshots of membership have revealed that membership is overwhelmingly South African, with the remaining largely southern African (Botswana and Namibia). All nine provinces are represented, but the majority of members come from Gauteng and KwaZulu-Natal. Rural provinces have been less well represented, which is a potential opportunity for the Society to increase membership by connecting with rural HCWs. The gender and racial makeup of the Society is representative of the diversity of South Africa.

Various factors contributed to membership growth in the early days. The fact that many clinicians felt under attack by government policies and as a result needed to gain the protection of a professional body added to its growth. The decision to expand membership beyond doctors was another major shift allowing for greater membership. The Society membership has extended beyond doctors, to nurses, lawyers, dieticians, pastors, etc. The collaboration with Foundation for Professional Development (FPD), whereby every person who attended an FPD training course in HIV automatically becomes a Society member, was innovative and of immense importance; thousands of members were recruited in this way.

*Every health-care worker comes into contact with HIV, but not many of them self-identify as being HIV clinicians. The range of 3,000 to 4,000 is probably a reasonable estimate of those who identify in the same way as we do. (Board President)*

Members are largely doctors with an equal split between public and private sector and a predominance of clinicians belonging to the paediatrics speciality. There are an increasing number of professional nurses who have become members in recent years. At the beginning a large proportion of membership (around 20 percent each year) stemmed from FPD-sponsored membership, but this has decreased in recent years.

*We may be at a ceiling of members because nurses are under no requirement to belong to organisations for CPD. Once nurse CPD comes into play, we can probably double membership. We are also piloting a student society at Wits medical school, which can be extended to other universities. (CEO)*



**Membership provides intangible benefits, such as a collegial network which gives advice and support regarding day-to-day patient care, clinical management, and HIV research**



Members enjoy a number of benefits, including:


- Access to updated guidelines;
- Quarterly issues of the *SAJHIVMED*;
- Quarterly issues of *HIV Nursing Matters*;
- Electronic newsletter *Transcript*;
- Online CPD-accredited case studies;
- *SMS Clinical Tips*;
- CPD-accredited learning opportunities;
- Reduced registration rates for the Society's conference;
- Study and conference bursaries and other sponsored educational opportunities;
- CPD-accredited branch meetings, which include dinner on a monthly or bi-monthly basis; and
- Inclusion in the Society's publicly accessible online HIV Provider Directory.

Membership also provides a host of intangible benefits, such as belonging to the 'brains trust' of HIV treatment and policy development in South Africa; belonging to a strong civil society network that gives members a voice within HIV health care in the region; and belonging to a collegial network where obtaining advice and support regarding day-to-day patient care, clinical management, and HIV research is easily accessible.

In 2011-2012, the Society worked with a database developer to develop a customised, web-based membership database that has automated many of the membership activities (e.g., invoicing, mass e-mailing) that were previously done manually. The website was also upgraded to allow for linkage — members can now login to the website to view (and update) their contact details, download invoices, and download CPD certificates received for branch meeting attendance or online clinical case studies. The new database has made member services considerably more efficient.

Membership income constitutes approximately one-seventh of the annual operating budget (including FPD's contribution of one year of membership for all HIV-related course attendees). A decision was made in 2011 to remove all non-paying members from the database. Membership fees were increased to ZAR 300 across the board in 2012 and then further increased for doctors to ZAR 400 in 2016. Members have struggled with this. The level of engagement of members appears to be passive, and the participation levels are low at branches.


The Society continues to grapple with the challenges of serving as a resource while also attracting more members.



*The problem is everything we do and offer is free and you don't have to be a member to access these benefits. It is difficult to get people to become members on their own when they are not sponsored. Our reach is enormous. There are people accessing the SAJHIVMED and guidelines from all over the world. We don't want to prevent this, but we feel CPD can only be for members. We are looking at charging members for CMEs, but I am anxious about it because the reality is you can go to pharma-sponsored CMEs for free. There needs to be a change in mindset to start charging. But then how do we charge nurses who earn very little. With HIV Nursing Matters, we are trying to increase our reach. (CEO)*

In January 2014, the Society changed its membership period to run on a calendar year. Previously, membership was one year from the date on which membership fees were paid, which resulted in hundreds of unique invoice dates and an undue administrative burden. The new system has invoices for membership renewal, sent in November each year, with payment due the following January.

To maintain a database of active members, members are given a six-month grace period before membership is terminated for non-payment. Applications for membership are accepted year-round, and membership fees are calculated on a pro-rata basis according to the month of payment.



## Members' survey

In 2010 the Society conducted a short, web-based survey to collect feedback from its members. The survey solicited input on several key Society programmes, including branch meetings, the quarterly *SAJHIVMED*, the newsletter, online discussion groups, the website, and advocacy efforts.

The survey was sent to 5,165 Society members who reported a valid email address, approximately 32 percent of the total membership. A total of 240 members completed the survey for a response rate of 4 percent. The majority were doctors, with a total of 170 (71 percent) identifying as a 'Doctor generalist' or a 'Doctor specialist'.

Respondents were asked to rank, on a scale of 1-5, how well the Society represents HIV HCWs in Southern Africa: 78 percent (180) rated the Society favourably. The perception of the Society in terms of leadership and credibility in southern Africa amongst members was good, with 72 percent of respondents giving a favourable rating. Members commended the Society for providing critical and valuable information in an environment that could be somewhat challenging.

Respondents were asked to provide examples of advocacy efforts undertaken by the Society that they supported or appreciated. Sixty-six respondents replied, many noting multiple efforts. Common themes included advocacy around treatment guidelines, including access to treatment, updating drug regimens, and supporting an increased threshold for antiretroviral treatment eligibility. Specific responses regarding treatment efforts included, 'using Tenofovir as first line even though Department of Health was refusing because of cost implications and constant push for updating clinical guidelines to keep up with international standards'.

Other advocacy efforts cited by respondents included issues around human rights, most notably advocacy regarding anti-homosexuality legislation in Uganda and advocacy supporting doctors victimised by the government. One participant stated: 'Support for doctors treated unfairly by the state because of their courage, standards, and professional ethics in their work with patients'.

Several members suggested that the Society be more inclusive of non-doctors, black Africans, members outside of Johannesburg and countries outside of South Africa. One respondent said: 'I believe nurse clinicians should be full members of the Society and not associate members. They should have a vote'. The Society changed the fee structure to have one category based on this feedback from members. Fees were later changed with a higher fee required of doctors, but voting rights remain equal.

The most utilised Society programmes were the *SAJHIVMED* and the clinical guidelines. Approximately 89 percent (198) of the respondents report utilising it in their clinical practice. Seventy-five percent, or 177 of respondents, reported sharing the *SAJHIVMED* with colleagues. Several participants also advocated for more frequent publication of the *SAJHIVMED* and more timely delivery.

Around 80 percent reported using the Society's clinical guidelines in their practice. One respondent commented that the guidelines were the most important aspect of the *SAJHIVMED*.

While feedback for the branch meetings and online discussion groups was generally positive, fewer members reported accessing those services. Approximately 12 percent of respondents attended all meetings, 36 percent attended most meetings, 25 percent attended half the meetings, and 16 percent attended fewer than half the meetings. Of the respondents who were aware of the discussion groups, 67 percent rated them a 1 or a 2 in usefulness on a scale of 1-5; while 73 respondents (30%) reported that they did not know of the existence of the online discussion groups.

The majority of respondents (139) reported visiting the website. Of the respondents who ranked the usefulness of the website on a scale of 1-5, 68 percent (102) rated its usefulness at 1 or 2. One respondent noted, 'The website is cumbersome to navigate (and the URL is difficult to remember) so I don't use it at all'.



# LESSONS LEARNED FOR ADVOCACY ORGANISATIONS

## VOICE OF REASON

*The Society has become a serious voice for both doctors and HIV-positive patients in the region. The activities of this professional society have been visible and have undoubtedly added significant value. Thus, the organisation should be commended for working in very difficult circumstances, often with significant opposition from government. They have been a voice of reason. (External evaluation, 2010)*

The Society is seen as the largest professional HIV interest group in the world. Traditionally, advocacy for HIV care in southern Africa has been led by patient and legal groups, from a rights-based position rather than from a clinical perspective. The Society is positioned as guardian of the standard of HIV care and has advocated for access to care for vulnerable groups, including orphans, prisoners, military personnel, refugees, and rural populations.



Members of the Society are amongst the most respected and influential HIV clinicians and policymakers within southern Africa and hold prestigious positions within academic, public, and private organisations in the field of HIV/AIDS in the region. Current and past members of the board are experts on the various South African National AIDS Council (SANAC) technical task teams and serve on other government advisory committees such as the Medicines Control Council and the National Essential Drugs List committee.

The Society represents a powerful and independent voice within southern Africa, with key representation from the most experienced and respected professionals working in the fight against HIV. The Society's expertise allows it to speak cohesively and authoritatively on all issues pertaining to HIV and AIDS. Furthermore, the Society's members are key opinion leaders and are routinely called upon to give advice and guidance by civil society and corporate organisations, government, and the media. This exposure gives them further credibility and influence.

***The Society speaks cohesively, authoritatively and independently on all issues pertaining to HIV and AIDS in southern Africa***

The Society has enhanced its leading role in advocacy and information provision to refocus HIV-related debates away from controversy and mixed messages toward practical, evidence-based solutions, and has continued to speak out against HIV-related unscientific and exploitative practices of organisations, governments, and companies.

The Society provides technical, clinical, and scientific advice to a range of organisations, including the Treatment Action Campaign (TAC), the AIDS Consortium and SECTION27. The Society has assisted civil society organisations in several high-profile court cases relating to the provision of HIV health-care services. The positioning of the Society as guardian of the standard of HIV care makes it imperative that it intervenes when standards are contravened. The Society's expertise allows it to speak authoritatively on all scientific and medical issues pertaining to HIV/AIDS.

The Society's scientific credibility has allowed it to facilitate consensus-building on best-practice and promote rational debate, and its promotion of best-practice standards has contributed towards improving the quality of health care offered to people living with HIV in the southern African region.

The Society held a 'Voices of Reason' conference in Johannesburg to enable a group of South Africa's acknowledged medical HIV experts to engage with more than 200 of the country's highly respected religious leaders. The conference considered transmission, testing, social/ethical issues, legal issues, and medical and nursing care. The conference was successful and enabled the participants to disseminate scientifically accurate and truthful messages on HIV to their respective constituencies, their current involvement in HIV-related support programmes, and to inform the medical community on how it can best support faith-based organisations in the field of HIV.



*The Society has undoubtedly achieved greater influence over time, and this influence has continued to increase during the Atlantic funding term. The Society plays a crucial role in the region, being a neutral voice of expert reason and scientific/clinical excellence. (External evaluation, 2010)*

The Society has informal collaborations with key opinion leaders and academic experts in the international field, through its senior members, and through the international board that edits the *SAJHIVMED*. The Society still seems to be largely under-recognised internationally but continues to be in active dialogue with organisations such as the U.S. Centers for Disease Control (CDC). The relationship with the World Health Organization (WHO) and the International AIDS Society (IAS) has been somewhat disappointing and vague, as although there is some recognition, there is not nearly enough engagement.

The Society is continuing to pursue recognition as a credible leader in the field of HIV/AIDS management and treatment in the region and internationally. The Society needs to become an internationally recognised credible point of reference. Continuous media interactions, press releases, and profiling at conferences will bring attention to the work of the Society and encourage more membership. Highlighting the role and work of the Society at international events will also be useful and can utilise initiatives of international organisations such as the IAS governing body to put pressure on national government for recognition.

## STRENGTH OF MEMBERS


Members are passionate HIV clinicians who really believe in the vision of the Society. They have their allegiances to the organisations that employ them, but belonging to the Society allows them to do things they couldn't otherwise do. For example, it is often specified in contracts that employees cannot advocate legalisation of sex work so while they would be constrained in publicly voicing an opinion on this matter as professionals employed by their organisations, they are encouraged to do so as Society members. The Society gives them the ability and forum to express a free voice.

*When I was the president and I needed to be more strident in making the point, I would talk on behalf of the Society, such as when I was placed on record calling the previous health minister 'the village idiot'. Now that relationships with government have improved, I have begun expressing the more strident opinions talking on behalf of my employer. This talks to the fact that the Society now needs to have a more cosy relationship with government as they can block funding by saying that the Society is not needed to fill a role that other PEPFAR-funded organisations can play. (Past President)*

The Society does not experience any tension arising from the fact that it is a membership-based organisation whose members also represent the organisations they are employed by. The Society encourages members to provide technical expertise representing the Society as well as their employers.

*The Society wants and needs members to wear both hats. Government can block funding by saying we don't need the Society to work on the guidelines process because we have all these PEPFAR partners. But the staff from those PEPFAR grantees are key Society members. ... We often ask people to make formal responses and statements as the Society and their organisation. It is important to also profile their own organisations that provide a lot of resources to the Society at no cost and donate intellectual capital. ... For the latest ART guidelines, three individual members were involved in their own capacities and not as representatives of the Society. They are all key Society experts as well as Board members so the Society did lots of support behind the scenes — producing master training audios, slides, and materials that would enhance training on treatment guidelines. (CEO)*

## VALUE OF PARTNERSHIPS, NETWORKS, AND ALLIANCES



The Society enjoys strong relationships with partner organisations and has carved out a unique niche for itself as the principal organisation coordinating and contributing scientific and clinical expertise to national HIV policy. The Society continues to be proactive in its advocacy and profiling role and is dedicated to maintaining mutually beneficial relationships with pharmaceutical companies, non-governmental organisations, and government departments (both national and provincial). The Society has continued to maintain positive relationships with several private-sector organisations committed to corporate social investment programmes. However, the Society does experience tensions trying to maintain relationships with its main stakeholders: government, civil society, and pharma. Each of these players struggle to work with the other.

***The Society carries out a co-coordinating and networking role with key players in the field of HIV in southern Africa***

The Society carries out a co-coordinating and networking role with other key South African and South African Development Community (SADC) players in the field of HIV, including corporate employee and home-based community programmes to increase access to treatment and care. The Society has strengthened and clarified relationships with other countries' clinicians' societies, including Botswana, Namibia and Zimbabwe. The Society has semi-official relationships with similar bodies internationally, such as the British HIV Association.

The Society appears well linked to the HIV-related structures within the southern African region. This includes traditional doctor-related affiliations — particularly the South African Medical Association — as well as community groups such as the Treatment Action Campaign (TAC). Organisations that the Society has collaborated with formally and informally include:

- Africa Health Placements
- Aurum Institute
- Beyond Zero
- Colleges of Medicine
- Foundation for Professional Development
- International AIDS Society
- Médecins Sans Frontières
- Right to Care
- Rural Doctors Association of South Africa
- Rural Health Advocacy Project
- SECTION27 (formerly AIDS Law Project)
- Treatment Action Campaign
- Wits Reproductive Health Institute

The Society has also had relationships with LifeLine and the South African Business Coalition on HIV/AIDS.

The collaboration with the Foundation for Professional Development (FPD) has been ongoing since 2001 and entails a relationship of mutual benefit and flow of revenues. All students on the FPD HIV clinical management courses automatically got membership with the Society free of charge for one year, thereby receiving access to the *SAJHIVMED*, *Transcript*, and other training. In return the Society would review content and provide training and resources for the FPD courses. Since 2001, more than 16,000 people across nine countries in southern and eastern Africa have been trained through FPD. In addition, the partnership between the FPD and the Society was instrumental in allowing the government to roll out its ARV programme in 2004 as they managed to train 3,500 doctors in three months.

*The FPD relationship appears to be very beneficial to the Society, with both membership benefits and financial benefit. This relationship should be nurtured, as it is a much-needed revenue stream, as well as being beneficial to both parties. (External evaluation, 2010)*

The memorandum of understanding (MOU) with FPD is still in place, but its share of training in South Africa has decreased and the income from sponsored membership fees has decreased greatly.

The Society has worked closely with SECTION27 and TAC, providing support through the provision of expert advice, evidence, and supporting applications in courts.

The partnership with LifeLine was instrumental in the development and updating of the Karabo platform. This mutually beneficial relationship also improved LifeLine's own data gathering and help lines.

The Society oversees the medical postgraduate diploma in HIV medicine for the College of Medicine — a huge amount of work done on a voluntary basis — giving the Society an ongoing professional relationship with the medical profession at large.

Members in private practice also partner with the Society. Pharmaceutical companies are long-standing partners of the Society, frequently sponsoring branch meetings, and poster publication and distribution, both regionally and within Gauteng.

These various relationships appear to be on a collegial basis, and most relationships are currently informal, where members of the Society interact and give expertise, time, or credibility to another body's activities. Where these are not formalised by MOUs, such documents may provide role and responsibility clarity and protect both parties in the event of conflict and may be required even where Society members perform mostly voluntary duties. However, the current informal style of interaction may well be a benefit, as contractually binding relationships are often of limited value in environments where the majority of interactions are voluntary and where there is no flow of money.

The defining characteristics of the Society's partnership with other organisations have been the commitment to consultation, collaboration, and joint decision-making, while employing a smart combination of partner roles. Utilising partners' strengths and leveraging their individual positioning has created effective relationships.

*There is some complexity being in a consortium and having different agendas. The Society's [agenda] is clinical best-practice and guidance to health-care workers. Ultimately, we are concerned with getting patients on treatment, and we don't care how that happens. If we need to stay out of the media in order for that to happen, we are OK with that, and it fits with our mission. Other organisations that we partner with such as TAC for example have their mission around public awareness and patient rights. They are not focused as much on solving the problem but on raising awareness. (CEO)*

## PIONEER LEADERSHIP

One of the successes of the Society has been the high-quality, pioneering leadership by the successive presidents and the current CEO, who employ a collaborative style, balancing and managing contrasting views and approaches to health and advocacy. It is clear that the passion of the start-up leadership was a major contributor to the Society's growth. The expertise and reputation of the Society's executive committee/board members and president, contribute significantly to the Society's credibility. The profile and visibility of the Society have also increased due to frequent press and media releases and high-profile events.

The president's role was seen as critical in taking the organisation to new levels and guiding it through a political maelstrom. However, the Society realised that it required a succession plan and that change of leadership would be crucial to the organisation's growth.

*We realised that organisations must have change of leadership, otherwise they don't grow. Many organisations with strong leadership are at risk of becoming 'mega churches' led by one individual, but this becomes unsustainable. ... The responsibility cannot rest on one person. The Society decided in 2013 to develop a succession plan and to grow up individuals to take over the reins. I was voted as new president during a term where the outgoing president remained on the board. (Board President)*

## PRIORITISING ORGANISATIONAL GROWTH AND DEVELOPMENT

Since its inception, the Society had effectively grown from a small organisation into a substantial organisation with a substantial budget, yet the organisational development, staff complement, operating procedures, and processes did not keep pace. The external evaluation in 2010 identified the limitation of the Society not having management structures other than the executive committee.

*Our impression is that the Society is very much driven and managed by the President, although it is not a full-time position. He does this without any remuneration, although the position requires a significant amount of time. Though this is admirable and we think he does an exemplary job (!), better structures need to be put in place to support the President and to ensure proper governance. There is a huge risk in an executive President acting without a properly constituted Board. The fact that the current President is of the highest integrity, does not mean future Presidents will be the same. (External evaluation, 2010)*

The Society has since undergone considerable organisational growth and development. The changes implemented assisted in addressing governance, capacity, and structural problems. The strengthened governance and operations allowed the Society to focus on programmatic goals and organisational sustainability in the following years. The Society has moved from the pioneering phase into the consolidation phase, where impact and sustainability are the main focus areas. This is a new, more organisationally mature phase (or 'performing phase') in which outputs and programmes become increasingly central. There is a high level of conceptual and organisational coherence that is regularly developed and refined by the Society.

The 2012-2015 period has seen significant growth in the staffing and structure. Adequate funding has been secured, and there has been positive interaction with, and feedback from, primary donors. However, there is an urgent need for fundraising for 2016 and beyond.

The Society has put great efforts into professionalising the organisation, increasing capacity and strengthening governance. However, it is still a small organisation with a lean structure. Staff loss could hamper the achievement of the intended outcomes. It is important that the Society hire competent staff members who are committed to the aims of the Society and who possess the relevant skills to fulfil the organisation's objectives. The Society is mitigating the risk of staff attrition by supporting staff development and providing staff with a generous leave package.

The Society still relies heavily on the goodwill and commitment of its members to provide resources. The Society has access to an array of practising HIV experts but lacks the resources to bring them together in a structured and coordinated way. Critical role players are not full-time employees and, in fact, perform critical tasks without any type of remuneration. This culture of volunteerism is a strength of the Society but, although highly admirable, it may not be sustainable.

***The  
Society's agenda  
is clinical best-  
practice and guidance  
to health-care  
workers***

## CLARITY OF PURPOSE

The external review raised important questions regarding the purpose and strategy of the Society, which are relevant for an organisation like the Society to periodically reflect on.

*An important aspect of the vision/mission that needs review relates to who the Society actually represents. Whilst the initial organisational documentation indicates that the Society represents the interests of doctors, one has to question whether the focus of all activities is not, in fact, to represent the interest of 'HIV-positive patients' or the 'carers of HIV-positive patients'?*

*Although we cannot fault any of the aspirational, directional statements that the Society has had over the years, there is a clear need to revisit these as a Society. We could not be provided with any documents delineating future strategy or strategic action plans. These seem to be produced on an ad hoc basis, e.g., the new focus on the nursing sector.*

*It is critical that all members of an organisation (including operational staff) are perfectly clear in their own minds about organisational direction as expressed through its vision, objectives, strategy, and strategic action plans. It is important that everyone is very clear about who the Society's target market is and what it ultimately wants to achieve. This is critical both for internal stakeholders' sake as well as external stakeholders like government, the private sector, and funders.*

*Uncertainty about mission, objectives, and strategy creates uncertainty amongst the operational staff. We found a staff complement that believes in the organisation and are obviously committed, yet often don't feel as if they have a clear understanding, clear guidance, direction, structure, procedures, and process. We go away with the sense that the organisation is both in need of clarifying and maturing its direction (mission/vision/aims) as well as execution (strategy and action plans). In the absence of the latter, it is very difficult to track direction and success or failure. (External evaluation, 2010)*

Quite a lot has been done on this since 2010. The Society worked hard to address the external review recommendations and put in place processes even beyond what Strategic Evaluation, Advising and Development Consulting (SEAD) had recommended, to put them in the running to access big grants. This was followed by a period of consolidation. The Society is now again starting to revisit those recommendations within the current context. The Society is continually looking at the professionalisation issue.

Much strategic work has been done by the board, Society staff, and other key stakeholders. Strategic conversations, linked with university and private management consultancies, allowed the Society to go through a series of strategic planning and review processes. The organisation's vision and mission got clearer. Consultants helped the Society to quantify what they thought the most important programmes were. Based on this the Society tweaked its mission, developed a values statement that it didn't have before, adjusted its strategic objectives (adding tuberculosis) and changing its framing to southern African, so as to have a regional footprint. It is intended that these would be revisited every two years.

## SHIFTING FOCUS AND TARGETING FOR GREATER IMPACT

Following the external review that made critical recommendations around the Society's need to sharpen its strategic focus, the Society has been working on refining its approach. A strategic planning process held in 2015 revealed that the Society is facing the challenge that funding for some of its programmes will not be renewed or obtained in the immediate future. It therefore needed to review the scope of its operations as its cost relative to income is likely to increase in a manner that may render the Society economically unviable. The focus of the strategy facilitation was therefore to prioritise the scope of the services that underpins the Society's mission.



The Society's current service offerings include:

- Writing guidelines;
- Contributing to policy;
- Writing journals;
- Providing a magazine for nurses;
- Educating nurses;
- Offering face-to-face CMEs (excluding nurses);
- Providing online education;
- Addressing stockouts;
- Providing HIV-resistance strategy;
- Conducting advocacy around HIV and TB policy and implementation; and
- Supporting conferences and hosting the Society conference.

Three critical concerns detracting the Society from achieving its mission were identified:

1. Potential lack of funding due to possible donor fatigue;
2. Lack of abundant support from the government; and
3. Others doing similar work to the Society with bigger budgets, hence they will receive prominence.

The Society used the following decision-making criteria to determine which programme areas it should prioritise, given funding constraints:

- Does it fit with their mission?
- Would they remain key opinion leaders?
- What is the scale of impact (on their mission)?
- Would donors favour implementation of this programme?
- Would Society members want this service?
- What is the cost to implement?
- Will this programme generate funds?
- Does the Society have a competitive advantage over other organisations to implement this programme?

The results were that writing guidelines and policy, stockouts, advocacy, and conferences are services that require emphasis in a paradigm where funding is less available.

## Branches

Branches have been underutilised as a way to both engage with the membership and to grow membership. Participation levels have been low in branches.

*We are a membership organisation, but our members don't really care for constant engagement and won't attend AGMs [annual general meetings]. They know that they are being represented and are happy to get their CPD [continuing professional development] points. Members don't want complicated branch structures. I have spent a lot of time looking at membership models but understand that despite being a membership organisation our engagement with members is limited. (CEO)*

A major challenge will be for the Society to continue to pursue and develop the creation of other branch structures, both regionally and particularly in rural areas to fill the huge vacuum of information in these areas. There are currently members in 45 countries and 19 active branches, with the majority of members and branches in southern Africa. There is considerable scope for expansion and consolidation in other countries. By marketing itself even more aggressively and becoming a stronger role player in the region, the Society can assist other countries to roll out their programmes by providing a blueprint

for this. A huge repository of HIV knowledge and expertise lies within the Society and can be exported to other areas in the region as well as within Africa itself.

The Society will support two regional branches through PEPFAR sub-grants; with plans to expand support to two more countries if funding is sourced. More regional branches need to be established. In addition, MOUs need to be established with the existing regional branches and clarity around being affiliated to the Society needs to be discussed.

*It would be nice to do more regional stuff. ... We learned from our experience developing the migrant guidelines how different countries were dealing with cross-border migration and how different national treatment programmes were dealing with refugees. There is an opportunity to support regional society groups. These groups often start as groups of clinicians that organise CMEs in their spare time. The Society can capacitate these small groups and share resources with them. The Society is trying to obtain funding for strengthening regional branches. (CEO)*

## Branch CME meetings

Whilst branch CME meetings have been a long-standing programme of the Society, there has been limited assessment of their cost and effectiveness. The Society's new financial management system has helped clarify the true costs of these meetings and has found that the organisation has historically under-budgeted for this activity, particularly in rural areas. Further, these meetings are administratively intensive, are time- and resource-intensive, requiring significant human resources from the secretariat, whilst little is required of the (volunteer) coordinators. Of particular concern is irregular attendance, high venue and food costs — especially for Johannesburg — and the role of the branch coordinator. Consequently, individual branches can vary considerably in outcomes, with the most successful benefiting from strong local leadership or infrastructure.

The Society has undertaken an assessment of the programme and experimented with redesign to better understand the objectives and purpose of the meetings, and the benefits to the organisation (e.g., increased membership, engaged members) and to the participants (increased knowledge). Ultimately, without dedicated funding it will be difficult to maintain branch activity at current levels. Understanding this, however, has allowed the Society to examine and debate the value and effectiveness of CME meetings as an educational and/or networking activity, and to determine how much the meetings, and rural initiatives, are a priority to the organisation.

The Society reconsidered how branch meetings run and designed a new branch meeting strategy to address some of the identified challenges:

- A new branch meeting strategy focuses on having longer, more detailed CPD meetings quarterly in big centres, and monthly smaller meetings focusing on case studies. The format has been changed to make it sustainable and more valuable to members; from one hour to one day CME meetings, which has increased attendance and provided members with all their CPD needs.
- Greater autonomy has been given to branches to develop a meeting structure that best meets the needs of their community. For example, in some rural and peri-urban areas meetings take place over an entire Saturday. This may result in fewer meetings taking place per year.
- Costs have been cut by reducing catering and using mostly free venues.
- Only paid members are eligible for CPD certificates.
- A policy decision was made not to hold CME meetings unless the costs are covered by a sponsor (usually a pharmaceutical company, but also other NGOs) or the speaker/venue/catering are of no cost to the organisation. Unfortunately, rural areas are most impacted by this decision.
- Branch members and coordinators are given incentives for participation (e.g., lotteries for bursaries) and non-Society, branch meeting attendees will be invited to future branch meetings.

The Society hired a full-time branch meeting programme manager in April 2012. Responsibilities include producing accurate and timely meeting reports; engaging with coordinators and visiting branches routinely; and assisting coordinators in the development of a meeting programme that is tailored to the individual needs of each branch. A contractual agreement between the Society and each individual branch coordinator clarifies roles, responsibilities, and expectations. Coordinators are chosen for administrative skill and paid a monthly honorarium dependent upon the meeting of agreed-upon deliverables.

## Training

An important change has been the adoption of the nurse programme. Changing the focus from doctors to a broader definition of clinicians allowed the Society to broaden its scope to include nurses. Since 2010 the Society has produced *HIV Nursing Matters*, the journal aimed at nurses, as well as nurse clinical tips and case-study workshops. The Society will be ready to be a CPD provider when nurse accreditation is introduced. However, funding constraints have resulted in the nursing programme being curtailed in many respects. The Society is also criticised that its board membership is still dominated by doctors and not representative of the changing context of nurse managed HIV and TB care. The danger of this is that the Society's priorities and focus for the coming years may not take nursing needs into account.

The Society has identified an opportunity for the future to work with lay counsellors.

*The success of counselling is what separates HIV from other programme like TB and hypertension, yet this cadre has been left out in cold and are in need of representation. (Past President)*

The Society has played a major role in HIV clinical training in the past. A large number of competent organisations have emerged in the last few years, which have provided good quality HIV training for HCWs, and the Society's energies are best spent re-focusing towards the application of its expertise to the complexities of the epidemic. Emphasis will move away from training and towards advocacy and facilitation.

## Conference

The decision of the Society to hold its own biennial conference came as a direct response to members who expressed the need for a conference with a clinical HIV focus. It was envisioned that it would be a relationship builder, bring in new members while also becoming a significant income generator. Three successful conferences have been held and have now become a core function of the Society as they provide a forum and opportunity to achieve everything the Society has set out to do as an organisation in one event. One opportunity for future conferences is to increase the involvement of the DoH. The DoH did not attend the last conference, and the Minister was conspicuously absent. Other opportunities are to use the conferences to serve as a link for front-line advocacy, and create fora for HCWs to engage with pharma.

**Society conferences have become a core function as they provide a forum to achieve everything the Society has set out to do as an organisation**

## Advocacy

The Society neither describes its role as advocacy nor does it have a written advocacy strategy. However, the Society has played a major role in the region as an advocate for HCWs and patients' rights.

*The Society has been a pillar of strength in a country where HIV denialism has played an extremely destructive role. The Society's leadership has responded to every controversy with appropriate levels of behind-the-scenes lobbying/advocacy as well as well-positioned public advocacy. (External evaluation, 2010)*

The Society needs to focus on broader issues of health systems strengthening, as there needs to be an improvement in the health system as a whole for any changes to be sustainable in the long run. Longer-term and more creative solutions are going to be needed if the pandemic is to be brought under control. The failure in getting prevention strategies right demonstrates the need for holistic approaches. Advocating for the disease to be treated like any other chronic disease may remove some of the stigma and increase the effectiveness of the efforts. The Society has also needed to shift focus to TB, which is 10 to 20 years behind HIV in terms of programme strength and performance.

The Society's leaders have reflected on some of the soft lessons they have learned in policy advocacy.

*We are learning constantly and making nuanced adjustment based on our experience. We understand the different clinical groups and which group needs what in nurturing key opinion leaders. (CEO)*

*We know that health policy is not made in a logical linear fashion from evidence to policy and the process at times seems arbitrary. We have learned to pick our fights, decide what we want to go into a meeting fighting for, and not leave until we have it. ... You have to build a trust relationship and grow your sphere of influence so you can be part of important decisions. (Board President)*

*One simple lesson in influencing policy has been to attend lots of meetings, ask to write the minutes and participate after the meeting in giving inputs to guidelines. The person who attends the most meetings gets their way. ... We have also realised that government doesn't stay your friend ... they have a vested interest in looking good so we have to make peace with it and continue to speak truth to power while always justifying what we say. (Past President)*

Finally, the external strategic planning consultants counselled on the Society's advocacy efforts:

*The author of this report would want to caution the Society about the manner in which it may go ahead to advocate. In this regard, advocacy from within, thus being a trusted advisor, may well be to the benefit of the Society at this present moment, as opposed to advocacy from the outside. Advocacy from the outside may well be in some stakeholders' interests, but could lead to unforeseen financial instability in the long term. (Strategic Planning Consultant).*

## USING EVIDENCE, RESEARCH, AND MONITORING AND EVALUATION

One of the challenges the Society faces in developing an effective monitoring and evaluation system is collecting information from members on the impact of its services. Members are busy and the past response rate to questionnaires has been low. To address this challenge, the Society is considering multiple strategies to reach members with rapid surveys. For example, through the use of cell phone technology, the Society could conduct a short survey after each branch meeting to assess the relevance of the topic discussed, evaluate the skill and knowledge of the lecturer, and increase in reported knowledge on the topic by the member. Where it is not possible to use cell phone technology, questionnaires could also be provided in hard copy. The Society could also conduct focus groups in areas with active branches to collect qualitative information on branch meetings and other Society activities.

The Society intends to conduct annual online surveys of its members to assess the quality and usefulness of its programmes. The Society will also introduce an e-mail and text-messaging system through which members will be encouraged to provide feedback on the services received from the Society. A more organised system for the collection of anecdotal and informal feedback will be implemented internally.

The Society and the *SAJHIVMED* websites also collect information on the number of hits received as well as other relevant data that can be used to assess the quality, usefulness, and impact of the information provided. The Society will ensure that the results of the surveys are disseminated to members by posting the results on its website and publishing them in *Transcript*. The external evaluation reports will be circulated to the various donors of the Society, as well as to executive committee members. Summaries of the external evaluations will be included in the Society's annual reports to its members. The Society will also focus on using its own data for internal monitoring & evaluation to better describe the organisation's reach and coverage.

## STATE OF THE HEALTH SYSTEM

In South Africa, where an estimated 6.8 million people are living with HIV, the Society has provided a voice of reason in the context of HIV denialism, which previously led to a slow and ineffective response to the epidemic by the state. Since 2008, the political landscape has dramatically shifted, and a new health leadership strongly committed to fighting HIV through a scientific, evidence-based approach is now in place. The Society is heartened by the progress made by the government leadership in addressing HIV/AIDS. The DoH issued new antiretroviral treatment guidelines for adults, paediatrics, and the prevention of mother-to-child transmission in line with international standards. Improved ARVs that were once only available in the private sector now comprise the standard treatment regimen for all public-sector patients, and the DoH has signed onto international pricing agreements that have significantly lowered the cost of ARVs. HIV and TB co-infection are being aggressively pursued through increased eligibility of TB patients to ARVs and programme integration at the clinic level. Nurses have been recognised as capable, competent health-care providers, and are initiating and managing ART in patients in primary health-care clinics across the country. Finally, the DoH is leading an unprecedented HIV counselling and testing campaign and implementing provider-initiated counselling and testing at all health facilities in South Africa.

Despite progress, the public health-care system has been devastated by decades of neglect, and the DoH faces significant challenges in responding to the HIV epidemic. Due to the legacy left by the former minister of health and the burden of the growing HIV epidemic on the already crippled health system, the implementation of these new policies has been challenging. The DoH experiences significant challenges in ensuring that programmes and policies are implemented appropriately across the country. The adoption of new treatment guidelines and incorporation of a new cadre of professionals in HIV management requires significant training and capacity building for HCWs across the country.

A skills and human resource crisis continues to hamper programme implementation at all levels of the public health system, and the DoH relies heavily on the non-governmental sector to assist in realising the HIV targets set in the national strategic plan (NSP). The Society, with its extensive membership and reputation as a credible source of better practice information, is strategically positioned to provide support to HCWs and the DoH in their efforts to achieve the NSP goals.

The Society leadership describes the challenge of sensitising and training health workers who have not experienced first-hand the challenges of fighting to access ART for their patients.

*Pre-1994 people united and fought a terrible apartheid system. We remember that and we are keen to fight it as we don't want to go back to it. The problem is health-care workers*




*who were raised in an era where it is normal to prescribe ARVs, don't have the same zeal and passion. ... They don't know what we fought to get to where we are now. We need to train health workers to understand HIV and the implications of not treating it properly. (Board President)*


The Society has well-established programmes to provide the most up-to-date, best-practice HIV education, training and information to its HIV health-care worker members, and systems to monitor the effectiveness of new policy implementation.

## RELATIONSHIP WITH GOVERNMENT

*During the Manto years, the Society served as the cold, hard voice of reason. While the [Treatment Action Campaign] had the more strident voice, the Society was the calm voice. We countered the prevailing misinformation with sound technical evidence. ... We were talking to media largely around getting treatment for patients and good quality care. In 2008 with the government change, the Society got behind the new minister [of health] and our role evolved to give independent affirmation to progressive decisions being made at the time. People were so beaten down [before] that we celebrated conventional good policy that made sense such as fixed-dose combinations. ... Now increasingly the tensions between civil society and government are starting to surface again; government do not allow any form of criticism and have invested in pacification politics around major issues that plague the department such as drug stockouts. The minister doesn't want to hear anything bad that happens in his tenure. The Society's position has again evolved in response to the times, and we are being called on to speak out and say for example that it's not OK to run out of treatment. The health system has not improved in the last 20 years, and if anything has gotten worse. (Past President)*



At its inception, the Society was supported by a small number of pharmaceutical companies that provided the early seed funding. Although huge strides have been taken to increase transparency and remove vested interests, this continued perception of being aligned with the pharmaceutical industry is seen to be one of the reasons that the relationship with government has not always been harmonious. In addition, at its initiation, the Society was, and perhaps to some extent still is (whether right or wrong) seen as a white elitist organisation. This has meant that traditionally there has been little support in government structures for the organisation. However, the reality at the time of the Society's inception in the late 1990s, was that all the treating doctors were white males and in private practice. It is felt that this perception has prevailed and has created a sense of mistrust among government structures.



The government leadership change in 2008 provided the Society with the opportunity to interact more constructively with the minister of health and senior DoH officials. South Africa's health leadership became more willing to accept outside opinion and expertise, and the Society strengthened its relationship with the DoH through the provision of expert clinical information and advice; technical support; and feedback from members on issues affecting the implementation of the department's policies and programmes.

*The Society had historically operated in a very antagonistic governmental environment, where developing a private-public collaborative system would have been extremely difficult. With an apparent government approach to more open engagements with all civil society stakeholders, an opportunity now exists for the Society to revisit this issue. (External evaluation, 2010)*

Continuous efforts were made to involve the government in discussions to build better relationships. However, although the Society offers its resources in terms of teaching, expertise, and assisting with roll-out at the disposal of government, the relationship seems to be in a constant state of flux.

*The [Society] President is a well-respected clinician and has been very outspoken and uses the press strategically to the benefit of the Society in getting correct and consistent messages out, as well as in making the Society much more visible. By taking up critical issues such as PMTCT [prevention of mother-to-child transmission], the Society is holding government to task about meeting targets and improving their performance. In order to improve this relationship and focus on increasing their influence and clout, the Society needs to find a way to interface and improve political dealings with government structures so that they accept, endorse and promote activities of the Society. Ongoing efforts need to be pursued in order for the Society not to be seen as the competition but rather as a valuable resource. (Mid-term evaluation, 2008)*

The Society has provided input into the development of the NSP and participated on key policy-making bodies, such as the technical task teams of the South African National AIDS Council (SANAC), and other important advocacy coalitions, including the recently revived Civil Society Coordinating and Monitoring Forum. Regular meetings have been held with DoH HIV/AIDS and the Affordable Medicines Directorates; successful meetings were held with the deputy-director general (DDG) of health programmes, Dr Yogan Pillay, to explore better working relationships with the department. The Society was invited to present its work to the parliamentary Portfolio Committee on Health, and the presentation was well received. Following this meeting, at the request of the committee, the Society began producing a monthly newsletter for the committee outlining current developments, publication, and initiatives.

The Society continues to work closely with SANAC and the DoH to advance evidence-based, best-practice care, through the work of its guideline committees.

*A challenge facing the Society is to further develop its relationship with government. As an organisation providing leadership and guidance, the Society is recognised for their highly dedicated and knowledgeable staff and members. However, the Society has not been able to influence policy to the level that it would like to. Although the relationship with government can at times be tenuous, the Society does carry a fair amount of political clout at the government level without antagonising, but rather being able to influence government. While Society guidelines do not become law, they are widely accepted as benchmarks and are also in line with government guidelines. (Mid-term evaluation, 2008)*

The department regularly comes into conflict with organs of civil society, and the Society has been involved in court cases with its partners to promote treatment access, where the department has been the protagonist. Conceivably, the department could exclude Society's key members from working with it, but this has not been the experience thus far, where the Department has appreciated that the Society's primary focus is on access to scientific, evidence-based care, which in itself tends to distance the Society's approach from emotive political agendas. Even if members were excluded at a national level, their assistance can continue within multiple levels of provincial government, so excluding the Society would require a major effort and would deprive health departments of key apolitical advisors.

*This relationship with the government is not unique to the Society, as there is a clear mistrust of NGOs and the private sector in South Africa, as in many other countries. Constant internal problems within the DoH itself has not lent itself to a conducive relationship either. ... The relationship is always a fine balance between managing a fragile relationship versus accountability to the people it aims to serve. (Mid-term evaluation, 2008)*

**The Atlantic grant has allowed the Society to draw the government into the consultation process**

## LESSONS FOR FUNDERS

There are many lessons for donors who may be interested in funding advocacy movements. The following lessons are extracted from a publication, co-written by the author of this report.<sup>4</sup>

### ATLANTIC'S APPROACH TO GRANTMAKING

Zola Madikizela, the programme executive responsible for Atlantic's public health programming in South Africa, describes how the impetus for the advocacy grantee portfolio came from the political context of shrinking civil society organising. Funders were shifting their funds towards government and many change-makers had moved into government; yet it was a period of AIDS denialism that needed advocacy. Funders needed to invest resources in organisations that held government accountable to the Constitution and were involved in constitutional advocacy and monitoring corruption, and Atlantic was one of few funders that had the foresight to do this.

Its first grants were to TAC and the AIDS Law Project (that became SECTION27), which were already leading the challenge against AIDS denialism. Atlantic began funding *Health-e* when its initial donor withdrew funds at short notice, possibly because the government was unhappy with *Health-e* generating media outrage against AIDS denialism. In contrast, Atlantic began funding the Society when it had no legal status and was operating from a back office. Its president knew Madikizela and approached him, arguing that with big funds they could be making an impact within a couple of years, both in influencing government policy and in providing Atlantic's advocacy grantees with scientific evidence.

*This aligned with Atlantic's approach — focusing on strong people whose perspectives aligned with ours, and taking big bets — having confidence in people to make a difference and giving them big funds that allow them to do so ... supporting groups that punch above their weight. (Programme Executive, Atlantic)*

Atlantic's style of funding also differed from other funders in that it did not require DoH to sign off in terms of selecting grantees. The Society believes that funders should not require government approval if they wish to fund an independent voice. The Society has had funding blocked by the DoH because the department did not see a role for the Society.

### GRANTEE SELECTION

One of the reasons why Atlantic was able to select an effective mix of grantees is that it had in-country staff with long histories of work and relationships in this sector. Hence Atlantic was continually reading the terrain — both the political context and civil society capacities. The most effective form of accountability lies in selecting the people and organisations who are most motivated and committed to particular goals.<sup>5</sup> The better the selection, the less likely the individuals or groups are to go off track or to fail to pursue the intended goals. This accountability results from effective selection and trust rather than relying on post-action sanction. Hence donor investment in having staff or consultants in-country, or at minimum an effective network of embedded informants over a long period of time, increases the likelihood of selection success.

4 Klugman B and Jassat W. Enhancing Funders' and Advocates' Effectiveness: The Processes Shaping Collaborative Advocacy for Health System Accountability in South Africa. *The Foundation Review* 2016; 8:(1): Article 4

5 Mansbridge, J. (2014). 'A contingency theory of accountability'. In M. Bovens, R. Goodin, & T. Schillemans (Eds.), *The Oxford Handbook of Public Accountability* (pp. 55–68). Oxford, UK: Oxford University Press.

## GRANTEE COHESION

The Atlantic programme staff argue that one of the weaknesses of their strategies was that they did not bring grantees together to learn about each other's work and hence Atlantic did not play a significant role in facilitating collaboration or scaling up of effective interventions. While it is true that not all of its grantees are aware of each other's innovations in training public health leadership, or in strengthening health service delivery, this is not the case with the groups Atlantic supported to do advocacy. They initiated their own connections with each other without Atlantic's prompting or assistance. In fact, in the SSP Atlantic is actually funding five out of the six consortium partners. While this was certainly not by design in initiating SSP, this talks to the care of Atlantic's approach in so far as its selection of grantees recognised the mix of capacities needed.

Atlantic did not issue instructions or create forums that forced collaboration; rather it recognised the hidden networks already embedded in the civil sector. Many partnerships have failed because they have been forced from the top down, often by well-intentioned funders. Hence part of the art of grantmaking is selecting for the values and competencies that would favour collaboration over competition and then trusting groups to collaborate when strategically necessary. Any grantee trying to predict in advance whom it should work with — and on what issues — would prevent it from finding synergies as needed.

There could have been more space for engagement between grantees. A community of reformers could be a convening process to bring grantees together, which though it did not happen during the life of the grant, it would align with the purpose of ensuring the legacy of grantmaking in the grant closure period.

## ENABLING GROWTH AND STRENGTHENING ORGANISATIONS

It is reported that in the Society's early years, the finances were tight and the organisation operated close to the break-even line. To some extent the Society was a victim of its own success with systems, staffing and structures not having kept pace with its phenomenal growth — and it is important to note that in this, the Society is no different to other emergent organisations.



Almost all work was done on a voluntary basis by clinician members and administrative staff. Initially the Society was dependent on membership fees only, later the SAJHIVMED advertisements generated additional income and branch meetings were sponsored by large pharmaceutical companies. Eventually Atlantic was approached for funding in 2006. This funding and support enabled the Society to professionalise the organisation and significantly expand its programmatic activities.

Atlantic provided the Society with the impetus to conduct an external evaluation in 2010.

*Towards the end of the first grant period, Atlantic advised us that they would not fund us again unless we conducted a [comprehensive] organisational assessment and acted on recommendations. Recipients usually prefer funders being hands off. But the breakthrough for the Society was being told to get an independent review that was more critical than the previous evaluation had been. The report was blistering and critical. The external agent came in to assess the organisation quite critically and then worked with us afterwards to fix it. They met all members of staff, identified the strengths and weaknesses of staff, and played a coaching role for the president to deal with the weaknesses that had been identified. Atlantic accommodated and even facilitated that. They did not have anxiety about losing money but rather wished to re-invest in an organisation that did have a lot of change to make. This was really important, and I haven't seen anything like it in my experience with other funders. (Past President)*

Atlantic funding of the Society has allowed for some stabilising of administrative and organisational capacity. Prior to this funding becoming available, the Society was housed in a back office of privately



owned Toga Laboratories, and had limited staff and systems. Since receiving the grant, the Society has moved into its own offices, and it expanded its IT capacity and organisational capacity in an effort to respond to its increased size. Atlantic funding enabled the Society to establish a fully functional office and to hire staff, including a CEO, a database manager and a bookkeeper. With Atlantic funding, the Society developed standard operating procedures and an organisation website.

The Society was able to support more branch meetings and the development of new/updated guidelines. Atlantic funding is certainly a major part of the reason for the Society's advocacy action being possible, as the Society's stability (with associated staff complement, systems, etc.) has allowed for greater activity.

**Atlantic funding in 2006 enabled the Society to professionalise the organisation and significantly expand its programmatic activities**

## LEVERAGING THE GRANT TO SECURE OTHER FUNDING

Atlantic was the first donor to fund the work of the Society. Atlantic funding has helped stabilise the organisation and has also in an indirect way facilitated access to other funding. Atlantic's requirement for matched funding has also enabled the Society to attract additional donors and corporate sponsors. The Society were also able to leverage Atlantic's grant to access income streams from the pharmaceutical industry who were interested in the fact that they could co-fund existing initiatives that had already secured part funding.

**Atlantic funding has facilitated access to other matched funding, especially the pharmaceutical industry**

## RELAXED OVERSIGHT AND CONTROL

Atlantic, compared with other funders, does not have onerous reporting requirements, and the Society found Atlantic to be relaxed in oversight and control. One observation, though, was that the Society did not receive much feedback when submitting a grant proposal or report.

*We take integrity seriously, and we want to account. Atlantic's systems for feedback and response were not great, and we did not receive acknowledgement that they had received reports. We had an enormous external evaluation done and succeeded in implementing all the recommendations. We would have liked some response — not to hear that we had done well but to get feedback that Atlantic felt that we were going in the right direction. (CEO)*

A further reflection from the grantees was that Atlantic did not require visibility and acknowledgement like other funders do. It seemed to prefer to operate in the background, influencing key developments in the South African public health sector over the past 15 years.

## CORE FUNDING

The Society and other Atlantic grantees could only achieve what they did because they had 'core' or 'general' support funds that allowed them to read the terrain and adapt accordingly. For example, as they identified the need for the Stop Stockouts Project (SSP), they were able to fund it, without having to wait for the next funding cycle to put it into a logical framework and raise funds specifically for it. Power over resources is one of the issues that shape a field.<sup>6</sup> The experiences of the Society and its partners in SSP illustrate how, by giving organisations funds they could allocate as needed, the donors ceded power to the grantees, who in turn chose to collaborate rather than compete and pooled resources

6 Lynn, J. (2014). Assessing and evaluating change in advocacy fields. Washington: Center for Evaluation Innovation.



of knowledge, expertise and money to make a stronger impact. Selection-based accountability lends itself to a different kind of reporting — not against outcomes committed in advance but against actual outputs and outcomes.

*You start off with an idea but circumstances change and opportunities arise and you want to adapt to the changing context. Having access to open funding to cover core cost enabled us to massively build on our core programme where we did not have to account for line items, and we could cover costs that had not been anticipated at the time of the grant proposal. Core funding enabled us to just get on and do our work. (Board President)*

The Atlantic grant has allowed for flexibility and consolidation for the Society which seems to have been much needed. The Atlantic funding structure was designed predominantly to increase the Society's ability to perform the tasks the Society was already doing, rather than fund a separate set of new activities. It increased the pool of existing funds to support and extend the existing activities.

*With hindsight I wish we had used Atlantic's 'no strings attached' approach to explore other models to sustain the organisation after the funding ended. Other donors wouldn't have been open to this, but Atlantic was always prompting us to think about sustainability. (CEO)*

The one caution with core funding that the Society identified is that while it does help an organisation to grow, when it comes to an end, it is more of a risk to the organisation that has not invested in sustainable initiatives.

## ENABLING INNOVATION AND ADAPTABILITY

One of the Society's lessons from advocacy work has been that you learn constantly and make adjustment as you go, but not many donors allow for such flexibility. As a funder, it is important to identify organisations that have the clear mandate, legitimacy, credibility and capacity to meet their objectives. An understanding is needed that influencing policy is complex and requires innovation and adaptability.



The increase in funding, and the certainty relating to that funding, has allowed the Society to function with a longer window period of financial stability. This has allowed staff to focus on the programmes rather than constant fundraising. Atlantic funding allowed the Society to develop and grow its programmatic activities, including quarterly publication of the SAJHIVMED; publication of its newsletter Transcript six times a year; the development of HIV clinical management guidelines; CPD-accredited branch meetings; and significant conference support, including a skills-building programme and bursaries for Society members. With additional staff and increased capacity, the Society was also able to formally weigh in on national HIV policy and regularly participate on HIV coalitions and policymaking bodies (e.g., the South African National AIDS Council).

*The Society has done exceptionally well in the area of guideline development. Atlantic should feel secure in the fact that their funding allowed the Society to play a very major role within the region in guiding clinicians in how to manage patients, often in trying political and socioeconomic conditions. (Mid-term evaluation, 2008)*

*With Atlantic support, the Society has grown into a strong, sustainable organisation, trusted by health-care workers, government, and partner organisations to provide vital resources and support to HIV health-care workers. (Society progress report, June 2009)*

*The Society will be remembered for standing for the highest scientific/clinical standards, and without Atlantic support, this would not have been possible to the same degree. ... The achievement is a direct outcome of the Atlantic funding. (External evaluation, 2010)*

## GRANTEE ACCOUNTABILITY

A funder's grantmaking approach needs to be based on careful selection followed by trust, since it is not possible for effective advocates to commit in advance as to what strategies or activities they will use. Grantees all describe Atlantic as an effective funder because its staff gave them the leeway to use funds as needed, based on their shared overarching goal of the right to health. Some of their other donors require reporting against results predicted often a year or longer before the actual actions will be taken, and the grantees fear failing to deliver these results, even when they are no longer the most strategic results to aim towards. This form of sanctions-based accountability is based on grantees' fear that failure to check the agreed boxes may result in denial of future funding even when, from a strategic point of view, flexibility in funding allows the groups to initiate more innovative approaches that constantly adapt to shifting contexts. Authors characterise this as 'indicator blindness'.

A fundamental problem is that some of the donors who choose to fund advocacy groups are actually motivated by the desire for civil society groups to take on roles of government (such as elements of service provision) given constraints in government budgets and capacities, which is why they require quantitative predictable deliverables. At the moment of funders selecting these advocacy groups, there is a mismatch in goals and hence tensions around reporting.

Also funders who expect outcomes in the same year that they award their grant misunderstand that advocacy is taking place in a highly complex terrain, where building recognition of the issues, building trust and collaboration between groups, and reaching a point that the public expresses dissatisfaction and decision-makers feel forced to act, all take time. It is impossible to know in advance which of the multiple strategies deployed will be most effective. In addition, lessons learnt over time strengthen relationships between civil society groups and strengthen the quality of their advocacy and effectiveness. Similarly, tight controls over what funds can be spent on would have precluded the pooling of funding for collective campaigns.

## UNDERSTANDING THE LONG-TERM IMPACTS OF FUNDING SOCIAL CHANGE ADVOCACY

The Society was most appreciative that Atlantic took a long-term view and had a good understanding of advocacy work. The funder understood that you cannot effect change in a short period of time and that the Society needed flexibility in adjusting their strategies.

*It was important for the Society to find a donor who understood our goal was longer-term influence and not short-term evidence. Atlantic has a focus on long-term impacts, working towards an equitable health system. Atlantic also understood our work would not quickly demonstrate changes in patient outcomes but that we were working to develop better capacitated clinicians. Atlantic understood this was a return on their investment, but this is not the same for all donors. (CEO)*

**Atlantic's long-term aims were for an equitable health system, matched by the Society's aims to develop better capacitated clinicians**

## SUSTAINABILITY

Sustainability is a complex web of interlinking factors. The external evaluation by SEAD in 2010 raised the concern about the sustainability of the Society, although it recognised that the Society had made big strides forward in increasing sustainability over the three years prior to the evaluation. In addition to a full-time secretariat to support its work, the Society also has reserve cash flows. The Society applied for funding from a range of different sources. Advertising revenue from the *SAJHIVMED* and *Transcript* has increased, and these two publications are now self-sustaining and have the potential to create income for the Society. Membership fees are also a source of income from the Society, but in the past only about 20 percent of membership fees were paid up.

### CHANGE IN LEADERSHIP

The Society has had strong individual leadership, particularly from the previous president, which has steered it through a politically stormy time. There were concerns regarding the lack of succession planning and transition if key individuals were to step down.

*Some stakeholders also raised concerns about sustainability of the organisation once the current president finishes his term in office. Although this may be a valid concern, historically, this is always a worry when an able and dynamic leader moves to different pastures. However, as long as a highly competent and enthusiastic replacement is available, this is not likely to be a long-term concern. (Mid-term evaluation, 2008)*

### VOLUNTEERISM AND IN-KIND SUPPORT

The Society receives significant in-kind support from its membership. Specifically, the *SAJHIVMED* editor (who would have required approximately an annual income of ZAR 500,000) has donated time to fulfil the required duties. All Society branch coordinators are volunteers. Further, members volunteer their time to participate on the Society's various committees, including the executive committee and guideline committees.

*Critical role players are not full-time employees and, in fact, perform critical tasks for the Society without any type of remuneration. This culture of voluntarism is a strength of the Society, but although highly admirable, it may not be sustainable. There are no sustainability plans in place either on an [executive committee] or on an HQ level. (External evaluation, 2010)*

### GROWING MEMBERSHIP

Society membership fees contribute to the overall funding of the organisation and are not earmarked for any specific programme activity. The Society recognises that without increasing the number of members paying their annual membership fee, the sustainability of the organisation is jeopardised.

Although the Society's membership had grown rapidly in the early years, the percentage of members who paid their annual membership subscription fee remained flat. In the past, the Society took a decision that unpaid members would be entitled to all of the benefits of paid members. Although significant efforts were made to collect these membership dues, the benefits of retaining members and

providing information and education far outweigh the costs of not collecting the dues. This has been taken as a conscious decision with the understanding that as a crucial service provider in the field of HIV/AIDS, the Society does not want to exclude non-paying members in the process. The decision was also made in the context of a denialist government that obstructed access to scientific, evidence-based HIV information and was resistant to international funders.

*Only about 17 percent of membership fees are paid up, and we did not gain the impression that there is any real possibility of this percentage increasing in future. In fact, membership income forms a small portion of the overall budget and it is clear that the Society cannot be sustainable without donor funding. Non-paying members are not treated as debtors and are kept on the mailing lists unless address details, etc., are found to be incorrect. (External evaluation, 2010)*

Currently the political landscape in South Africa is vastly different. South Africa now boasts supportive health leadership, committed to advancing HIV programmes and treatment, and the country is granted millions of dollars from international funders to support HIV training and education, among other programmes. In recognition of this, the Society instituted a number of activities to encourage payment of membership fees:

- Members in arrears for more than two years are no longer posted the *SAJHIVMED* and *Transcript*;
- Members in arrears are no longer awarded CPD points for branch meeting attendance; and
- Members in arrears for more than five years are currently blocked in the Society's database, effectively taking them off the Society's membership list.

Membership fees have comprised less than 20 percent of the Society's overall budget. Approximately 20 percent of members pay their annual membership subscription. The Society has initiated a membership funding drive to encourage members to pay their fees and has begun removing members who are in arrears from its mailing list. By instituting these changes, the Society expects to reach its goal of 35 percent of members paid and will continually assess and revise strategies to encourage payment over the next two years.



The Society also believes that its strong programmes will attract paying members and funders. Since the publication of the first nursing magazine, the Society has been flooded with applications by nurses to join the organisation. The decision by the Society's executive committee to grant nurses full voting membership also added additional members and attracted funders. The International Council of Nurses expressed interest in partnering with the Society on a national conference for nurses in HIV although this has not yet materialised.

## CUTTING COSTS

In addition to ongoing fundraising and proposal development, the Society has also made a number of changes to ensure the financial sustainability of the organisation. In the event that funding is not obtained, the Society has a formal plan delineating steps to reduce costs, which include limiting branch meetings to those with pharmaceutical company sponsorship and reducing the number of publications of the *SAJHIVMED* and *Transcript* each year.

*The restructuring process that was undertaken during 2012 has contributed to keeping the expenditure increase as minimum as possible. The CEO and her team have been doing a tremendous job in maintaining costs and curbing expenditure. Most operating costs have been reviewed by management and spending has been undertaken within the constraints of information available from budgeted projects. (Society Annual Report, 2012-2013)*

## FUNDRAISING IN A TIME OF ECONOMIC CONSTRAINT

International donors are withdrawing, and there is more competition for funding. Funders are less inclined to give money to organisations that struggle to demonstrate impact. As a result, there is a tendency for narrow sorts of NGOs being funded: those involved in service delivery rather than advocacy. These organisations are often not working towards social transformation and are not representative of people's interests on the ground.

The Society is a not-for-profit organisation and thus always seeking funding from external sources for its continued existence. The Society will not be able to achieve its intended outcomes if it is not able to secure funding. The Society faces a challenge to secure donor funding and income from other sources due to the global economic slowdown as well as the downturn in the South African economy. It is thus important for the organisation to try and secure income from other local sources to ensure its sustainability in the long term.

The Society's financial sustainability is critical to maintain and grow the organisation. The Society has a number of funding proposals under review which, if awarded, will provide needed financial resources to support programmatic activities. The Society has written funding proposals to a number of organisations including Elma Philanthropies, the Gates Foundation, Unitaid, Anglo American, and Discovery Health. Funding has recently been granted by Unitaid and Anglo.

The Society has also collaborated with other local NGOs and jointly written proposals to serve as sub-grantees on PEPFAR grants. The Society believes that it is well-placed to act as an intermediary between big PEPFAR grantees because it has a large database of Society members who are a key target for training on these grants. The Society is also not competing for resources or funding and the other organisations are not threatened by them. The Society can serve as a vehicle for disseminating resources and materials. For example, the Society has been involved with nurse case-study work in North West province in collaboration with Wits Reproductive Health Institute and The Aurum Institute. The Society provides material and case studies while the other organisations provide training facilitators and local capacity.

The Society is dependent to a small degree on the pharmaceutical industry. One risk is that this reliance will compromise the Society's independence. Also the pharmaceutical companies have seen their support budgets cut recently, and a separate risk is that the Society will lose this as a revenue stream. However, this stream has been tied to specific projects (conferences for young doctors, branch meetings), and alternatives are available.

Pharmaceutical companies contributed a minimum of ZAR 250,000 annually to support Society branch meetings. This represented around 5 percent of the Society's operating budget. The Society recognises the advantages and pitfalls of receiving funding from the pharmaceutical industry.

*At the moment we are massively underfunded. Sponsorship relationships are really important. Two or three key pharmaceutical companies typically that do generics and get the tenders ... are very useful for sustainability as they are very generous. Again a fine balance must be maintained between what is appropriate and how much content pharma can dictate and establish strict guidelines on how much they can be allowed to market their products. (CEO)*



When the Society first partnered with the Foundation for Professional Development (FPD), it agreed to pay ZAR 150 per person per course and pay the Society a percentage of its annual profit.

The Society is reliant on FPD for most of its current funding. The Society would be severely compromised should this be terminated. (Society funding proposal, 2006)

The profit share was not a guarantee, however; in some years, no funds were received from the FPD profit share. Over the following years FPD funding decreased due to both a decrease in trainings and company profit. FPD funding in the last few years has represented less than 5 percent of the Society's operating budget.

## FUTURE FUNDING PROSPECTS

The Society has debated the options of revenue-generating activities to ensure sustainability and decrease reliance on donor funding. The Society conference is an important income generator. Having gained skills and capacity in managing the conference, the Society is intending to run it in house from 2018 to maximise revenue generation.

*The Society would have to run CME every day with 25 people attending in order to sustain the organisation. We now need something to make us permanently sustainable such as running a business like an in-house conference department. The Society for Family Health developed a separate revenue-generating stream selling condoms. This was very profitable so they changed their structure and now have a profit-making company (where the organisation remains a shareholder) that sells condoms and runs clinics. They charge a small amount and still raise funds from their grants. (CEO)*

However, the Society is aware of the risks associated with running businesses that are not core activities.

*The business thing scares me. I worry it will be a distraction from our core business because of the amount of time we will need to invest in it. I have been involved in the past with organisations which invested time and effort into income generating schemes to generate a profit of ZAR 100,000 when we could have more easily written a grant to access that money. (Past President)*

The Society realises it might always rely on donor funding. Whereas donor funding covers the costs of core programmes, the Society would also like to find a way to fund other areas that members have expressed interest in embarking on that donors would not fund. The Society will investigate using the efficiency of donor-driven programmes to co-fund other activities.

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