

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.

MANAGING A TEAM

I'm here to empower patients – teaching them how to assemble the necessary medical professionals, and help them to communicate and work together.

RISK OF NOT KNOWING

Thousands of people in the US currently have no clear diagnosis for their medical problems – delayed diagnosis often means **permanent disability or death**

ONE IN TEN AMERICANS has a rare disease.

30 million Americans are dealing with some rare disease – **the experience is not rare**, and getting a correct diagnosis is particularly challenging.

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, 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: your health
7. TAKE NOTES. Take a friend or a tape recorder – you will forget the details.
8. DO YOUR HOMEWORK Read up on your diagnosis, or your tumor type. Is this one incident all there is? or is there more to it?

MOST PEOPLE WONDER
IF THEY'LL GET CANCER
... WE WONDER **WHEN**



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. They provide information in 8 languages, fund research, and help connect people with the best available medical information.



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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
- Access to hundreds of patients and doctors who can share compelling stories demonstrating the dramatic power of teamwork in finding diagnoses and saving lives

Ten More Show / Story Ideas

1. JOYCE'S STORY How a mother survived breast cancer, donated a kidney to her son and founded an organization for his rare cancer.
2. MOTHER'S DAY Mom gave you life, her eyes, her cancer. Get a genetic test on Mother's Day. (or Father's Day)
3. TRADING NFL FOR VHL How a genetic test derailed a pro football player's career ... and saved his life.
4. HATFIELD-McCOY FEUD and some of the medical sources of feelings of fear or anger. Since the AP article we have been deluged with callers looking for possible cures for anger. Excellent stories or radio discussions.
5. GENE HUNT Kidney cancer is rising in America, especially among African Americans. A New York rapper can talk about his operations, and how preventive screening saves lives.
6. RARE DISEASE STRIP-TEASE Amy, a burlesque dancer, is bringing sexy back to women with cancer. She teaches dancing to enhance self-esteem and healing following surgery.
7. IT'S ALL IN YOUR HEAD. The first doctor sent Sarah to a psychiatrist, but it turned out to be a brain tumor. He was right – it was all in her head.
8. GONE DIGITAL How to use the internet to find information and support for nearly any issue. How to tell the authoritative medical information from the hearsay.
9. BRANCH OUT How to make a medical family tree. Knowing your family history could save your life.
10. WORDS THAT HURT Changing the words you use –not suffering but surviving – and seeing healthier results.