



## PVRI South Africa & Sub-Saharan Africa Task Force Report 2018

Paul Williams



As the end of yet another year, it is once again time to reflect at how modest the achievements have been and how they measure against the aims and idealism of the stated and hoped for objectives at the beginning of the year.

There have been many areas of growth and advancement in the field of PVD in the region as whole. These have however been modest in comparison to the unmet needs of our patients, who remain inadequately provided in general.



The major reason for optimism lies in the increasing interest shown in PVD by young and newly qualified specialists in the fields of pulmonology, cardiology and internal medicine. They are enthusiastically continuing to improve matters at service provision, as well as academic level, and are committed to increasing competency and research locally. A major role the PVRI should continue to play is to help professionals to overcome the sense of isolation. This is particularly prominent working in the field of orphan disease as experienced in a developing or under-resourced medical environment.

The documentation of the nature of the impact of PVD on the local population remains fundamental in addressing unmet needs. To this end, the growth of a local registry has continued with two centres reporting consistently. Each of these centres provides dedicated care to more than 50 incident patients a year. This provides some insight as to what is being done at both state level and in the private sector.

Education is fundamental to improve care and maintain momentum. The regional Task Force remains committed to this goal. Progress is being made towards holding a local PVD meeting with the support of global PVRI members, to whom we are indebted to for their support, interest and understanding. The provision of care at times can be all consuming to the detriment of other commitments.

Supporting the planned PVRI meeting for 2019 is a new collaboration formed with a lay advocacy group under the guidance of the Jenna Lowe Trust. Jenna

Lowe was a remarkable young 20-year-old woman with PAH, who during her short-life had a huge impact on patients with PAH and their families. She not only increased awareness of PVD, but her influence extended into the transplant arena, where she managed to substantially increase awareness of organ donation and local organ donation rates among young adults. Sadly, Jenna Lowe succumbed to complications arising from a lung transplant. Her equally remarkable parents, Gabi and Stuart Lowe, are continuing in the pursuit of Jenna's goals to increase awareness of PAH, to improve access to advanced medical therapy and to increase organ donation rates among young adults in Southern Africa. Our Task Force is actively supportive and is very enthusiastic at the opportunity to partner with the Jenna Lowe Trust in the organisation of a PVRI meeting in 2019 in South Africa, with substantial input from the Trust as well as other emerging lay advocacy groups.

### Thus our collective aims for 2019 are:

- On-going growth in numbers and expertise of local PVRI members.
- Establishing a more coherent and collaborative approach of the local PVRI.
- Cementing of established links with local lay organisations.
- Maintaining and strengthening local links with the global PVRI leadership.
- Expanding of the well-established local PH Registry into two centres which will provide accurate data regarding local PH needs to the PVRI leadership.
- Holding a local PVD meeting, with global PVRI assistance, in order to inject enthusiasm and expertise into the local medical community providing care for patients with PVD.
- Expanding the reach of the PVRI throughout Southern Africa through collaboration.

