

## Should children be permitted to get genetic testing for BRCA 1/2 mutations?

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It's an ethical dilemma with serious implications. Should children be tested for gene mutations that predispose them to developing breast cancer and/or ovarian cancer later in life" New research suggests the next generation of parents may support testing minors even when any steps to reduce that risk will be postponed until adulthood – a finding that challenges current policies.

In the study published today online in the *American Journal of Medical Genetics* (Vol. 148C, Feb. 15, 2008 in print), researchers surveyed 53 BRCA mutation carriers who had children under 25 years of age at the time they received their genetic test results. In addition, 22 adult offspring of these parents were interviewed. The majority of parent participants were mothers (89%) although the offspring included both sons (45%) and daughters (55%). Interview subjects were recruited through the University of Chicago Cancer Risk Clinic.

Combining the responses of parents and offspring, 40% supported genetic testing of minors with half in favor only in certain circumstances. A majority of sons and daughters –potential consumers of genetic testing, supported testing minors.

"The latter finding is interesting," said lead author Angela Bradbury, M.D., of Fox Chase Cancer Center. "It signals that the next generation may be more comfortable with genetic testing. This could be because their generation grew up with genetics, learning about it in school or from the news, unlike their parents. To them, genetic testing may not be



## exceptional."

A majority of professional groups recommend against the genetic testing of minors in the absence of medical benefit. Carriers of a BRCA 1/2 mutations will not necessarily develop cancer but their risk is increased. Men with an alteration, face an increased risk of developing prostate, breast and pancreatic cancer. Women with an alteration are at an increased risk of developing breast and/or ovarian cancer. Risk reduction options such as prophylactic surgeries, heightened surveillance and or chemoprevention are generally not recommended until the age of 25.

"We already know that many adults who choose to undergo genetic testing do it 'for their children's sake,' so it's not a far stretch to imagine that parents might grapple with whether or not their children should be tested," explained Bradbury, director of the Margaret Dyson Family Risk Assessment Program at Fox Chase.

Bradbury says while the results are interesting, they are exploratory and need to be reproduced in a larger and broader sample. "Nonetheless, there is urgency for more research because current policies advising against genetic testing for minors may not hold up.

"Increased demand and availability of testing dictates a need to better understand the risks and benefits of early counseling and/or testing," she said.

Proponents of testing minors have argued there is harm in uncertainty and withholding information and the potential for later misdiagnosis. Other arguments in favor of testing include the fostering of autonomous decision making abilities. Additionally, many argue that parents and their children are more likely than health care professionals to most appropriately asses the risks and benefits of testing an individual child.



Those opposed to testing argue that the development of mature decisionmaking is variable during adolescence and letting parents make testing decisions for their minor children violates the future autonomy of offspring. Others cite potential adverse psychological consequences to early testing including increased disease-related distress and anxiety, distortion of family relationships, interference in normal development of self-concept and feelings of unworthiness.

"Despite this debate, empirical data to support either argument are lacking, especially in the setting of families affected by BRCA mutations," Bradbury concluded.

Source: Fox Chase Cancer Center

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