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Bilingual Cancer Information: Access is the First Line of Defense

By Patrick Boudreault and Christina Palmer

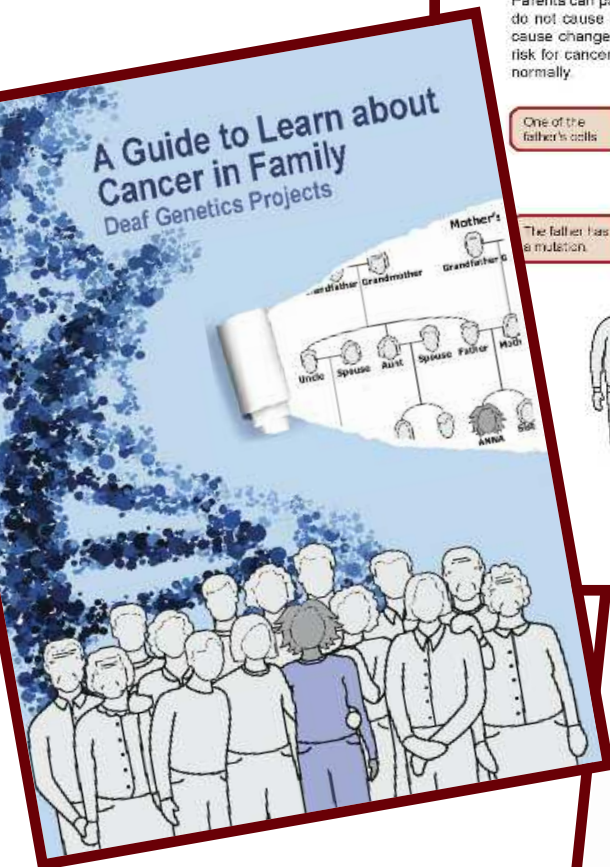
Information about cancer, the disease that kills more Americans than any other except heart disease, is essential. In some ways, information is our first line of defense. It allows us to identify individual risk factors, to note when a problem means we should see a professional, and to avoid activities that might put us at risk. Information allows individuals to use the latest research and to live healthy lives.

However, researchers have found that many people are prohibited from getting information because facts about cancer and other health-related issues are couched in language that is difficult to understand. In fact, though the U.S. Department of Education recommends that educational materials aimed at the public be written at a level no higher than eighth grade, King, Winton, and Adkins (2003) found that the reading levels for health-related materials on the Internet ranged from 11.1 to 14.8 grades.

This prohibits many individuals—young people still in school, adults who never learned to read well, those who learned English as a second language, and some deaf and hard of hearing individuals—from accessing information. Not only are these individuals frustrated in trying to access information through the Internet, McEwen and Anton-Culver (1988) found that deaf individuals may be at great risk for poor provider-patient communication. Further, Harmer (1999) found that deaf individuals have inadequate access to health education through channels such as the media, the Internet, friends, and the community.

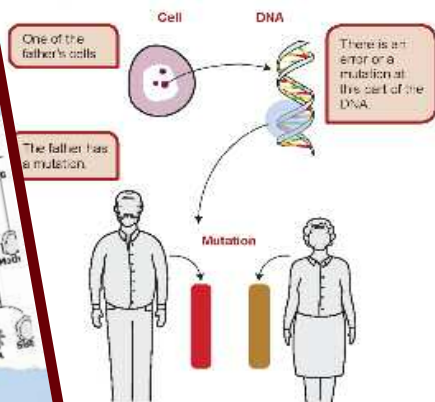
Although many deaf individuals are able to read at a high level and deaf academicians use medical terminology and explain complex genetic information in American Sign Language (ASL), this terminology—as well as its spoken counterpart—is not widely understood. Further, many deaf people distrust the medical community due to a long history of not only insensitivity on the part of medical professionals but outright discrimination against deaf individuals. Deaf people have experienced a lack of acceptance of themselves as human beings from medical personnel, and, in the not very

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How is Inherited Cancer Passed Through Families? 3

Parents can pass mutations to their children. Some mutations do not cause a change in our bodies. And some others can cause changes in our bodies. Some mutations can increase risk for cancer. These mutations can cause cells to grow abnormally.



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distant past, endured attitudes and healthcare sabotaged by the policies of eugenics (Middleton, Hewison, & Mueller, 1998). In addition, family members of deaf adults cannot be relied on to transmit their family health history, especially the risks associated with cancer genetics, due to the complexity of the subject and the stigma that surrounds the disease.

In response, the National Cancer Institute and the Genetic Alliance have funded the Deaf Genetics Projects research team, and the team is developing bilingual materials to help individuals in the Deaf community understand the complex information about cancer. The materials are designed for a wide audience that includes deaf high school students, deaf adults with minimum education, and deaf adults with some college education. The materials may be aligned with established curricula for science, biology, and health classes.

In order to take advantage of today's technology and to make these materials available for people throughout the United

States, they are available on the Internet at <http://aslcanccergenetix.org>. They open with a presentation by Patrick Boudreault, a professor and researcher who is deaf and who addresses his audience in ASL. In clear signs with supporting visuals, he compares cancer to normal cells, notes the risk factors for developing cancer—those that are inherited and those that are encountered or introduced into our environment—and explains the importance of knowing family medical history.

In a following lesson, Boudreault introduces Anna, a fictitious 28-year-old woman with a family history of breast and ovarian cancer. As the visuals illustrate her relationships—to her mother, father, aunt, uncle, and cousins—he outlines the major questions facing Anna as she evaluates her own risk for cancer. Explaining the importance of genetic counseling and genetic testing, Boudreault



notes that there are three important questions:

1. Which of Anna's relatives had cancer?
2. Which cancer did they have?
3. How old were they when they developed cancer?

This is one of six lessons packaged in 35-minute modules. The modules are:

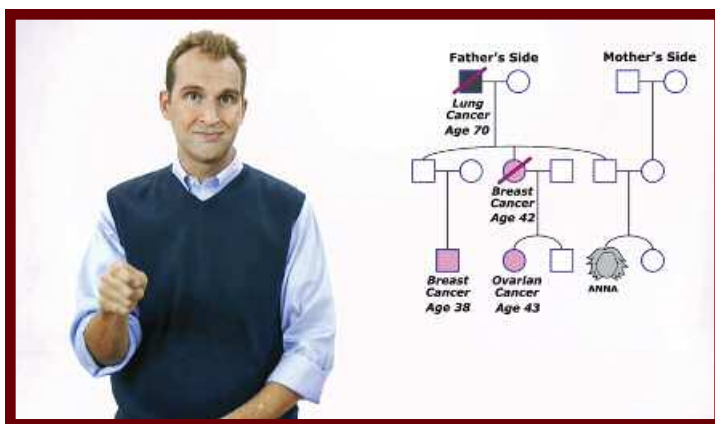
- Introduction
- Family History (and four quizzes)
- Evaluating Risk Factors of Cancer in Family (and two quizzes)
- Understanding Genetics (and four quizzes)
- Genetic Counseling and Genetic Testing (and three quizzes)
- Review

The most effective way to reach the Deaf community is in person by attending various deaf-related events (Kobayashi, Boudreault, Hill, Sinsheimer, & Palmer, 2013) and by working in partnership with Deaf organizations and educational institutions serving deaf and hard of hearing students. Information about the website, along with a supporting booklet, will be distributed during Deaf events and mailed to advocacy and health-related organizations across the United States.

Still under development on the website are the educational components for those who teach deaf and hard of hearing students. The materials will include downloadable lesson plans and existing on-line resources (e.g., videos with captions, websites on how to align materials with curricula in science, biology, and genetics). The unit plans will revolve around the bilingual educational modules that have already been developed. Teachers can also directly use these existing educational modules to develop their own lesson plans or as a way to generate discussion in science class.

Increased understanding of genetics and the increasing availability of personalized medicine—medicine tailored to an individual's genetic composition and lifestyle—have improved the prognosis for many of those who experience cancer. The result is that many more people survive cancer today than at any other time in history. Genetic counseling and testing can help to prevent cancer. Still, individuals have to be able to access this information to benefit from it. This is the goal of our project.

Thanks to technology, full, free, and direct access to health information through sign language is possible. The United Nations (UN) has recognized this access as a human right. The UN Convention on the Rights of Persons with Disabilities (2007) notes in Article 25 that all individuals have a right to the highest standard of care. Developing health information in ASL ensures access to information about health for deaf and



hard of hearing people. As a result, they may learn to better understand their family health history, have an opportunity to pursue genetic counseling, become aware of cancer risk factors, and perhaps save their own lives and the lives of those they love.

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