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Parents favor genetic testing for melanoma in their children

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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. 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 their 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 that 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 gene mutations that 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 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 also have 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.

Provided by University of Utah