

January 2010

*I have read your articles with interest and this is my story.*

*My name is Sandra Small I am 52 years old and have a daughter, Shanna, who is 26.*

*I was diagnosed with PPH in October 2000, after having collapsed on a short hike at Suikerbos Rand near Heidelberg in Gauteng in August of the same year.*

*The Pulmonologist, who was one of a team of specialist's who were instrumental in diagnosing the condition, said that a lung transplant was the only solution and that my life expectancy without it, and supplementary oxygen, was 2 - 5 years.*

*The Cardiologist did not agree that a transplant was the best option as she felt it was too risky and the mortality rate was far too high. I was put onto Wafarin (7,5mg) and oxygen (4L/ minute) 18 - 20 hours per day. Imagine my horror at having to walk around with tubes in my nose! But do you know what, we humans are very adaptable! I continued to work, thanks to a portable impulse oxygen machine, but my condition deteriorated and I was put on a disability pension in June 2002. This was a traumatic experience for my family and me.*

*I researched the condition on the Internet and found nothing but doom and gloom and so I decided that I would rather not know!*

*I was very fortunate, however, to be in the right place at the right time as my Cardiologist, and a Specialist Physician colleague of hers, was asked to conduct the South Africa leg of World Wide Trial of a long acting version of Sildenafil (Viagra). They thought that I would make a perfect candidate.*

*My details were submitted to Pfizer and I was accepted as a trial patient in April 2003. I was one of the last patients to join the trial as it had officially started in*

*December 2002. There were 6 of us on the trail in South Africa and I think about 165 worldwide. We received the most amazing treatment from the specialists taking care of us. We became a family and were referred to as "The Viagra Junkies".*

*The trial lasted until December 2006 and was considered to be successful so the drug, registered in America under the name "Revatio", came into being.*

*Sadly one of the trial patients, Marguerite, passed away in April 2007. She had been very ill when the trail started and she lived 5 years longer than anyone thought she ever would. Sarah, another trial patient, passed away last week but I am not sure yet if it was from the PPH or if it was something else. The rest of us are doing pretty well all things considered, thanks to "Revatio".*

*The Specialist Physician, Dr Walter Scott, who actually diagnosed my condition in 2000, told us that there were so many developments in the study of this condition that he was sure they would find a cure within a few years. Sadly he is not here to see the strides that have been made as he was killed in a Motor vehicle accident a few years ago.*

*We may not have a cure for the condition but he was correct in many respects! Things are definitely better that they were! Take the oxygen concentrator for example, the one I have at home is the size of a gas heater, Sarah named it "R2D2" after the Star Wars character. The portable one I carried, so that I was not completely housebound, weighed 4Kg including the refillable cylinder, which lasted about 2 hours. Long distance travel was difficult and overseas travel was out of the question! About 5 years ago I was asked to test a prototype of a portable concentrator. It weighed 20Kg and had a battery life of 4minutes, not exactly portable but at least you did not need cylinders! I gave them my comments and I suppose they must have gone back to the drawing board because 2 years ago I received the best birthday present ever, a portable oxygen concentrator that weighs 2 Kg and, with the additional battery belt, lasts up to 10 hours depending on the oxygen flow required.*

*The batteries can be charged at a main supply or using the cigarette lighter in the car. This has changed my life because as long as there is electricity or a car I can go anywhere! In fact in December 2008/January 2009 I went on a 12 day cruise and in April 2009 I traveled to London to visit Shanna!*

*I consider myself very fortunate!*