

Family History, Social Media, and a Diagnostic Surprise

The editors of *AFP* welcome submissions for Close-ups. Guidelines for contributing to this feature can be found in the Authors' Guide at <http://www.aafp.org/afp/authors>.

This series is coordinated by Caroline Wellbery, MD, Associate Deputy Editor, with assistance from Amy Crawford-Faucher, MD; Jo Marie Reilly, MD; and Sanaz Majd, MD.

A collection of Close-ups published in *AFP* is available at <http://www.aafp.org/afp/closeups>.

I was in my mid-30s when during one of my searches into my family tree, I entered my mother's unusual surname into Google to see if there were others who shared it. The search immediately led me to a mysterious post. Someone from a branch of the family I'd never known about, it turned out, was looking for my parents. By chance, I learned that this person was my half sister. We wrote back and forth, excited to have found each other. Not long afterward, she traveled from her country to visit me.

During the days we spent together, I noticed she had a scar on the back of her neck. It was exactly the same scar I had on the back of my neck. I'd had a surgery to remove a large hemangioblastoma from my cerebellum when I was 27 years old, and like my sister, I'd had some hearing loss in my right ear. My health problems for the past 20 years had never been diagnosed, but my sister's had. Needless to say, it didn't take long for me to be tested, and for the doctors to confirm that I had her genetic mutation. I had von Hippel-Lindau disease.

Since then, I've been treated at the National Institutes of Health, undergoing multiple surgeries to remove the cysts and tumors associated with the disease. Knowing what I'm fighting against, along with the professionalism and kindness of the agency's staff, has made it much easier for me to accept my illness. The Internet gave me a sister, and my sister gave me a diagnosis. Some blessings come in disguise!—J.A.



COMMENTARY

As family physicians, we are primed to consider the entire family in our holistic approach to patient care. We should encourage patients to arm themselves with information about their family history and work together to create a care plan emphasizing mitigation of genetically inherited risks. Social media and the Internet can be fertile resources for patients, especially for those who have been estranged from their families. Although patients may consult “Dr. Google,” physicians should base their care on a solid understanding of disease heritability.

REBECCA DIVERS, MD, and CAROLINE WELLBERY, MD

RESOURCES

For patients

AAFP's Patient Information Resource
<http://familydoctor.org/familydoctor/en/prevention-wellness/staying-healthy/healthy-living/genetic-testing-what-you-should-know.html>

My Family Health Portrait

<https://familyhistory.hhs.gov/FHH/html/index.html>

National Institutes of Health Genetics Home Reference

<http://ghr.nlm.nih.gov/handbook/inheritance/familyhistory>

For physicians

Wattendorf DJ, Hadley DW. Family history: the three-generation pedigree. *Am Fam Physician*. 2005;72(3):441-448.

Welch BM, Dere W, Schiffman JD. Family health history: the case for better tools. *JAMA*. 2005; 313(17):1711-1712. ■