Professional Supplement to the *Healthcare Communication Review*
Volume 3 Number 1 Online Edition January 2003

Talking with Patients About Genetic Testing for Inherited Breast Cancer Risk

By Jonathan Clyman, PhD

Talking with patients about inherited breast cancer and the possibility of genetic testing is really about listening. When women are referred to me for genetic counseling, a question I will often ask is: "Why are you here now?" These women typically have known of their increased risk for some time. They are getting appropriate screening and understand that they may need to make decisions about more aggressive monitoring or prophylactic surgeries. A recurring answer I hear is that another relative in her family – often the first in their own generation, such as a sister or cousin – has now also been diagnosed with breast cancer. The disease, always a distant drumbeat, has gotten closer. Other women may have arrived at a point in their lives where this is now something appropriate to look at and there is a more urgently felt need to make decisions for herself and her family. Perhaps one is thinking of starting a family while another is done having her children. Some women simply want to know that they are doing whatever they can in the face of their increased cancer risk. There are as many reasons as there are women.

When considering genetic testing in response to a personal or family history of cancer, a complex path of decisions must be undertaken – complex because the path is confounded by seemingly shifting sands of complicated, incomplete, and sometimes contradictory and ambiguous medical information. The benefits and limitations of an array of screening procedures, medications, or surgeries need to be weighed by each woman against her medical history, her own family history and other risk factors. Genetic testing for one of the known inherited genes that greatly increase the risk of both breast and ovarian cancer can be a critical piece in the decision process leading to the most appropriate medical care. The questions are: should she, or should she not, undergo the test and what should she expect if she wants to move in this direction. The process of finding these answers begins in consultation with her primary care practitioner.

If, as a primary practitioner, you want to help patients find these and other answers about DNA testing, a good place to start is by asking yourself if you need clarification about its risk or appropriateness as a medical management tool. With respect to particular patients, you might note whether they have expressed concerns or asked about testing, and/or if their fears (or lack of concern) are out of proportion to actual risks. The primary reason to pursue genetic testing is to clarify risk. Even where this is a valid intent, however, testing is not for everyone. First, most breast cancer, even where there is a family history, is not inherited. Second, where a family and/or personal cancer history does suggest a high likelihood of segregating a cancer susceptibility gene, the issue of *who* to test needs to be considered. For an unaffected patient, it is preferable, when possible, to first test a family member who has had cancer in order to determine if there is a detectable gene alteration. The patient can then be tested for the presence or absence of that mutation.

Where a familial mutation has not first been identified, proceeding with genetic testing may have limited value. A negative result in such a situation would not necessarily reduce a women's cancer risk. Taking the patient's personal and family cancer history to determine the extent that it is consistent with the presence of a dominant, familial, cancer-susceptibility gene is therefore central to the process of determining whether or not a DNA test is appropriate. In talking about this with your patients, especially when you feel the need to raise the subject, a place to start is to point out the patient's cancer history and discuss your own reasons for addressing it now. A referral to a genetic counselor to discuss in detail her risks, along with the process and appropriateness of testing, can be offered. The genetic counselor (or other genetic professional, e.g., geneticist or trained nurse) can also help you to arrange the testing as well. Before seeing the counselor, it can be very helpful if you were to advise her to collect specific information about her family cancer history, including the precise types of cancer, ages of onset, and whether the cancers were primary cancers or metastases. You might suggest she get this information from family members, medical records, or even, in some cases, death certificates. This information can be very important for evaluating her risks and appropriateness of genetic testing – an evaluation which, in-and-of-itself, is very important.

Because cancer is a topic fraught with fear and anxiety, the decision to be tested is often, in the end, as much a personal one as it is a medical one. By helping patients understand what's involved, primary practitioners can help patients as they begin to explore this possibility. If you'd like to find out more about circumstances that suggest a need for testing and/or the counseling and referral process, you can check with a genetic counselor. To find a genetic counselor in your area, visit the website of the National Society of Genetic Counselors.□

Jonathan Clyman, PhD, is a Board Certified Genetic Counselor affiliated with the Mid-Hudson Family Health Institute, in Kingston and New Paltz, NY.

Professional Supplement to the *Healthcare Communication Review*
Volume 3 Number 1 Online Edition January 2003

Women's Health in the News: A Free Literature-Watch Service

By Judith A. Greenfield, PhD, RN

Women's Health in the News (WHIN), a publication for healthcare professionals and women, provides brief summaries of time-sensitive news items (with source citations), which appear in both clinical journals and the general press. Distributed every two weeks by Breakaway Media, a healthcare marketing firm, this free service came into being when a physician asked for something to put in his waiting room that would alert his patients to important health matters. While many physician-subscribers continue to post WHIN in their waiting rooms, distribution has since expanded to any professional or lay decisionmaker who asks for a free subscription. The publication, which is available by email, fax or on websites of partnering associations, currently reaches over 24 thousand healthcare professionals and a half million women.

The costs of this service are underwritten by a variety of pharmaceutical companies and health associations. In return for their financial support, the publication features an educational column, "Of Note", which highlights the products (some of which are free) of publication sponsors. Whether your interest is in keeping up-to-date with key developments in women's healthcare or in providing this information to your patients, WHIN can help. To subscribe, visit their website at www.womenshealthinthenews.net or call 845-634-9140. Archived copies are also available at their website.□

Judith A. Greenfield is contributing editor of the *Healthcare Communication Review* and President of the Healthcare Communication Project, Inc.

Click here for your free subscription to the *Healthcare Communication Review*. (Note that in order to receive the Professional Supplement to the *Review* you must indicate that you are a healthcare professional.)