“What have you done to prevent it?” – SASOPs program on human rights for people with mental illness

The South African Society of Psychiatrists (SASOP), in partnership with: the German Association for Psychiatry, Psychotherapy and Psychosomatics (DGPPN); local advocacy groups such as South African Depression and Anxiety Group (SADAG), the South African federation of Mental Health (SAFMH), SECTION27, the Rural Health Advocacy Project (RHAP); as well as the University of the Witwatersrand’s (WITS) Adler Museum and Steve Biko Centre for Bioethics (SBCB); and the University of Pretoria’s (UP) Centre for Ethics and Philosophy of Health Sciences, has recently embarked on a program “Human Rights for People with Mental Illness”. The program consists of discussions and presentations in different cities - Johannesburg, Pretoria, Durban and Cape Town, as well as the travelling exhibition of the DGPPN, entitled "Registered, Persecuted, Annihilated - The Sick and the Disabled under National Socialism". The main aim with these discussions is to explore the role of professional societies and individual clinicians to uphold and protect the human rights of people living with mental illness. The DGPPN's activities and the exhibition in this regard, is an example of a professional society’s engagement in this area of work and forms a backdrop for the discussion of the local South African situation and context.
1. **Opening Lecture.** The Johannesburg leg of the program and exhibition was opened on the 12th July 2018, at the WITS Adler Museum, by Prof Martin Veller, Dean of the WITS Faculty of Health Sciences. Prof Veller identified some parallels between the recent South African context and the European context of the DGPPN exhibition during the first half of the 20th century, including that the most vulnerable in society were left to their own devices with the South African scenario also likely to have been a part of a system of patronage with political intent. A second parallel seems to be the fact that incidents in both contexts, apart from the decision makers, occurred with the acquiescence of other parties, such as civil society that should have been more involved. Prof Veller alluded to the symptoms of current levels of patronage that may be present in the South African society, including that, although many honest people talked out during the recent South African events - even when speaking out loud enough, they were not heard because they didn’t have enough political connectivity to be heard. In addition, much of the current discourse about the implementation and meeting objectives of a fair and equitable health system, also currently requires political connectivity, while the process should have been led by civil society.

**Prof Ames Dhai**. Director of the Steve Biko Centre for Bio-ethics delivered the first presentation in the lecture series, entitled: “Life Esidimeni tragedy: Moral pathology and an ethical crisis”. She referred to the LE tragedy as an ongoing tragedy of mammoth proportions that ought to have touched the consciences of all South Africans. The question is, “ . . . do all South Africans have consciences?” She stated that the LE experience raised a number of ethical issues at various levels, including ethical dimensions of health care practice, dual loyalty conflicts, moral authority of codes and professional oaths, as well as human rights violations. Alluding to the World Medical Association’s core values in this regard, Prof Dhai noted that ethics are put to the test when professionals’ own interests need balancing against competing claims. Regarding dual loyalties, which develop when expressed or implied obligations exist simultaneously towards a patient and to an involved third party - which is often the state, health professionals should maintain undivided loyalty to the welfare of patients. This would be in alignment with agreements since ancient times, such as the Hippocratic Oath, as well as with regard to other current international and local codes. Codes and professional oaths provide the moral authority required, while setting standards for ethical conduct, defining new ethical issues, and supporting one position or another in ethical discourse. She referred to the many ethical infringements during the LE tragedy by the Director of Mental Health, the Head of Department and the MEC, as well as in terms of how death certificates were managed. She concluded that healthcare professionals are the natural advocates of their patients, that for the sick, treatment is a matter of life and death, while our struggle for healthcare access for our patients, is also a matter of life and death.

2. **Colloquium.** On the 16th July 2018, the colloquium panel consisted of retired Deputy Chief Justice of the Constitutional Court, Justice Dikgang Moseneke, who presided over the LE Arbitration Process, as well as Prof Werdie van Staden, Director UP Centre for Ethics and Philosophy of Health Sciences, Prof Annelize Nienaber, Head UP Department of Public Law. Prof van Staden introduced the arguments for discussion with his presentation “Is a battle the best option for ensuring human rights in mental healthcare?”, followed by Prof Nienaber, with her talk on “Human Rights for people with Mental Illness: The Life Esidimeni tragedy as a violation of international law”. Justice Moseneke’s presentation on “Activism, State Accountability, Ethics and Healthcare”, concluded these arguments and called for continued advocacy by civil society and professional organizations, to keep holding government officials and politicians accountable for the access to and quality of care delivered to health care users.
From a philosophical perspective, **Prof van Staden** compared the breakdown of the relationship between clinicians and the community on the one side and government on the other, with that of an acrimonious divorce battle between spouses. He argued that interventions should have been undertaken long before such severing has taken place, through identifying what mutual values all parties can aspire to, and to find common ways of achieving it, even if differences of opinion exist on how to achieve it. This agreement on mutual values must occur through a process of consultation, but will require significant leadership skill to be carried forward constructively. Consensus must be reached on how, in a framework of distributive justice, to achieve equality and fairness in a resource constrained environment and where all, e.g. through illness, disability and financial means, are not equal.

**Prof Nienaber** reviewed the LE experience in terms of the principles and conditions of international law and demonstrated how, in addition to the South African Constitution, the government’s signing and endorsing of international human rights treaties, such as the United Nations’ Convention on the Rights of Persons with Disabilities (CRPD), should have protected against the violation of the human rights of the LE victims. In the case, however, where rights have already been violated, despite such protective national and international agreements and a government’s commitment to such treaties, she emphasized the importance of civil society’s (which include medical and legal professionals’) responsibility, to report on, complain about and intervene in such violations, in order to document such occurrences and demand redress. This can be done, with the confidence that such action is being protected by national and international agreements.

**Justice Moseneke** posed the question of what kind of protection should come from activism. In the LE experience, families did realised that a gross injustice was performed and started a quest to address this, by marching, holding vigils, etc. He alluded to SASOP’s and other’s attempts during the LE to communicate their concern about potential problems, and reiterated the importance of such voices and for professionals to even find unorthodox ways, outside of their narrow clinical responsibilities, to sound the alarm on potential and actual violations of human rights of their patients. Justice Moseneke further explained that when decision makers do not accept accountability, that activism is required, over and above having blue prints available in the form of good policy and constitutional documents. Civil society should hold government accountable in order to mitigate against bullying, while resisting evil and horror. Through his awarding to LE victims and their families of also a significant monetary recompensation, the Justice pointed to the current need that have arisen, namely, to re-examine the value and dignity of society and individuals in it, especially of those regarded to be least important - the “down-and-out”, the poor, the disabled.

3.  **Panel Discussion.** The Johannesburg leg of the program was concluded on the 18th July 2018, with presentations and a panel discussion, consisting of the representatives of SASOP, SADAG and the SAFMH - three of the respondents in the court application in March 2016 to interdict the Gauteng Department of Health at the time, to not proceed with their decision to discharge more than 1700 mental health care users to ill equipped NGOs. Panel members reflected on their experiences of the LE process as it unfolded over more than two years. **Ms Sasha Stevenson (SECTION27)** reflected on the experience of LE as the story developed, singling out the importance of having different partners and alliances, as well as of being persistent and flexible, being able to adjust an advocacy strategy when necessary. **Dr Mvuyiso Talatala (SASOP),** who was also called as a witness in the LE Arbitration process, focused on the importance of professionalism, and of clinicians and health workers having to resist political interference and manipulation by political principals. A professional association should protect the interests of its members and clinical discipline, as well as serve the community. **Ms Bharti Patel (SAMHF)** noted that the Federation tries to be a voice for those community-based facilities and care takers working in the actual environment created by the implementation of decision makers’ plans and programs. While they aim to promote a recovery
model, more often challenges are contended with, such as alienation and stigma of residents, poor funding and inadequate subsidies to NGOs, as well as fragmented and poorly staffed medical and community psychiatric services, which are supposed to be residential facilities’ health care support system. **Dr Lesley Robertson (SASOP),** alluded to the process of deinstitutionalization that has been occurring in Gauteng for more than 20 years, but that the poor planning and resourcing of the Gauteng Department of Health’s “Marathon Project” precipitated all the inherent risks of such an operation. She also emphasised the importance of professionals’ obligation to provide adequate clinical information to receiving colleagues, when a patient is being referred or transferred - a medico-legal principle which, in the LE experience, was also grossly compromised. **Ms Cassey Chambers (SADAG)** described the subsequent experiences, following the advocacy position that SADAG took during the LE events. This included the ongoing need for support of families and mental health care users, and the ongoing strain that such sustained demand is putting on the resources of SADAG and personally, on the individuals involved in the group.

The President of the Health Professions Council of South Africa (HPCSA), **Dr. Tebogo KS Letlape,** who attended and participated in the discussion, also alluded to medical professionals as the only group of health workers who can discharge a patient. He extended the conversation to the current attempts by the government to extend universal access in the South African health system through the proposed National Health Insurance (NHI) system. Reacting to proposals from the floor, Dr Letlape agreed to the arrangement of an open, “non-punitive” meeting between the HPCSA and relevant stake holders. Such a meeting will explore different issues regarding professionalism of professional role players during the past LE experience, as well as of the current, ongoing health care challenges in Gauteng, not only with regard to Psychiatry and Mental Health, but including the scope of medical clinical disciplines from Surgery to Paediatrics and Internal Medicine, etc., as represented by the local WITS School of Clinical Medicine.

Although some of these presentations will be repeated on Monday the 6th August 2018 from 17h00, at the **Johannesburg Holocaust and Genocide Centre in Forest Town Johannesburg,** ([www.holocaust.org.za](http://www.holocaust.org.za)) as part of the SA Holocaust and Genocide Foundation’s program while hosting the US Holocaust Memorial Museum’s exhibition **“Deadly Medicine: Creating a Master Race”,** the SASOP program on human rights for people with mental illness and DGPPN exhibition moves to Pretoria in September. Here it will be opened by Prof Tiaan de Jager, Dean of the Faculty of Health Sciences on the 6th September 2018 at the UP Medical Library, while the Pretoria program will culminate during the 19th biennial SASOP National Congress held at the CSIR Congress Venue, with a key-note presentation by the curator of the DGPPN exhibition, Prof Frank Schneider from Aachen University, Germany, on the 23rd September 2018.
### SCHEDULE: SASOP PROGRAM on HUMAN RIGHTS for PEOPLE WITH MENTAL ILLNESS

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<th>Date</th>
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<td>9 July to 24 August 2018</td>
<td>Johannesburg</td>
<td>WITS Faculty of Health Sciences, Adler Museum</td>
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<td>3 to 24 September 2018</td>
<td>Pretoria</td>
<td>University of Pretoria –Venue TBC (3-20 Sep) CSIR Conference Centre (21-24 Sep, SASOP Congress)</td>
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<td>8 October to 30 November 2018</td>
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<td>14 January to 28 Feb 2019</td>
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### Event Details / Programme

**Johannesburg**

*“What have you done to prevent it?” was a question often posed during the life Endgames investigations. The South African Society of Psychiatrists (SASOP) has embarked on a program “Human Rights for People with Mental Illness” during the second half of 2018, consisting of discussions and presentations in different cities (Johannesburg, Pretoria, Durban and Cape Town), as well as the travelling exhibition of the German Association for Psychiatry, Psychotherapy and Neurology (DGPPN), entitled “Registered, Insured, Assisted The Suffering under National Supervision”. The aim of these discussions will be to explore the role of professional societies and individual clinicians to uphold and protect the human rights of people living with mental illness. The DGPPN’s activities in this area of work and the exhibition, will be an example of a professional society’s engagement and will form a backbone for discussion of the local South African situation and context.*

**Event Details / Programme**

**12th July 2018**

**SASOP Programme on Human Rights for People living with Mental Illness**

- **10:30-10:45** Registration
- **10:45-11:00** Welcome and Introduction
- **11:00-11:45** Keynote: ‘What have you done to prevent it?’ – Dr. Susan Mithbally
- **11:45-13:00** Panel Discussion on the Life Endgames Experience: SASOP and Advocacy Partners

**16th July 2018**

**SASOP Colloquium on Human Rights for People with Mental Health**

- **10:30-10:45** Registration
- **10:45-11:00** Welcome and Introduction
- **11:00-11:45** Panel Discussion on the Life Endgames Experience: SASOP and Advocacy Partners

**18th July 2018**

**SASOP Panel Discussion on the Life Endgames Experience: SASOP and Advocacy Partners**

**Endorsed By:**

**Cipla**

**Steve Evans**
GAUTENG LECTURE SERIES
SASOP Program on Human Rights for People with Mental Illness

(1) 12th July 2018 (16h00-18h00) Adler Museum WITS – SASOP Program on “Human Rights for People with Mental Illness” Chair – Prof Hellen Myezwa (WITS FHS School of Therapeutic Sciences)
  o 16h50-17h00 Opening of DGPPN Exhibition - Prof Martin Veller, Dean WITS Faculty of Health Sciences
  o 17h00-17h30 “Life Esidimeni tragedy: Moral pathology and an ethical crisis” - Prof Ames Dhai, Director WITS Steve Biko Centre for Bioethics

(2) 16th July 2018 (18h00 - 19h45) Adler Museum WITS - SASOP Colloquium on Human Rights for People with Mental Health Chair – Prof Laetitia Rispel (WITS FHS School of Public Health)
  o 18h10-18h40 “Is a battle the best option for ensuring human rights in mental healthcare?” - Prof Werdie van Staden, Director UP Centre for Ethics and Philosophy of Health Sciences
  o 18h40-19h10 "Human Rights for people with Mental Illness: The Life Esidimeni tragedy as a violation of international law" - Prof Annelize Nienaber, Head UP Department of Public Law
  o 19h10-19h45 “Activism, State Accountability, Ethics and Healthcare” - Justice Dikgang Moseneke

(3) 18th July 2018 (16h00 - 19h00) – SASOP Panel Discussion on the Life Esidimeni experience: SASOP and Advocacy Partners (SADAG, SAFMH, SECTION27) Chair – Prof Daynia Ballot (WITS FHS School of Clinical Medicine)
  o 17h00-18h00 Presentations. 10-15 minute by panel members - Dr Mvuyiso Talatala, Ms Cassey Chambers, Dr Lesley Robertson, Ms Sasha Stevenson, Ms Bharti Patel

(4) 6th August 2018 16h30 for 17h00 -19h00 Johannesburg Holocaust Centre - Human Rights for People with Mental Illness
  Chair – Prof Bernard J/van Rensburg (SASOP)
  o 17h10-17h40 “Life Esidimeni tragedy: Moral pathology and an ethical crisis.” - Prof Ames Dhai, Director WITS Steve Biko Centre for Bioethics
  o 17h40-18h10 “Ethical strategies to prevent domination in healthcare” - Prof Werdie van Staden, Director UP Centre for Ethics and Philosophy of Health Sciences
  o 18h10-18h40 “Protecting the human rights of patients” - Prof Bernard Janse van Rensburg, SASOP President, WITS Department of Psychiatry

(5) 6th September 2018 16h00-18h30 UP Faculty of Health Sciences – SASOP Program on “Human Rights for People with Mental Illness”
  o 16h50-17h00 Opening of DGPPN Exhibition - Prof Tiaan de Jager, Dean UP Faculty of Health Sciences
  o 17h00-17h30 “Is a battle the best option for ensuring human rights in mental healthcare?” - Prof Werdie van Staden, Director UP Centre for Ethics and Philosophy of Health Sciences
  o 17h30-18h00 “Biolegitimacy: Valuation, Evaluation, Devaluation of Life” - Prof Ulrike Kistner, Professor of Philosophy, UP

(6) 12th September 2018 16h00-19h15 UP Faculty of Health Sciences – SASOP Lecture and Panel Discussion on the Life Esidimeni experience: SASOP and Advocacy Partners (SADAG, SAFMH, SECTION27)
  o 17h00-17h30 "Human Rights for People with Mental Illness: The Life Esidimeni tragedy as a violation of international law." - Prof Annelize Nienaber, Head UP Department of Public Law
  o 17h30-18h45 “Presentations. 10-15 minute by panel members - Dr Mvuyiso Talatala, Ms Cassey Chambers, Dr Lesley Robertson, Ms Sasha Stevenson, Ms Bharti Patel
(7) **21-24 September 2018, CSIR Conference Centre: SASOP Congress**

- Sunday 23 September 15h00-15h30 Key-note speaker "**Psychiatry during National Socialism: Lessons in advocacy and reconciliation.**" - Prof Frank Schneider, Director Clinic for Psychiatry, Psychotherapy and Psychosomatics, University of Aachen, Germany

(8) **26 September 2017, 19h00-20h00 Johannesburg Holocaust Centre - Human Rights for People with Mental Illness**

- 17h10-17h45 "**Psychiatry during National Socialism: Lessons in advocacy reconciliation**" - Prof Frank Schneider Director Clinic for Psychiatry, Psychotherapy and Psychosomatics, University of Aachen, Germany