

## Sharing Genetic Test Results with Children

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Genetic testing for diseases that do not develop until adulthood, such as most hereditary cancer syndromes, is not recommended before the age of 18<sup>1,2,3</sup>. It is thought that the risks of testing (psychological, life insurance discrimination, etc.) in children outweigh the benefits as screening or other interventions typically would not start in childhood. Many parents also have concern that their underage children are not mature enough to understand or cope with their genetic test results.

Even before genetic testing, children of all ages may express curiosity about why a parent is having a preventive surgery, the family history of cancer, or why a parent who may have just learned his/her test results is upset. These are opportunities to start to discuss 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.
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 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](http://www.nsgc.org).
2. Please see the fact sheet "Sharing Genetic Test Results with Adult Family Members" on our website for more helpful information on this topic.

### References

1. Ross LF, Saal H, David K, et al. Technical report: ethical and policy issues in genetic testing and screening of children. *Genetic Med*. 2013 Mar;15(3):234-45.
2. Botkin J, Belmont J, Berg J, et al. Points to Consider: Ethical, Legal and Psychosocial Implications of Genetic Testing in Children and Adolescents. *Am J Hum Genet*. 2015 July 2;97(1):6-21.
3. Committee on Bioethics, Committee on Genetics, American College of Medical Genetics, et al. Ethical and Policy Issues in Genetic Testing and Screening of Children. *Pediatrics*. 2013 Mar; 131(3):620-2.
4. Bradbury AR, Patrick-Miller L, Egleston B, et al. Parent opinions regarding the genetic testing of minors for BRCA1/2. *J Clin Oncol* 2010; 28:3498-505.