

My name is Denneys Niemandt, a 50 year old male from Cape Town in South Africa, and was diagnosed with PULMONARY HYPERTENSION 3 years ago.

At that stage I was 1 of only 10 known cases of Pulmonary Hypertension cases in South Africa. My frustration is not the fact that I have this dreaded disease, but because comparing to the UK and other overseas countries, there is so little known about the disease in South Africa.

In the UK for instance they have clinics, support groups, newsletters, fundraisers and many more. (Detail can be viewed on one of many websites - *puckerup4ph.com*)

Included you will find a copy of my case study and some photos of me and my family. I would love to get something started in South Africa, but the condition is not well known here in South Africa. When I was diagnosed, it was thought as per my case study, that I was one of first diagnosed with PPH in South Africa. People here just do not know much about PPH.

I am currently doing quite well under the circumstances. My medication is: Warfarin, Disprin, L- Arginine and Revatio(Sildenafil). The Sildenafil was imported for me by Pfizer on a compassionate basis and we are very glad that it is now officially registered at the South African Medical Council. The medical aids however are very reluctant to supply Revatio under Chronic medicine prescription as Pulmonary Hypertension is not on the list of 27 Chronic Illness Benefits yet.

My Cardiologist is Dr Smedema, who wonderfully diagnosed me and is still treating me for the condition. However, because of the fact that so little are known about PPH in South Africa, I do not know if there is doctors that specialize or research PH in South Africa. In fact very few Specialists, GP's or Medical aids are aware of this condition, which is a bit of a frustration.

How sick am I? I do not really know. Dr Smedema is very positive. I feel good some days, and very bad on other days. The biggest challenge for me is that I used to be very active, and now I get tired all the time. I try and be active as far as possible. The other down part is because it sometimes makes one feel depressed, as it is difficult sometimes to control one's emotions.

Mentally my biggest problem is that I do not know if progress is made, if the condition has improved considerably and what the future holds for me and my family. My wife works at the University of Stellenbosch, Faculty of Health Sciences where she facilitates different medical workshops, conferences, seminars and training workshops for General Practitioners and specialists. She is my pillar of strength and try on regular basis to speak to the Pulmonologists and Cardiologists at the University for advice and feedback. I also try to keep up to date with PPH on the internet and communicate with Indirani Govender from time to time. I am very glad to say that she and Elzarie Devenish is fantastic with all their input to try and continue the work started by Indirani's sister, Sharon Chetty. We are busy to establish a Pulmonary Hypertension support group in South Africa and to be registered as an Official Organisation, so that we can raise funds for our campaign.

I trust that this gives a bit of a better picture of the life of a normal person, living with a very rare and unknown condition, such as Pulmonary Hypertension.

Thanks.

Kind regards

DENNEYS NIEMANDT.