

ACMG NEWS

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ACMG Updates Recommendation on "Opt Out" for Genome Sequencing Return of Results

Bethesda, MD - April 1, 2014| There has been significant discussion surrounding the initial ACMG recommendations for the return of results from genome-scale sequencing issued in March of 2013. The ACMG Board of Directors has listened carefully to the members' views and appreciates the many forums in which divergent and valuable opinions have been expressed. The positions of ACMG members regarding the issues raised by the recommendations have been assessed through a variety of mechanisms, including direct feedback, participation by Board members in numerous forums exploring these issues, informal conversations, published articles, commentaries and, most recently, through an extensive member survey, the results of which were presented at the ACMG Annual Business meeting at the 2014 ACMG Annual Clinical Genetics Meeting in Nashville on Thursday, March 27.

There appears to be a consensus among ACMG members that patients should have an opportunity to opt out of the analysis of medically actionable genes when undergoing whole exome or genome sequencing. While the ACMG Board still considers the IFs to be important medical information that can be a great value to families, it has voted to recommend that such an "opt out" option be offered to patients who are considered candidates for clinical genome-scale sequencing. "This update to our recommendations moves the opt out discussion to the point where the sample is sent rather than at the time when results are received by the ordering clinician, as was originally recommended," explained Gail Herman, MD, PhD, FACMG, president of the American College of Medical Genetics and Genomics. Explanation to patients of the opt-out option and its implications should be part of the general education and informed consent process undertaken by the ordering clinician prior to ordering the test.

Dr. Gail Herman added, "The ACMG Board wishes to sincerely thank the ACMG membership for the spirited debate surrounding the optimal use of emerging testing and the Work Group who labored so hard on this incredibly complicated issue and developed the recommendations in 2013. The vibrancy of the debate is a testament to the importance and relevance of our field to the lives of our patients. There remain many complex issues to be addressed regarding the implementation of genome-scale sequencing in clinical care and we plan to keep having dialogue. It was our understanding from the beginning and was stated in the Recommendations that they would evolve over time. The ACMG is committed to working to ensure that promising new technologies are used now and in the future for the benefit of our patients and their families."

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Analysis of ongoing member feedback and data from both the clinical and laboratory realms may lead to additional conclusions and updates as our field continues to evolve. The Board will continue to update membership through direct communication, the newsletter and in the peer-reviewed journal, *Genetics in Medicine*.

About the ACMG and ACMG Foundation

Founded in 1991, the American College of Medical Genetics and Genomics (www.acmg.net) advances the practice of medical genetics and genomics by providing education, resources and a voice for more than 1700 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals, nearly 80% of whom are board certified in the medical genetics specialties. ACMG is the only nationally recognized medical organization dedicated to improving health through the practice of medical genetics and genomics. The College's mission includes the following goals: 1) to define and promote excellence in the practice of medical genetics and genomics and to facilitate the integration of new research discoveries into medical practice; 2) to provide medical genetics and genomics education to fellow professionals, other healthcare providers, and the public; 3) to improve access to medical genetics and genomics services and to promote their integration into all of medicine; and 4) to serve as advocates for providers of medical genetics and genomics services and their patients. *Genetics in Medicine*, published monthly, is the official ACMG peer-reviewed journal. ACMG's website (www.acmg.net) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Resources, and a Find a Geneticist tool. The educational and public health programs of the American College of Medical Genetics are dependent upon charitable gifts from corporations, foundations, and individuals through the ACMG Foundation for Genetic and Genomic Medicine (www.acmgfoundation.org.)

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