

HOW TO SAVE YOUR GRANDCHILDREN

What do we pass down in the family? Recipes, jewelry, photos. But none of those will save your life. Careful notes about the family health history might well save lives.

In the press recently there has been broad publication of a story by Marilyn Marchionne of the Associated Press, discussing the feud between the Hatfields and the McCoy's and suggesting that the disease that runs in the McCoy family might have contributed to the explosive tempers involved.

I am proposing a follow-up piece featuring a Pennsylvania family that has the same disease in the family, but without the anger. This family, known in the medical literature as the Black Forest family, has been in the United States since the 18th century, solid and productive citizens, dealing with periodic medical issues due to a hereditary condition called von Hippel-Lindau disease (VHL). Many family members have had adrenal tumors called pheochromocytomas. But their behavior is very appropriate. Why are the same symptoms interpreted differently in different families?

This family came from the southwest corner of Germany in the 1700's to settling in Pennsylvania. Some relatives stayed behind in the Black Forest region, where there is an extensive family today. Ten years ago Dr. Hartmut Neumann of Freiburg, working with colleagues at the U.S. National Institutes of Health, compared the DNA of the Pennsylvania family with his patients in Germany and determined that they have a common ancestor before the emigration to the U.S.. This is called the Founder Effect – the founder of this family line gave rise to these two large populations in two countries.

Members of this family are willing to appear on camera, and be interviewed. Experts from the University of Pennsylvania are willing to accompany the family to provide medical input. Some of the issues the report might focus on include:

- What does it feel like to be born into a family with a serious disease in the genes?
- How do you tell a potential spouse that there's significant disease in the family?
- How do you raise a child to be responsible for his or her own health?
- How do you convey health information within the family, to make sure people know to bring it up with their doctor?

Medical experts could talk about the importance of building your family health tree, keeping it up over time, and keeping it available to the family. It is as important as the Family Bible.

Joyce Graff, Executive Director of the VHL Family Alliance, coaches families in the assembly of family health information and creation of family health trees, and in working in partnership with your doctors. She can appear as a guest to give tips to your audience (both on the show and more on your news website). She has 8 Ways you can Help your Doctor Save Your Life that apply to all medical conditions, especially ones that are complex.

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



MRIs, EEG, PETs all pale in comparison to the importance of a Family Health Tree

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Larry S. is a member of the Black Forest Family of Pennsylvania and Germany, a large and long-documented extended family which has lived in the United States since coming from Germany in the 18th century.

Larry's sister Marie. She is the family historian.



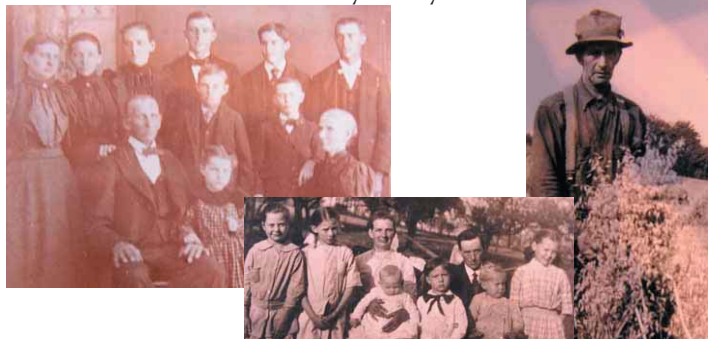
Joyce Graff, Founder and Executive Director of the VHL Family Alliance, Joyce has been dealing with VHL since 1962. She is the co-author with family historian Myra Vanderpool Gormley of *Your Family Health Tree*, and editor of *The VHL Handbook, What You Need to Know about VHL*. Formerly an industry analyst for Gartner Inc., Joyce has appeared on radio and television.



Katherine Nathanson, M.D., University of Pennsylvania Medical Center. Geneticist focusing on understanding inherited genetic susceptibility to cancer. She heads the VHL Clinical Care Center at the University of Pennsylvania in Philadelphia.



Catherine Stolle, Ph.D., Children's Hospital of Philadelphia. Board certified in Clinical Molecular Genetics. Dr. Stolle is the foremost authority in the world on DNA testing for VHL. She has been an active member of the team at the National Cancer Institute studying the genetics of VHL for nearly 20 years. She is a co-author on the Atuk paper on the McCoy family.



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.