



PVRI South Africa & Sub-Saharan Africa Report 2019

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The past year has once again flown by with a speed that leaves one wishing for more time to spare and to reflect on what still needs to be achieved in the year ahead.

The medical fraternity in Southern Africa continues to be beset with many challenges, most of which are of special relevance to the PH fraternity. The vast disparities in the level of access to healthcare, even at basic level, are cause for concern among all in the profession. The plight of patients suffering from PH is merely emblematic of this problem. The State sector has the responsibility of care for the medically un-insured population, which constitutes about 77% of a population of over 50 million people. This sector also falls under the scope of teaching universities, which service the hospitals in their respective districts.

The appropriate investigation and management of the various forms of pulmonary hypertension are clearly of lesser importance than more prevalent and devastating and yet also treatable conditions such as HIV and TB. One must at the same time give credit to health authorities for the progress made in the implementation of large-scale programmes to combat these illnesses.

The PVRI South Africa & Sub-Saharan Africa Task Force continues to voice the needs of those patients and healthcare practitioners who maintain that it is simply inadequate from a medical, societal and social justice point of view to not give due regard to those patients suffering from rare, difficult or expensive to treat maladies.

In this regard, we have taken the following steps:

- The collaborative PH registry continues to grow with the intent that this will provide authorities and funders with a clearer perspective on the PH landscape in South Africa. The total enrolment is now over 300 patients (*mainly incident*), almost split equally between the Groote Schuur Hospital- University of Cape Town PH Clinic, representing largely state sector patients, and the Milpark Hospital Centre of Chest Disease PH Clinic representing mainly healthcare insured patients. This REDCap-based registry, modelled on the REVEAL registry format, will provide not only epidemiological data, but outcome data from the increasing number of patients on PH specific therapy. A wealth of data will be available to researchers at all levels and will help attract new blood into the field.
- There has been recent and increasing interest shown by other clinics, who will hopefully be in a position to submit data to this registry. We remain convinced that the only way to overcome the inbuilt inertia we seem to experience is by providing high quality data of the existence of an unmet need.
- Collaborative efforts are also well underway in the planning and organisation of the upcoming collaborative meeting, co-hosted by the PVRI Working Group for PH in South Africa and the Jenna Lowe Trust, to be held in March 2020. The meeting will consist of a 2-day medical conference in Johannesburg with an International Faculty per kind sponsorship of the PVRI addressing broad topics of relevance to a general pulmonology and cardiology forum. This will be followed by an additional 2-day

patient-centred forum in Cape Town addressing the needs and interests of an increasingly well-informed patient advocacy group. This aspect of the meeting is being arranged by the Jenna Lowe Trust, named after an inspirational patient who, along with her equally inspiring parents and sister, went through the tumultuous journey from PH patient to transplant recipient.

This story is tough yet inspirational and well told by the patient's mother, Gabi, in her recent book "Get me to 21".

We hope to increase both public and medical awareness in this field with this collaborative approach, as well as demonstrate to our patients that their voices is being heard.

