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Genetic testing in children

DOI: 10.1038/GIM.2012.176

New guidelines for genetic testing and screening of children support screening of newborn babies for select genetic diseases, but suggest that broader screening should be delayed until adulthood. Ethical justifications and empirical data in support of the proposed policy recommendations are discussed in a paper published this week in *Genetics in Medicine*.

The policy recommendations proposed by the American Academy of Pediatrics (AAP) and the American College of Medical Genetics and Genomics (ACMG) support the mandatory offering of newborn screening for all children for a select number of genetic targets, in order to allow doctors to intervene early. It is recommended that carrier screening for recessive diseases and predictive genetic testing

generally be delayed until the child reaches adulthood, although there may be limited circumstances in which predictive testing for adult-onset disorders is appropriately done in childhood.

Statements about genetic testing and screening of children need to be reevaluated periodically to consider the ethical issues that arise with advances in our knowledge about genetics, technological developments, and increased usage of genetic testing. Lainie Friedman Ross and co-authors provide supporting evidence for the proposed policy recommendations by reviewing literature on the psychosocial and clinical effects of genetic testing. Ross and colleagues comment that as a general rule, decisions about whether to offer genetic testing and screening should be driven by the best interest of the child.

Given that the desire to know results about late-onset disorders is variable, deferring predictive testing until adulthood allows individuals to make their own decisions. The recommendations warn parents to be wary of direct-to-consumer genetic testing, because the effects have not yet been adequately evaluated in children, some of the testing in adults have been shown to provide unfounded genetic predictions and misleading test results, and some companies use deceptive marketing and other questionable practice.

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An accompanying policy statement will be published in *Pediatrics*.

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