Parent Attitudes Favor Melanoma Genetic Testing for Their Children

Research Featured in Genetics in Medicine

Salt Lake City, December 21, 2010—The vast majority of parents who tested positive for a genetic mutation that increases the risk of melanoma (the most serious form of skin cancer) support genetic testing of their children or grandchildren. Results of the two-year study at Huntsman Cancer Institute (HCI) at the University of Utah (U of U) appear in the December issue of the journal Genetics in Medicine. The data could lead to the establishment of formal, evidence-based guidelines for genetic testing of people younger than 18 years.

The study, led by Sancy A. Leachman, M.D., Ph.D., of the University of Utah Department of Dermatology and Lisa G. Aspinwall, Ph.D., of the University of Utah Department of Psychology, both HCI investigators, surveyed 61 adults tested for the CDKN2A/p16 mutation that increases the risk of melanoma concerning their attitudes toward genetic testing of minors. Overall, 86.9 percent expressed support for melanoma genetic testing of minors. They cited the importance of risk awareness and the likelihood of improved prevention and screening behavior as reasons for this support. Participants were surveyed when they received their genetic test results and again two years later; their attitudes remained stable over that period.

“Developing guidelines for genetic testing of minors is complex and controversial,” says Leachman. “But knowledge of their genetic status could help them make appropriate lifestyle decisions. For example, a child who tested positive might decide not to choose a summer job that demands lots of sun exposure, such as lifeguard.”

Generally, genetic testing of children is recommended only when a clear benefit to the child will result. For example, testing minors is generally supported in families who have the syndrome called familial adenomatous polyposis (FAP) which causes polyp development in adolescence and confers a near-100 percent risk of colon cancer. Children found to have the genetic mutation which causes FAP are recommended to have early and frequent screening and sometimes even removal of the colon to avoid cancer development.

However, for other genetic conditions, such as the BRCA1/2 genes that when mutated can lead to breast and ovarian cancer later in life, testing for minors is not recommended because there are no known prevention strategies that could benefit these individuals during childhood. In fact, a similar study, led by Jeffrey Botkin, M.D., HCI director of bioethics, was conducted at HCI with
people who had genetic testing for a BRCA1 mutation. It showed significantly little support for testing of children; only 17 percent supported testing for their own children.

“Genetic testing for melanoma occupies a middle ground,” says Wendy Kohlmann, M.S., C.G.C., an HCI genetic counselor and study co-author, “because with or without the mutation, cancer screening and prevention measures remain the same. However, children and adolescents who know they have an increased risk of the disease have many opportunities to make lifestyle changes and choices that potentially reduce their melanoma risk.” Kohlmann says that children with this knowledge may be more consistent in practices such as increased skin cancer screening and reduced exposure to harmful ultraviolet rays through wearing protective clothing, using sunscreen, and avoiding tanning beds.

According to the study, ethical arguments related to the child’s autonomy and the balance of potential psychological harms and benefits have also been raised concerning genetic testing for minors. However, these concerns were raised infrequently by participants in the study. While more than one-third of those surveyed indicated they would consider a child’s maturity level in deciding about genetic testing, only two respondents opposed testing all children because of the possibility of producing worry and stress. In other words, most participant responses seemed not to correspond to frequently raised ethical concerns.

“People can use this knowledge to proactively manage their familial cancer risk when they have the most options to do so,” says Aspinwall. Other study authors include Jennifer Taber, M.S., and Reed Dow, also from the U of U Department of Psychology.

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The mission of Huntsman Cancer Institute (HCI) at The University of Utah is to understand cancer from its beginnings, to use that knowledge in the creation and improvement of cancer treatments, to relieve the suffering of cancer patients, and to provide education about cancer risk, prevention, and care. HCI is a National Cancer Institute-designated cancer center, which means that it meets the highest national standards for cancer care and research and receives support for its scientific endeavors. HCI is also a member of the National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of the world’s leading cancer centers that is dedicated to improving the quality and effectiveness of care provided to patients with cancer. For more information about HCI, please visit www.huntsmancancer.org.