



PVRI South Africa & Sub-Saharan Africa Task Force Report 2017

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As we look back on another year for the Task Force, we have the opportunity to reflect on what has been achieved, as well as looking at the challenges that lie ahead.

This has been a year marked by political upheaval and uncertainty, which is then magnified in a society with vast inequalities in resources. It is all too easy to allow this to distract us from our specific goals and give in to despondency.

It is a relief to realise that one is a part of the PVRI global community of like-minded professionals who, facing challenges of their own, are willing, indeed eager, to ensure those in the developing world remain focused on the task at hand.

We were given very welcome encouragement and a boost to the Task Force by receiving generous sponsorship for additional paid memberships by the PVRI, supported by United Therapeutics. This is beginning to yield fruit albeit at a slow pace.

Most of the activities of the Task Force have been behind the scenes and include discussion and planning that will eventually result in tangible achievements.

The vast disparity in access to healthcare between medically insured patients and those without remains a major concern in South Africa. The Task Force has made significant strides in the further development of two Pulmonary Hypertension Referral Centres in Johannesburg and Cape Town. The latter providing care for State sector patients. These clinics both see approximately 50 incident patients a year and provide continued care for an expanding number of patients. As a result, post-fellowship graduates expressed enthusiasm by making this a specific area of focus and research.



The Task Force has identified the need for a PH Registry to collate high quality data from the region and, in the latter half of the year, we saw the implementation of such a Registry. We express specific gratitude to Prof David Badesch who provided invaluable input and, in collaboration with the members from the University of Cape

Town, guided the implementation of this across South Africa with aim of expanding this to the whole Sub-continent. Data thus obtained will assist in driving further research as well as the allocation of National State resources, while assisting Medical Insurers in the funding of insured patients.

Access to appropriate therapy has remained the ongoing focus of the Working Group for Pulmonary Hypertension in South Africa and, despite what seems agonisingly slow progress, 2017 saw the registration of an Endothelia Receptor Antagonist (ERA) with the Medicine Control Council of South Africa, removing an important obstacle to widespread access to their use. Whereas up until now access to ERA and prostanoids has been on a "named patient compassionate use" basis, the remaining obstruction to ERA use remains cost.

A significant behind the scenes progress has been made in cooperation with two active lay advocacy groups in moving forward with collaborative efforts to raise awareness of the general public and medical professionals about PH.

Although much has been achieved, it is clear that individual passion and good intentions are simply not enough to make an impact. We look to the PVRI to assist us in galvanising these disparate groups into a more cohesive force.

Our goals for 2018 are to move forward with assistance.

The following areas of need will serve as focus points:

- Developing closer collaboration with the PVRI leadership to garner input from experienced internationally recognised opinion leaders. The means of actioning this would be a regionally held PVRI meeting in collaboration with the Pulmonary Hypertension Working Group and representatives from Cardiology, Pulmonology and other specialities including those outside of South Africa in the region.
- Broadening contact with representatives from the rest of Sub-Saharan Africa and identifying common ground.
- Formalising practical adaptation of the ERS/ESC 2015 Guidelines which are de facto adopted by South African Thoracic Society and SA Heart, but need modification to local needs in order to be widely implemented.
- Identifying and promotion of unique research opportunities that present themselves from the region and development of interested individuals.

Our thanks once again to the PVRI for their ongoing support of this region.