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Sharing Genetic Test Results with Children

Genetic testing for diseases that do not develop until adulthood, such as most hereditary cancer syndromes, is not recommended before the age of 18\textsuperscript{1,2,3}. In the absence of timely medical benefit to the child, the risks of testing (e.g. psychological, life insurance discrimination, etc.) likely outweigh any benefits. In an article by Bradbury et al.\textsuperscript{4}, parents who had undergone genetic testing of the genes BRCA1 and BRCA2 were asked to answer ‘yes’ or ‘no’ about whether they supported genetic testing for their children who were under the age of 18. The majority of parents (55\%) did not support the testing of children under age 18. The most common reasons for opposing testing in children included the possibility of inducing fear, anxiety, and burden among children and lack of medical intervention or preventative measures that would be initiated in childhood. Many parents also expressed concern that their underage children were not mature enough to understand or cope with their genetic test results.

In the absence of genetic testing of minors, children of all ages may express curiosity about why a parent is having a preventive surgery, the family history of cancer in general, or why a parent who may have just learned his/her test results is weepy. These are opportunities to broach the topic of hereditary cancer risk in a developmentally- and age-appropriate way with your child. Parents should avoid waiting until a child is 18 to ‘have THE talk’ about the risk for a hereditary cancer syndrome. Here we list some suggestions for sharing risk with your children.

For small children

1. Incorporate information about cells, genes, and DNA when they are learning about their bodies. Normalize the information (e.g. “We all have genes. Some genes are for eye color, while other genes are for skin color’’). There are great books and Internet resources available for children of all ages, which can be found on our website or in our past newsletters (available at https://medicine.yale.edu/cancer/patient/specialty/genetics/).
2. As your child gets older, begin to introduce more advanced topics and be open about your family history (e.g. “Every family has different genes. In our family, a lot of people have curly hair and freckles. Grandma had diabetes, so we make sure to eat healthy food and get plenty of exercise.’’).
3. Let your child ask the next questions, answer them truthfully, and use positive framing (e.g. “Does this mean I am going to get cancer, too?” “No, it doesn’t. One of the many things we have in our family is a gene that increases the risk of some types of cancer. When you grow up, you can be tested to see if you have this gene. If you do, we will know about it ahead of time and can hopefully stop those cancers from overdeveloping in you.’’).

For the tween/teen child

1. Do not underestimate your child or what they know, have heard from their friends or at school, or have seen on the Internet.
2. Reassure them you are okay and explain what you are doing to keep yourself healthy and there for them.
3. Answer your child’s questions truthfully and with positive framing.
4. If you can, discuss how lucky we are that science has advanced enough to allow us to know this information and use it to stay healthy and how quickly science is continuing to advance.

**Adult children**

1. Find them a good genetic counselor to discuss their risk and the timing of genetic testing. If they live in the Connecticut area, they can schedule an appointment with Smilow Cancer Genetics and Prevention by calling 203-200-4362. Alternatively, they can find a genetic counselor using the “Find a Genetic Counselor” tool at www.nsgc.org.
2. Reassure them you are okay and explain what you are doing to keep yourself healthy and there for them.

**References:**