

## Powerful Patient, 2008 Week 14

Host: Joyce Graff, WebTalkRadio.net

### Report from South Africa

In March 2008, Altheada and Fred Johnson went with Joyce to South Africa for the first meeting of the 18<sup>th</sup> International Affiliate of the VHL Family Alliance International.

Markus van Vuuren and Dr. Lizette van Rensburg had organized the meeting, hosted by Sappi, the world's largest paper manufacturer, at their headquarters building in Johannesburg. Lunch was provided by the South African Inherited Disease Association (SAIDA).



Altheada and Fred Johnson, Markus and Corrie Jansen van Vuuren, at Sappi headquarters in Johannesburg

A report from the meeting, with a collection of photographs from the trip, can be found at <http://vhl.org/newsletter/vhl2008/08ayafrica.php>

#### 1) **Our Guest**

**Altheada Johnson**, a registered dietitian, retired, has been a volunteer with the VHL Family Alliance since 1994. She has served twelve years on the Board of Directors, and continues to chair the Hotline Committee, managing the group of volunteers who share administration of the toll-free Hotline service for VHLFA.

#### 2) **About von Hippel-Lindau disease**

VHL is a genetic cancer syndrome, which causes vascular tumors of the retina, brain, spinal cord, kidney, pancreas, and adrenal glands. It is difficult to diagnose because of the widely variable expression. Symptoms depend on which tumor you get first, so there is not a clear list of symptoms. Each of the tumors occurs also in the general population as a “sporadic” tumor (just by chance), so even when a tumor is found it is often attributed to a sporadic tumor, and the patient is not warned about the other tumors that may also occur. With a diagnosis, however, there are strategies for finding issues early when they are more likely to be treated successfully.

The rate of diagnosis is low in every country. In countries where there are established VHLFA groups working to raise the visibility of this condition and supporting families, the rate of diagnosis is rising. See <http://www.vhl.org>

### **3) About South Africa**

South Africa was first visited by a European explorer in 1486. The first European settlement was established at Cape Town in 1652, as a way-station for ships traveling to the Dutch East Indies.

Many of the early settlers in South Africa came involuntarily – sailors shipwrecked on the treacherous rocks around the Cape, slaves from Indonesia and Madagascar, and prisoners “transported” to the colonies rather than face hanging, as so many were sent to America and Australia at the same time.

Britain took control of South Africa during the Napoleonic wars, and struggled with the Dutch (the Boers) until 1814 when South Africa was ceded to Britain. Britain controlled the Cape Colony through the 1800's. The Dutch took control again, but were defeated by the British in the Second Boer War (1899-1901), after which Britain established the Union of South Africa, a member of the British Commonwealth of Nations.

Diamonds were discovered in 1869, and gold in 1886, bringing many people from Europe and from other African nations, hoping to strike it rich, or at least to find work in the mines.

From 1948 to 1990 there was a political system in force known as Apartheid, classifying people according to race – White and Non-White. Mixed suburbs were demolished, and the people forcibly relocated to distinct areas for blacks, whites, and coloreds. The system was abolished in 1990, democratic elections held in 1994, and new constitution written 1994-96. Nelson Mandela, who had been held as a political prisoner with many others for 28 years, led the effort to create a truly integrated and just South Africa.

For statistics and other background, see <http://www.state.gov/r/pa/ei/bgn/2898.htm>

### **4) Quotes from Nelson Mandela**

"Never, never and never again shall it be that this beautiful land will again experience the oppression of one by another..." -- *Nelson Mandela, Inaugural Address, Pretoria 9 May 1994.*

"We enter into a covenant that we shall build a society in which all South Africans, both black and white, will be able to walk tall, without and fear in their hearts, assured of their inalienable right to human dignity – a rainbow nation at peace with itself and the world." -- *Nelson Mandela, Inaugural Address, Pretoria 9 May 1994.*

"Our single most important challenge is therefore to help establish a social order in which the freedom of the individual will truly mean the freedom of the individual. We must construct that people-centred society of freedom in such a manner that it guarantees the political liberties and the human rights of all our citizens." -- *Nelson Mandela, speech at the opening of the South African parliament, Cape Town 25 May 1994.*

### **5) Music selections**

The marimba band at Mama Africa Restaurant in Cape Town, performing their version of “Somewhere Over the Rainbow”

Selections from Unico Muzico, music by Mduduzi Mbuyazi, for Zulu Kingdom brand, <http://www.zulu.org/za> He is playing an electric wire conduit pipe (not a flute) and the shaker is a ball valve ball filled with 20 cent pieces.

Selections from the Abonwabisi Brothers, from the Waterfront in Cape Town. For bookings, contact Simphiwe, +27-73-732-4195.

### **6) Funding for the trip**

Basic transportation was funded by the VHL Family Alliance. All touring side trips including the airfare to Cape Town were privately funded.