

Powerful Patient #24, 2008 Week 18

Host: Joyce Graff, WebTalkRadio.net

Caregiving – A Heartbeat Away

Everyone is potentially a heartbeat away from becoming a patient or a caregiver. Fred Johnson shares his twenty years of experience as a caregiver for his wife.

1) About Our Guest

Fred Johnson is recently retired as a trainer in information technology with the Global Ministries of the United Methodist Church. He accompanied Altheada and Joyce on their trip to South Africa, and spoke about caregiving at the VHL meeting in Johannesburg.



Fred Johnson at Cape Point, South Africa.

2) More about VHL

Von Hippel-Lindau is a genetic condition caused by one tiny misspelling in one gene. Because of this flaw, an individual is at higher risk of having tumors in one or more of the following places: retina, brain, spinal cord, kidney, pancreas, and adrenal glands.

<http://vhl.org>

Altheada began having pain and difficulty walking for several years before the doctors figured out that she had multiple vascular tumors in her spinal cord. They were able to successfully remove the two largest tumors in the mid-1980's, but the impact of the tumors and the surgery left her with severely reduced use of her legs.

You will hear Fred talk about the changes this wrought in both their lives, and how they have worked together to strengthen their partnership and deal with their daily challenges.

3) Resources

The International Center for the Disabled (ICD) is a nonprofit outpatient rehabilitation center in New York City serving people of all ages with disabilities and other rehabilitative and developmental needs. Since its founding in 1917 as the first outpatient rehabilitation center in the country, ICD has pioneered new programs and services to help thousands of individuals achieve better health, greater independence, and more productive work, school, and family life.

ICD currently serves over 4,000 people a year, from all five boroughs of New York, who come to its Manhattan center where they receive medical, speech and language, mental

health and vocational services all at one site. ICD is a recognized leader in providing integrated rehabilitative care. <http://www.icdnyc.org>

There are number of other centers for “integrated rehabilitation medicine” – search for those words and your state name.

International Center for Disability Resources on the Net
(<http://www.icdri.org/index.html>)

Many medical conditions can cause loss of function in legs and/or arms. Look for your medical condition, or try these key words:

- Traumatic Brain Injury
- Spinal Cord Injury
- Stroke