

Consumers desire more genetic testing, but not designer babies

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A new study by researchers at NYU Langone Medical Center found a high desire for additional genetic testing among consumers for life altering and threatening medical conditions including mental retardation, blindness, deafness, cancer, heart disease, dwarfism and shortened lifespan from death by 5 years of age. Consumers, however, are less interested in prenatal genetic testing for traits including tall stature, superior athletic ability and superior intelligence.

"Our research has discovered that although the media portrays a desire for 'designer babies', this does not appear to be true among consumers of genetic testing services," said Feighanne Hathaway, MS CGC, a certified genetic counselor at the NYU Cancer Institute. The article entitled, "Consumers' Desire towards Current and Prospective Reproductive Genetic Testing" published online early by the *Journal of Genetic Counseling* finds that consumers desire more genetic testing than what is currently offered but their selection of tests have limits on enhancements.

Prior to their initial visit with a genetic counselor at NYU's Human Genetics Program, 999 patients completed a one-page, 10 question categorical survey to assess their attitude towards reproductive genetic testing between July 2006 and February 2007. These consumers were asked to indicate traits and conditions for which they would choose reproductive genetic testing by circling answers from a list of thirteen that included both diseases and enhancements.

The study found that the majority of respondents would elect for the screening of the following conditions: mental retardation (75%), deafness (54%), blindness (56%), heart disease (52%), and cancer (51%). The results indicate that less than half of population (49.3%) would choose testing for a condition that resulted in death by 5 years of age, whereas even less parents (only 41.1%, 24.9%, and 19%) would choose testing for conditions that results in death by 20, 40, and 50 years of age, respectively. Only a minority of respondents would want genetic testing for enhancements such as athletic ability (10 %) or superior intelligence (12.6%). Also, the majority of respondents (52.2%) indicated that there were no conditions for which genetic testing should never be offered.

"As our knowledge and abilities in molecular genetics continues to expand, so does our ability to detect certain conditions and traits prenatally," said Dr. Harry Ostrer, Director of Human Genetics Program at NYU Langone Medical Center. "Our study gauged the consumers' opinion towards reproductive testing for diseases and enhancements. Our research has found that a majority of respondents would elect to have prenatal genetic testing for life altering conditions but most respondents did not desire testing for enhancements. This survey also demonstrated that there was a desire for additional reproductive testing for medical conditions or life altering diseases, than currently offered."

In addition researchers investigated whether learning about risk for disease to oneself might dissuade an individual from undergoing prenatal genetic testing. The survey revealed that about 80% of all respondents would still have testing if it revealed increased risk for disease for oneself including Parkinson's disease, early menopause, breast cancer and if it revealed non-paternity.

According to researchers, this study recognizes the increased consumer demand for genetic testing and this higher demand may already be

exceeding the number of available genetic counselors. Consumers may have also followed their own personal values or belief systems when assessing choice for genetic tests and that genetic counselors may want to develop a policy statement about new genetic tests that are becoming available and the ethical concerns regarding prenatal testing for life altering conditions.

The authors concluded that, "it seems unlikely that the 'Age of Designer Babies' is near at- hand."

Source: New York University School of Medicine

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