

Genetic Testing of Children for Adult-Onset Diseases developed

George Chung

Department of Pediatrics, Columbia University, New York



Abstract (600 words):

The importance of family interests in medical decision-making has received a lot of attention. Although the correct role of family interests in medical decision-making is still debated, it is widely acknowledged that families routinely make decisions that take into account both communal and individual family interests. Physicians feel that for incompetent patients, families routinely incorporate family interests into medical decision-making, and that family interests should play an essential part in medical decision-making. Physicians, it has been claimed, should have a bigger role in fostering and supporting family-centered decision-making, or at the very least avoid discouraging it. Ross advocated "limited parental autonomy" as a criterion for paediatric medical decision-making to recognise that parents frequently and correctly consider the interests of other family members and the family as a whole when making decisions for their children. Although there is no clear cut limit to this autonomy, generic guidelines have been provided that aim to define clear-cut infringements on children's rights. It appears that there is a growing consensus that family members' interests should be considered when making medical decisions. Now we must figure out how

they should be counted in medical encounters between doctors, patients, and their families. Recently, family interests have been invoked to support genetic testing of children for adult-onset disorders, at least in part. Recommending that these findings be made public is a substantial policy move that has sparked much debate.

Importance of Research (200 words):

The ACMG recommendations cover adult and paediatric genetic testing, and they are relevant to the families of both adults and children, although a discussion of adult genomic testing is outside the scope of this article. The ACMG recommendations take the family into account when evaluating children for adult-onset genetic diseases, although they do so differently than the AAP. They, like the AAP, appeal to the child's best interests in a variety of ways. They argue that testing is in the best interests of the child's health because they may never be checked for these disorders again, putting them at risk and unprepared for sickness in maturity.

Biography (200 words):

George Chung is the Department of Pediatrics, Columbia University, New York. He has lectured nationally and internationally and has published on many aspects of pediatrics care. He attended medical school and completed his surgical residency in Columbia University, and completed a surgical pediatrics fellowship in New York. He has been named to the Top Docs list and has won awards for the development of multidisciplinary pediatric care programs.

Information of Institute (200 words):

Columbia University is a private Ivy League research university in New York City. Established in 1754 as King's College on the grounds of Trinity Church in Manhattan, Columbia is the oldest institution of higher education in New York and the fifth-oldest institution of higher learning in the United States. It is one of nine colonial colleges founded prior to the Declaration of Independence, seven of which belong to the Ivy League. Columbia is ranked among the top universities in the world by major education publications

Institution:



References (15-20):

1. Hardwig J. What about the family? Hastings Cent Rep. 1990;20(2):5–10
2. [Lindemann Nelson H, Lindemann Nelson J. The Patient in the Family. New York, NY: Routledge; 1995](#)
3. [Blustein J. Parents and Children: The Ethics of the Family. New York, NY: Oxford University Press; 1982](#)
4. Ross LF. Children, Families, and Health Care Decision-making. Oxford, United Kingdom: Oxford University Press; 1998
5. Hardart GE, Truog RD. Attitudes and preferences of intensivists regarding the role of family interests in medical decision making for incompetent patients. Crit Care Med. 2003;31(7):1895–1900
6. Hardart G. Including the family's interests in medical decision making in pediatrics. J Clin Ethics. 2000;11(2):164–168
7. American Academy of Pediatrics Committee on Bioethics . Religious objections to medical care. Pediatrics. 1997;99(2):279–281
8. Kopelman LM. The best interests standard for incompetent or incapacitated persons of all ages. J Law Med Ethics. 2007;35(1):187–196
9. Green RC, Berg JS, Grody WW, et al. American College of Medical Genetics and Genomics . ACMG recommendations for reporting of incidental findings in clinical

- exome and genome sequencing. *Genet Med.* 2013;15(7):565–574
10. American Academy of Pediatrics; Committee on Bioethics, Committee on Genetics; American College of Medical Genetics, Social, Ethical, and Legal Issues Committee. Ethical and policy issues in genetic testing and screening of children. *Pediatrics.* 2013;131(3):620–622
 11. Duke DC, Geffken GR, Lewin AB, Williams LB, Storch EA, Silverstein JH. Glycemic control in youth with type 1 diabetes: family predictors and mediators. *J Pediatr Psychol.* 2008;33(7):719–727
 12. Hanson CL, De Guire MJ, Schinkel AM, Henggeler SW, Burghen GA. Comparing social learning and family systems correlates of adaptation in youths with IDDM. *J Pediatr Psychol.* 1992;17(5):555–572
 13. Rivara JB, Jaffe KM, Polissar NL, et al. . Family functioning and children's academic performance and behavior problems in the year following traumatic brain injury. *Arch Phys Med Rehabil.* 1994;75(4):369–379
 14. May T, Zusevics KL, Strong KA. On the ethics of clinical whole genome sequencing of children. *Pediatrics.* 2013;132(2):207–209
Klitzman R, Appelbaum PS, Chung W. Return of secondary genomic findings vs patient autonomy: implications for medical care. *JAMA.* 2013;310(4):369–370