



The Cancer Research Fund and the VHL Family Alliance International are dedicated to improving diagnosis, treatment, and quality of life for individuals and families affected by von Hippel-Lindau disease and related tumor conditions.

8 Ways to Help Your Doctor SAVE YOUR LIFE!

Most people believe that doctors make you better. But each of us needs to work with our doctors, helping them do their best job for us. HMOs often limit the doctor to 12 minutes per patient. You need to work at making the most of this brief visit!

YOU NEED TO MANAGE A TEAM,

and I am here to empower you – to teach you how to assemble the necessary medical professionals and to help them to communicate and work together.

REMOVE YOUR RISK OF NOT KNOWING!

Thousands of people in the US currently have no clear diagnosis for their medical problem, and getting a correct diagnosis can be challenging. Delayed diagnosis could lead to permanent disability or death.

ARE YOU THE ONE OUT OF TEN AMERICANS

who has a rare disease? 30 million Americans are dealing with a rare disease. Yet, **the experience is not rare!**

HOW TO BE AN ACTIVE PATIENT

- 1. BE THERE** Don't ignore symptoms, ask for help.
- 2. MANAGE YOUR FEARS** Don't deny them, but manage them. Breathe. Gather data. Do you need to worry?
- 3. NEVER WITHHOLD CLUES** Don't expect your doctor to guess what you're not saying.
- 4. KNOW YOUR GENES** Understand genetic risk factors by making a family health tree and seeking genetic counseling.
- 5. KEEP A LOG** Map your pain or discomfort by time of day, time of month, and what you eat. Take a copy for the doctor to keep in your file and review.
- 6. PLAY BALL** Assemble a team of professionals who bring the right skills to the game.
- 7. TAKE NOTES.** Take a friend or a tape recorder, because you may forget the details.
- 8. DO YOUR HOMEWORK** Read up on your diagnosis and your tumor type. Could you develop more tumors or symptoms?



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- Graff has dealt with VHL since 1962.
- Lost her husband to VHL.
- Survived breast cancer in 1979.
- Donated kidney to her son with VHL in 2001.
- Executive Director of the VHL Family Alliance International & Cancer Research Fund.
- Editor of the *VHL Handbook: What you Need to Know About VHL*.
- Co-author with Myra Vanderpool Gormley of *Your Family Health Tree*, a guide to assembling essential family information.
- Edits a quarterly newsletter on managing VHL.
- Board member of the National Organization for Rare Disorders.
- Can access hundreds of patients and doctors who share compelling stories demonstrating the dramatic power of teamwork in finding diagnoses and saving lives.

powerfulpatient.org *a service of the Cancer Research Fund of the VHL Alliance.*

This service offers free, weekly prerecorded discussions for anyone interested in complex medical conditions or disabilities. Visit www.blogtalkradio.com/powerful-patient and find archived discussions at www.powerfulpatient.org.

A complex medical condition is anything that requires you to work with more than one medical specialist. In that situation, you have to work with your doctors to make sure they are communicating with one another and that they have all the information they need to give you the best possible advice!