

Guidelines for genetic testing of healthy children – addendum

A joint statement with the Canadian College of Medical Geneticists



RESEARCH TESTING

The understanding of the complex role that gene abnormalities play in individual disorders is quickly evolving and is frequently undefined. The parent or the child, when there is adequate capacity, should be informed of the potential difficulties in interpreting the results of gene testing within research protocols. It should be recognized that some laboratories that provide results have a primary research focus and thus, may not have the same standards of quality assessment and controls expected in clinical laboratories. In addition, the reliability and validity of the interpretation of the consequences of documented gene abnormalities should be discussed with recipients of this information, underscoring the importance of involvement of a qualified geneticist or genetic counsellor who can help differentiate between the uncertainty of research results and accepted clinical practice testing (1).

Parents, and children who are capable of making decisions, should be cautioned about acting on results that may have inadequate clinical accuracy or confidence (ie, where there may be an inability to interpret data with respect to established norms). Finally, it should be clear before testing, how research results may be distributed and to whom.

RECOMMENDATION

- Research testing: Paediatricians should inform parents, and children with adequate capacity to understand the information, that the reliability and validity of individual research results may vary with the understanding of the gene disorder and its testing. Recipients of this genetic information should be cautioned about acting on research results that may have inadequate clinical accuracy or confidence.

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REFERENCE

1. Shalowitz DI, Miller FG. Disclosing individual results of clinical research: Implications of respect for participants. *JAMA* 2005;294:737-40.

For more information, please refer to the full text position statement available on-line at <www.cps.ca/english/statements/B/b03-01.htm>

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate. *Internet addresses are current at time of publication*