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Considering Enrollment?

Getting involved in a family registry is typically not a decision that's made lightly. Even so, participants should make sure they've weighed all of the emotional and logistical angles.

Before enrolling, participants should consider how they might use any genetic results—if the registry provides them—says Sylvia Rickard, a patient advocate for the National Cancer Institute's Breast Cancer Family Registry and a breast cancer survivor. Parents, for example, will be faced with whether to tell their children. "It's not just a matter of getting the test," Rickard says. "What are you going to do with that information afterward?"

As for the logistics, read up on the registry's procedures, says Wendy Kohlmann, a genetic counselor for the Huntsman Cancer Institute at the University of Utah. Huntsman has several registries, including ones focused on melanoma and pancreatic cancer. Ask how the information will be stored and privacy protected, Kohlmann suggests. How frequently will participants be needed in future years for additional questions, samples, or other information? If relevant genetic findings are discovered, will they be passed along? Participants might name an alternate contact in case they can't be located.

Also keep in mind that genetic material, once donated, may not be available for personal use later, Kohlmann says. One option is to preserve some genetic material through DNA banking in the event a family member one day wants to be tested. The cost ranges from \$50 to \$350, according to the National Society of Genetic Counselors. For more information, call 312- 321-6834 or consult www.nsgc.org

In the end, though, participants shouldn't enroll in a family registry out of any desire for individual benefit, Kohlmann says. "We make a very strong effort to clearly communicate that this is research. There are no guarantees this will help you or your family personally. We hope [the participants] will feel good about helping the overall field of cancer research."

For that reason, Kohlmann and others involved with family registries say they remain indebted to the thousands of people who participate. "They do it out of the goodness of their heart," says Alice Whittemore, PhD, co-investigator of the

Northern California Cooperative Family Registry for Breast Cancer. "Without them, we could do nothing."