Event Report
June 22-24, 2003
Washington, D.C.
The purpose of the Hispanic/Latino Genetics Community Consultation Network (HLGCCN) Summit is to provide a forum for Latinos to identify, prioritize and disseminate information on genetics issues, particularly those that confront the Hispanic/Latino community. The initial invitational HLGCCN summit meeting, a first-of-its-kind conference conducted June 22-24 in Washington, DC, attracted 119 participants: key opinion leaders and genetics experts from Hispanic/Latino communities across the United States, as well leading federal government health officials.

The full proceedings with a comprehensive report of the summit recommendations, strategies and action steps will be posted on the Redes En Acción web site (www.redesenaccion.org).

The Hispanic/Latino Genetics Community Consultation Network (HLGCCN) Summit is a combined effort of Redes En Acción: The National Hispanic/Latino Cancer Network and the following sponsor institutions of the National Institutes of Health: National Institute of General Medical Sciences, National Human Genome Research Institute and National Cancer Institute (specifically, the Specialized Program of Research Excellence, Cancer Genetics Network and Center to Reduce Cancer Health Disparities). Participating institutions are Baylor College of Medicine and the University of Maryland. In addition, Redes En Acción would like to thank the members of the HLGCCN Planning Committee and Advisory Committee.

Redes En Acción is a Special Populations Networks initiative of the National Cancer Institute. NCI Grant No. U01 CA 86117-01.
Welcome to Summit Participants

Panel Chair: Jorge Gomez, MD, PhD, Chief, Organ Systems Branch, National Cancer Institute

Panel Participants: Raynard S. Kington, MD, PhD, Deputy Director, National Institutes of Health
Judith H. Greenberg, PhD, Acting Director, National Institute of General Medical Sciences

Summit Agenda

SUNDAY, JUNE 22, 2003
5:00 – 8:00 p.m. Registration
7:00 – 8:00 p.m. Reception
MONDAY, JUNE 23, 2003
7:15 – 8:00 a.m. Continental breakfast
7:15 – 9:00 a.m. Registration continues
8:00 – 8:15 a.m. Welcome and Overview
A. G. Ramirez, Dr.P.H.
Chair:
Deputy Director, Chronic Disease Prevention and Control Research Center
Bayor College of Medicine
8:15 – 9:00 a.m. Professional Education and Training
Victor Penchaszadeh, M.D., M.S.P.H.
University of Miami School of Medicine
José Fernando Arena, M.D., Ph.D.
National Institutes of Health
9:05 – 9:15 a.m.
Session 1: Develop Strategies to Address Genetics Issues and Research Pertinent to Latinos (4 breakout sessions)
Co-Facilitator: Anne Hippocrates-Springer, Ph.D.
Facilitator: H. T. Landro
Group 4: Public Education and Outreach
Facilitator: Louise A. Vidal
9:45 – 10:30 a.m. Session 2: Develop Short-Term (<2 years) and Long-Term (2-5 yrs) Action Plans to Address Genetics Issues and Research Pertinent to Latinos (4 breakout sessions)
Group 4: Public Education and Outreach
Facilitator: Louise A. Vidal
11:15 – 12:00 p.m. Discussion
LUNCH
Cancer, Genetics and Hispanics: An NCI Epidemiological Perspective
Speaker: Edward J. Trapido, Sc.D., M.S.P.H.
Co-Facilitator: Anna Nápoles-Springer, Ph.D.
Group 1: Research
12:00 – 12:30 p.m. Conclusion
Members:
Raymond Kinghorn, M.D., Ph.D.
Deputy Director
National Institutes of Health
12:15 – 1:20 p.m.
Group 3: Professional Education & Training
Frank J. Penedo, Ph.D.
University of Maryland
10:45 – 11:05 a.m.
Group 2: Healthcare Services
Co-Facilitator: Frank J. Penedo, Ph.D.
Epidemiological Perspective
Speaker: Edward J. Trapido, Sc.D., M.S.P.H.
Co-Facilitator: Anna Nápoles-Springer, Ph.D.
Facilitator:
8:15 – 9:00 a.m. Professional Education and Training
9:05 – 9:15 a.m.
8:45 – 9:15 a.m.
8:45 – 9:15 a.m.
9:05 – 9:15 a.m.
9:15 – 9:25 a.m.
9:25 – 9:45 a.m.
10:00 – 10:45 a.m.
12:30 p.m. Meeting Adjourns
10:45 – 12:00 p.m. Panel of NIH Representatives Responds to Strategic, Action and Dissemination Plans
Chair: A. G. Ramirez, Dr.P.H.
Group 1: Research
Anne Hippocrates-Springer, Ph.D.
Group 2: Healthcare Services
Victor Panchazadah, M.D., M.S.P.H.
Group 3: Professional Education & Training
Lillian Gayá-González, Ph.D.
Group 4: Public Education & Outreach
Louise A. Vidal, M.P.H.
10:45 – 10:55 a.m.
10:55 – 11:05 a.m.
11:00 – 11:15 a.m.
11:15 – 12:00 p.m.
12:00 – 12:30 p.m.
12:30 p.m.
10:45 – 11:05 a.m.
8:30 – 8:45 a.m. Review of Day 1 and Goals for Day 2
8:45 – 9:45 a.m.
Session 2: Develop Short-Term (<2 years) and Long-Term (2-5 yrs) Action Plans to Address Genetics Issues and Research Pertinent to Latinos (4 breakout sessions)
Session 1: Develop Strategies to Address Genetics Issues and Research Pertinent to Latinos (4 breakout sessions)
Session 1:
Group 1: Research
Anne Hippocrates-Springer, Ph.D.
Group 2: Healthcare Services
Frank J. Penedo, Ph.D.
Group 3: Professional Education & Training
Gregory A. Tsaiwana, M.D., M.P.H.
Group 4: Public Education and Outreach
Louise A. Vidal, M.P.H.
12:00 – 12:30 p.m.
10:45 – 12:00 p.m.
8:45 – 9:45 a.m.
8:00 – 8:15 a.m. Welcome
Welcome and Overview
Welcome
Panel Chair: Jorge Gomez, M.D., Ph.D.
Chief, Organ Systems Branch
National Cancer Institute
Panelists:
John Castillo
President, Castillo and Associates Consultants, Inc.
Lillian Gayá-González, Ph.D.
Professor, Inter American University of Puerto Rico
Victor Penchaszadeh, M.D., M.S.P.H.
Director W.H.O. Collaborating Center for Community Genetics and Education
University of Maryland
Louise A. Villejo, M.P.H.
Group 4: Public Education and Outreach
Facilitator: Diane Fragana
10:45 – 12:15 p.m.
Group 2: Healthcare Services
Co-Facilitator: Frank J. Penedo, Ph.D.
Group 3: Professional Education & Training
Co-Facilitator: Gregory A. Tsaiwana, M.D., M.P.H.
5:15 – 5:45 p.m.
Lunch
Hsmith/Latino Genetics
Community Consultation Summit
3
10:45 – 10:55 a.m.
10:55 – 11:05 a.m.
11:00 – 11:15 a.m.
11:15 – 12:00 p.m.
12:00 – 12:30 p.m.
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Chair: A. G. Ramirez, Dr.P.H.
Panelists:
Andrew C. van Eschendro, M.D.
Director
National Cancer Institute
Judith H. Greenberg, Ph.D.
Acting Director
National Institute of General Medical Sciences
Francis S. Collins, M.D., Ph.D.
Director
National Human Genome Research Institute
Discussion
Conclusion
Meeting Adjourns

“The HLGCCN Summit is an important milestone in identifying genetic issues of importance to the Hispanic/Latino community and developing constructive plans to address these issues. The enthusiasm of the participants makes me hopeful that the momentum will continue.”
— Dr. Greenberg

“Efforts such as this summit must cast the net widely to reach the various diverse populations within the Latino population across the United States...requiring also that we recognize the diversity within the diversity. This is incredibly fierce work. It’s hard work. But it’s essential work.”
— Dr. Kington
Executive Summary

Our nation’s 37 million Latinos, the largest minority group in the United States, is both underserved and underrepresented in genetics research and services. That conclusion by the historic Hispanic/Latino Genetics Community Consultation Network (HLGCCN) Summit was among the findings of participants in the two-day national conference in Washington, DC.

More than two years in the planning, the summit meeting brought together 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 determine recommendations for the future. The summit, drawing participants from across the country and leaders of federal health institutions, provided a forum to develop strategies for improving access to the benefits of genetics research and healthcare services for Latinos.

The first-of-its-kind conference was the result of a combined effort of Redes En Acción: The National Hispanic/Latino Cancer Network (a Special Populations Networks initiative of the National Cancer Institute) and Baylor College of Medicine, with the National Cancer Institute (NCI), National Human Genome Research Institute (NHGRI) and National Institute of General Medical Sciences (NIGMS). Playing support roles within NCI were the Specialized Program of Research Excellence (SPORE), Cancer Genetics Network (CGN) and Center to Reduce Cancer Health Disparities (CRCHD).

In addition to participants who gathered in Washington for the summit, a larger number of Latinos around the country took part in identification of priority genetics issues through pre-meeting surveys using the Delphi process. The surveys were administered in collaboration with the University of Maryland.

The conference gave participants an opportunity to hear leading genetics authorities report on key areas of historic and current genetics advances and their impact on Latinos. The status of the various genetics issues was discussed in the context of research, healthcare services, professional education and training, and public education and outreach.

After dynamic discussion and debate in smaller breakout sessions, the entire group reconvened to present their recommendations for strategies to address the key genetics issues confronting the Hispanic/Latino population and to incorporate these positions into action plans. These recommendations include strategies for improving community understanding of genetics and genetics research, promoting access to genetic healthcare services, and building on the work developed for this initial meeting.

Recommendation Summaries

The following represent summaries of the top recommendation and strategy from each of the summit breakout session work groups. A comprehensive account of the recommendations, goals, strategies and action plan steps will be included in the formal scientific proceedings of the HLGCCN Summit, which will be disseminated and posted on the Redes En Acción web site (www.redesenaccion.org) upon completion.

RESEARCH

No. 1 Recommendation: Identify priorities for research among Hispanic/Latino populations, attract and develop more Latino genetic researchers and others to work with Hispanic/Latino populations, and promote genetic research collaboration among Latino community members and scientists.

Strategy: Convene a multidisciplinary conference on Latinos and genetic research.

HEALTHCARE SERVICES

No. 1 Recommendation: Improve accessibility to and maximize Hispanic/Latino use of available resources in genetic services within current healthcare systems.

Strategy: Disseminate information about available genetic services at both the healthcare system and community-based levels.

PROFESSIONAL EDUCATION AND TRAINING

No. 1 Recommendation: Increase representation and recruitment of healthcare practitioners and researchers in genetics who serve Hispanic/Latino populations.

Strategy: Provide genetics training to any interested professional serving Hispanic/Latino communities in the workplace (healthcare or other professional).

PUBLIC EDUCATION AND OUTREACH

No. 1 Recommendation: Develop bilingual/bicultural genetic education resources for use in elementary, high school and college, as well as non-traditional community settings.

Strategy: Prioritize age group for developing first series of genetic education materials and utilize the participatory model to develop educational modules.

This presentation was followed by further small-group sessions to determine plans for dissemination of the recommendations. The final step in the summit process was to report the strategic, action and dissemination plans to a panel of top-echelon leaders from NCI, NIGMS and NHGRI, who then offered their response to the recommendations and plans.

As a result of the summit meeting, the HLGCCN is sharing the conference’s recommendations with the NIH and other agencies and leaders working toward addressing these needs in the Hispanic/Latino community.

On a personal note, I would like to take this opportunity to offer my heartfelt appreciation to each and every individual who played a role in the planning and implementation of this summit meeting. I want to thank and congratulate those who contributed their time, energies and expertise as conference participants as well as the many others who provided their input during the pre-meeting Delphi process. And to the leaders of the NCI, NHGRI and NIGMS, you should know that without your support this event could not have taken place, and I am extremely grateful.

¡MIL GRACIAS!

— Amelie G. Ramirez, DrPH
Principal Investigator
Redes En Acción: The National Hispanic/Latino Cancer Network
Panel Title: Response of NIH Leaders to Strategic, Action and Dissemination Plans
Moderator: Amelie G. Ramirez, DrPH
Panel Participants: Andrew C. von Eschenbach, MD, Director, National Cancer Institute
Judith H. Greenberg, PhD, Acting Director, National Institute of General Medical Sciences
Francis S. Collins, MD, PhD, Director, National Human Genome Research Institute

Culminating two days of vigorous groundbreaking discussion and debate about genetics issues concerning the Hispanic/Latino population, facilitators of the HLGCCN breakout groups reported their strategic, action and dissemination plans to a distinguished panel of medical experts from the National Institutes of Health. Research, healthcare services, professional education and public education were the priority agendas addressed. The panel session provided a unique opportunity to obtain immediate response to the HLGCCN proposals from the country’s top-echelon medical science authorities.

NIH leaders: ‘We need your advice and guidance’

Dr. von Eschenbach
“We recognize that the problem is not simply a medical or scientific problem. It’s much broader than that and we are going to have to address it from a systems point of view… looking at the problem comprehensively. The NCI is providing the infrastructure and resources for that process and the mechanism is already underway with you having representation in that activity.”

In addition, he said, “We’re going to look at allowing for more diversity in the cancer centers program, and also more integration… changing guidelines in a way that fosters more vertical integration so that these centers are more embedded into the community and community networks. So your input is very timely because this is the time when the guidelines are being revisited.”

With regard to workforce development and the ability to create opportunities specific to research in the field of Hispanic/Latino genetics, “I need you, your advice, your guidance, your leadership, your contributions intellectually as well as your contributions from the point of view of the heavy lifting to raise the opportunities for research.”

One of the missions of NIGMS is core research training, and “we are strongly committed to bringing more minority scientists into research.” A summit such as this is the first step, and “we all have to work together… I think the relevant word is partnership.” The fact that this is such a grassroots effort is so important because this is not an agenda that the NIH can impose on any community. “We have to be able to hear what you want, what you need, and we can certainly help you respond to it.”

The HLGCCN summit is an important milestone in identifying genetics issues of importance to the Hispanic/Latino community and developing constructive plans to address these issues. “This will not be the last meeting like this… we are committed to supporting follow-up. The enthusiasm of the participants makes me hopeful that the momentum will continue.”

Dr. Greenberg
“It’s gratifying to have been involved in the inception of the idea to have a Latino community consultation like this, and it’s exceeded my wildest dreams.”

Dr. Collins
As the person in charge of leading the Human Genome Project (HGP), “I am committed to constantly gathering input as to whether or not what we are doing is right and whether we’re taking this incredible opportunity and applying it in a way that has a maximum likelihood of benefiting all the groups involved.” We haven’t had nearly enough input from the Hispanic/Latino communities, and that’s why “I am delighted that this meeting is happening.”

The training of minority researchers and building the bridge for their delivery into the Hispanic/Latino community has been lacking in the past, but “this is a high priority for us and I take your agenda very seriously. It’s ambitious, it’s awesome and (it’s impressive to see) the very exciting plans you have collectively put together.” With regard to disparities, “we need your advice,” Dr. Collins added. “This type of connection should be a regular interaction, not just every couple of years,” and the opportunity to build the proper foundation for that network is welcomed.
Dr. Arena, Research
 Genetic isolation over long time periods has allowed mutations and gene substitutions to generate genetic diversity with a highly patterned geographic distribution. Human beings are 99.9 percent equal. The remaining .1 percent makes humans look and behave differently from one another. Being able to completely map someone's genetic make-up can, in the future, help scientists know ahead of time if someone is prone to developing a particular illness. If genotypes cannot be changed, the environment can be changed. Genetics also plays a major role during treatment. Whenever a drug is administered to patients, scientists are aware that one group will be respondent, another group will be non-respondent, and there will be a group of adverse respondents that is responsible for a high number of deaths per year. With the help of advanced human genetics, all patients in the future will be respondent to targeted treatment.

Dr. Gayá-González, Professional Education and Training
 Minorities are scarcely represented in the field of genetics in this country. Minorities represented less than 15 percent of Bachelor of Science graduates in biochemistry, biology and psychology. Only 5 percent of PhD graduates in biochemistry and biology are minorities. Completion rate for doctoral degrees for minorities is 25 percent, compared to 50 percent for non-minorities. The paucity of minority representation in the field of genetics in this country emerged as an issue during the first round from the Delphi study:
  ▶ Lack of Latino researchers doing genetics research
  ▶ Few Latino genetics specialists in practice

Mr. Castillo, Public Education and Outreach
 “The government should provide funding to support community outreach activities and education about genetics.” Increasing awareness and understanding of genetics and its potential benefits, as well as risks, is a first step in involving Latinos in genetic research. Latinos need to be empowered and educated in this area by using the media, schools, churches, community organizations, community leadership and local businesses. This educational outreach process should consider the ethno-cultural distinctiveness of each community. The public, as well as scientists, health professionals and health authorities, must be educated in cultural competence methods for the successful design and implementation of genetic research studies and delivery of genetics services to the Hispanic/Latino community. A commitment must be made to solicit representation of the entire strata of Hispanic/Latino society in policy and decision-making and to consider and incorporate the cultural values of significance to this population.
The Delphi Process: Community prioritization of genetics issues

To build consensus on issues regarding genetics education, outreach, health services and research, University of Maryland researchers Drs. Robert Gold and Nancy Atkinson used the Delphi process to prioritize those issues in the weeks leading up to the HLGCCN summit meeting.

Issues identified in an extensive literature review and in-depth interviews of Hispanic/Latino stakeholders served as the basis for the pre-meeting surveys, and the results from the Delphi process were presented at the summit. Surveyed were 147 individuals from varying backgrounds, including researchers, community stakeholders, healthcare representatives, federal representatives and advisory group members.

“The Delphi process began with our understanding of the genetics education and research issues from past studies, and the participants enriched this understanding with certain nuances that could only be borne from their experiences,” said Robert Gold, PhD, DrPH, FAAHB.

Added Nancy Atkinson, PhD, “The Hispanic/Latino community deserves to have input into such an important issue, and the Delphi process allowed even those who could not come to the community consultation to have a voice in its outcomes.”

The Delphi results provided valuable data to enable HLGCCN breakout groups to choose the highest priority issues and barriers to build strategies around and to develop action plans.

Dr. Trapido: An NCI epidemiological perspective

Edward J. Trapido, ScD, MSPH, is Associate Director of the Epidemiology and Genetics Research Program in the Division of Cancer Control and Population Science of the National Cancer Institute.

“There is a lot we know... but a lot more we don’t,” Dr. Edward Trapido told the HLGCCN summit, referring to cancer genetics issues and Latinos. “We don’t have adequate information on genes and the environment among the Hispanic/Latino population.” Data are lacking on specific issues, such as genetic heterogeneity, variable gene expression and penetrance among this population, he noted.

Dr. Trapido, the former Co-Principal Investigator of the Southeast Regional Network Center of Redes En Acción, has had extensive involvement in the Hispanic/Latino community, particularly in population-based research of diseases that disproportionately affect this growing minority.

The examination of disproportionate rates of certain cancers in one population versus another is significant, but “the emphasis also has to be on what are the most important etiological factors,” he said.

What’s the use of genetic information? Dr. Trapido asked. “First, it’s to identify biological risk factors for prevention and intervention in individuals, families and populations. Genetics has to be based on understanding the mechanism of the problem.”

The role of government, in keeping with its objective to eliminate death by cancer by the year 2015, will focus on understanding how genes and the environment interact, “enhancing how interventions are developed and implemented, together with the ability to identify the relationship between subpopulations and specific risk factors,” said Dr. Trapido.

Referring to future endeavors, he expressed a need for more novel studies. Examining the Hispanic/Latino population and cancer more comprehensively in terms of both high and low risk because “determining why certain populations suffer less from certain disease... can have a great impact on populations that don’t.” Dr. Trapido noted that there is much to learn from this type of research, and how his department “would love to see a grant application” for such investigation.

Recommendations from the Delphi Process

- Latinos need to know:
  - The link between genetic factors and disease
  - Potential benefits of genetics research and healthcare services
  - Ways to reduce the risk of developing genetic-based diseases
  - Look for linkages with many other groups.

- Cultural issues:
  - Consider the diversity of the Latino community and where genetics fits into day-to-day needs.
  - Remain accountable to the community by actively encouraging the exchange of information, sharing understandable information throughout the process and evaluating the effort.
  - Involve Latinos as the agents of these efforts rather than simply the targets.

- Research:
  - As a basis for a media campaign, researchers should conduct surveys of knowledge and awareness related to genetics.
  - To build the genetics research base, research on the differences between Latinos and other populations and the differences among Latino subpopulations should be included.
  - Interdisciplinary research and increased research funding should be priorities.