Genetics and Latinos: Proceedings of a National Summit

The impact of scientific achievements in human genetics on cancer and on many other diseases and conditions is enormous. These achievements and their potential multi-faceted effects on humans are often discussed in professional scientific and academic forums, but involvement of the lay public has been minimal.

The 2003 Hispanic/Latino Genetics Community Consultation Network (HLGCCN) Summit was an ambitious effort to bring the U.S. Latino public into the discussion and receive input from representatives of the country’s largest minority group. The two-day conference in Washington, D.C., was sponsored by the National Cancer Institute and National Institutes of Health, Redes En Acción: The National Hispanic/Latino Cancer Network (a Special Populations Networks initiative of NCI), and Baylor College of Medicine. NIH sponsor institutions were the National Institute of General Medical Sciences, National Human Genome Research Institute, and NCI (specifically, the Specialized Program of Research Excellence, Cancer Genetics Network and Center to Reduce Cancer Health Disparities). We are pleased to announce that the full report of the summit is now available online (http://www.aacr.org).

The summit brought together 115 Hispanic/Latino genetics researchers, program administrators, government workers, and community leaders to discuss the current status of genetics research/services with regard to Latinos and to make recommendations. In addition to those attending the summit, a larger number of Latinos around the country identified genetics issues through pre-meeting surveys using the Delphi process.

The summit meeting thus provided both a forum for developing strategies to improve access to the benefits of genetics research and health care services for Latinos and a model for involving Latinos in identifying and discussing these issues.

Leading genetics authorities reported on key areas of historic and current genetics advances and their impact on Latinos. Genetics issues were discussed in the context of research, health care services, professional education and training, and public education and outreach. Recommendations for strategies to address key genetics issues for the Hispanic/Latino population and action plans were developed as were strategies for improving community understanding of genetics and genetics research, promoting access to genetic health care services, and for building on the recommendations from the meeting.

The HLGCCN summit was a first step. The real journey begins as administrators, scientists and the public work together to implement strategies that will make a far-reaching and permanent impact on genetics policy. Underrepresented populations play an integral part in the discovery and the vision of the future for genomics research. In a field that holds extraordinary possibilities to find the origins of disease, reduce or eradicate chronic illnesses, and improve the quality of life in ways that are yet to be imagined, Latinos and other minority populations must not be left behind.

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