



C.S. Mott Children's Hospital National Poll on Children's Health

Vol. 10 Issue 2 ■ July 19, 2010

A publication from C.S. Mott Children's Hospital, the University of Michigan Department of Pediatrics and Communicable Diseases, and the University of Michigan Child Health Evaluation and Research (CHEAR) Unit

Most Parents Interested in At-Home Personal Genetic Testing for Their Kids

People interested in knowing their genetic risk for developing different diseases such as heart disease, cancer and diabetes can order genetic testing kits online and have test results sent to them. The US Food and Drug Administration (FDA) recently has questioned whether such personal genetic tests should be regulated, to ensure that the public is getting reliable and useful health information.

While not widely advertised, genetic testing may be ordered by parents on behalf of their children. The potential for personal genetic testing on children creates medical, ethical, and legal challenges that go beyond the current discussion about the regulation of such tests.

In May 2010, the CS Mott Children's Hospital National Poll on Children's Health asked parents about their interest in getting personal genetic testing for their children and reasons why they would be interested in getting testing for their children.

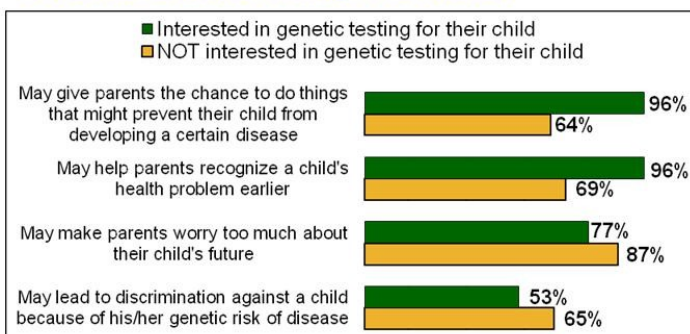
Parent Interest in Genetic Testing

More than half (53%) of parents are either very or somewhat interested in personal genetic testing for their child. 90% of parents who express interest in genetic testing for their children are also interested in genetic testing for themselves.

Among parents who were *interested* in personal genetic testing for their children, almost all agree that genetic testing may give parents the chance to do things that might prevent their children from developing a certain disease and may help parents recognize a child's health problems earlier (Figure 1).

Among parents *not interested* in genetic testing, the vast majority agree that genetic testing may cause parents to worry too much about their children's future. Two-thirds agree that genetic testing may lead to discrimination against a child because of the child's genetic risk of disease (Figure 1).

Figure 1. Parent Agreement with Opinions About Personal Genetic Testing for Children



Source: C.S. Mott Children's Hospital National Poll on Children's Health, 2010

Report Highlights

- **53% of parents are interested in personal genetic testing for their children.**
- **96% of parents interested in genetic testing for their children think it may give them the chance to prevent diseases.**
- **87% of parents not interested in genetic testing for children think that it may make parents worry too much.**

Implications

Recent actions by the FDA have focused attention on personal genetic testing, but very little discussion has addressed such testing for children. Results of this national poll indicate that a majority of parents are interested in this testing for their children. Yet, the appropriate use of personal genetic testing for children has not been fully explored. Some advocates argue that personal genetic testing may motivate parents and children to take preventive actions. Critics assert that personal genetic tests may provide inaccurate or incomplete information that may worry parents and children more than it helps them. While there is currently a scarcity of data to support any of these claims, the results of this poll indicate that many parents may be ready to move ahead with genetic testing for their children.

Data Source

This report presents findings from a nationally representative household survey conducted exclusively by Knowledge Networks, Inc, for C.S. Mott Children's Hospital via a method used in many published studies. The survey was administered May 1-18, 2010, to a randomly selected, stratified group of parents aged 18 and older (n= 1,461) with children 0-17 years of age from the Knowledge Networks standing panel that closely resembles the U.S. population. The sample was subsequently weighted to reflect population figures from the U.S. Census Bureau. The survey completion rate was 56% among parent panel members contacted to participate. The margin of error is plus or minus 2 to 5 percentage points.

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Director: Matthew M. Davis, MD, MAPP

Faculty Collaborator: Beth Tarini, MD, MS

Associate Director: Sarah J. Clark, MPH

Manager & Editor: Dianne C. Singer, MPH

Data Analyst: Amy T. Butchart, MPH

Contact us! Email: NPCH@med.umich.edu

<http://www.med.umich.edu/mott/npch>

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