



The National Hispanic/Latino Cancer Network

www.redesenaccion.org

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Summit participants set Latino genetics priorities

Federal health agencies should identify priorities for genetic research among Hispanic/Latino populations, attract and develop more Latino genetic researchers and others to work with Hispanic populations, and promote genetic research collaboration among Latino community members and scientists.

That conclusion from the Hispanic/Latino Genetics Community Consultation Network (HLGCCN) summit meeting summarized the primary genetic research recommendation made by participants in the historic two-day national conference in Washington, DC. In addition to research, the prioritized recommendations were also delivered in the context of healthcare services, professional education and training, and public education and outreach.

Response to the recommendations by leaders of three major components of the National Institutes of Health in attendance at the first-of-its-kind summit meeting was extremely positive. Andrew C. von Eschenbach, MD, Director of the National Cancer Institute (NCI), summed up the feelings of his colleagues when he told participants that federal authorities “need you, your advice, your guidance, your leadership, your contributions...”

Added Francis S. Collins, MD, PhD, Director of the National Human Genome Research Institute (NHGRI), the training of minority researchers and building the bridge for their delivery into the Hispanic/Latino community have been lacking in the past, but “this is a high priority for us and I take

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Inside



Redes En Acción's impact can be felt in various arenas — nationally, regionally and at the state and community levels. Future effects of the recent Redes-coordinated

Hispanic/Latino Genetics Community Consultation Network (HLGCCN) summit meeting in Washington, DC, may eventually reach all of these levels.

This ambitious national conference was indeed a historic occasion. The HLGCCN brought together — for the first time ever — 120 experts and other stakeholders in Latino genetics issues from across the country, heads of three components of the National Institutes of Health, and representatives from major federal health agencies.

This distinguished assemblage discussed, debated and, finally, prioritized a set of recommendations for future federal health policy consideration that covered the realm of genetics issues significant to our nation's 38 million Latinos. The overview of this cutting-edge conference is our lead story in this *Redes Report*. And a more complete picture of the event's proceedings can be found in the summit report available on our web site at www.redesenaccion.org.

Another excellent example of the impact of *Redes En Acción* can be found in the story on six recently approved *Redes* pilot cancer research projects. Significantly, these projects focus on diverse aspects of colorectal, prostate, breast, cervical and skin cancers. Look for the story inside this issue.

Also, inside you'll find profiles of individuals from around the United States who are exemplary role models in the areas of Latino cancer research, training and awareness: research clinicians in New York and Arizona, an educator and mentor in Houston, and a cancer registry administrator in Florida.

Amelie G. Ramirez, DrPH
Principal Investigator
Redes En Acción



Highlighting the recent 4th Annual *Redes En Acción* National Steering Committee Meeting was a panel of experts from diverse organizations and agencies, who responded to recommendations for a *Redes Latino Cancer Report*. Panel participants included (seated, l-r) Jennie Cook, Intercultural Cancer Council; Nadarajen Vydellingum, PhD, Center to Reduce Cancer Health Disparities, National Cancer Institute; Ralph Caraballo, PhD, MPH, Office on Smoking and Health, Centers for Disease Control and Prevention; Elena Rios, MD, National Hispanic Medical Association; and Rebecca Garcia, PhD, Susan G. Komen Breast Cancer Foundation. Armin Weinberg, PhD, left, moderated the panel discussion.

Redes En Acción: The National Hispanic/Latino Cancer Network is a major Special Populations Networks initiative supported by the National Cancer Institute.

The primary purpose is to create a national and regional infrastructure for collaboration among grassroots leaders, local communities, researchers and public health professionals to stimulate cancer control research, training and awareness. Through network activities, *Redes En Acción* is establishing training and research opportunities for Latino students and researchers, generating research projects on key cancer issues impacting Latinos and supporting cancer awareness activities.

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RESEARCH

Focus on disparities

Olveen Carrasquillo, MD, MPH
New York, New York

As Director and Principal Investigator of the Columbia Center for the Health of Urban Minorities funded by the National Center for Minority Health and Health Disparities, Olveen Carrasquillo, MD, MPH, brings unique insights and experience to the field of research.

“Coming from Caguas, Puerto Rico and growing up in the Bronx, I witnessed a variety of social injustices and inequalities,” says Dr. Carrasquillo. “These disparities guided my interests in medicine, and are the focus of my research and advocacy work.”

Graduating summa cum laude from the Sophie Davis School of Bio-Medical Education at City College, Dr. Carrasquillo subsequently obtained his MD degree from the New York University School of Medicine. He served a three-year internal medicine residency at Columbia Presbyterian Medical Center, then completed Harvard’s General Internal Medicine Fellowship and Faculty Development Program. He complemented Harvard’s



development program by simultaneously receiving a masters of public health degree from the Harvard School of Public Health.

Dr. Carrasquillo believes that “as a Latino doctor I can make a difference in the community.” As an Assistant Professor of Medicine and Health Policy at Columbia University’s College of Physicians and Surgeons in New York City, as well as serving on the Internal Medicine Residency Admissions Committee, he is in an excellent position to assist minority candidates seeking residency. In addition, he continues to practice medicine in the predominantly Latino community of Washington Heights, located in upper Manhattan.

“Most of the work I currently do involves research in minority health and disparities, health insurance, access to care and managed care issues,” says Dr. Carrasquillo. “Most people who know me quickly realize that my devotion to these issues is genuine and longstanding.”

He has been involved in various research projects, particularly focused on access to care among minority groups – from examining cancer screening services to exploring the impact of managed care among privately insured populations. One of these studies is comparing disparities in mammogram and Pap smear screening among persons with Medicare and supplementary insurance to those with Medicare alone. “We found that those with Medicare alone are still somewhat less likely to have such screenings,” he says.

Dr. Carrasquillo is sought by both English and Spanish media to discuss his research, as well as to share his knowledge of cancer and other health care topics that are particularly relevant to the Hispanic/Latino community.

Contributed by: **Nereida Borrero, RN, MSN, GNP**
Redes En Acción Coordinator, Brooklyn, New York



AWARENESS

Tracking the numbers

Martha Oliva, RHIT, CTR
Miami, Florida

Martha Oliva is passionate about getting the numbers right. As Assistant Manager of the Cancer Registry for Jackson Memorial Hospital, that is no easy task, but is one that she has spearheaded and cultivated since the registry’s inception in 1977.

In her years of service, she has adopted those essential reports, gathered data and made sure the program runs smoothly. However, these figures are more than mere numbers for her. Martha understands that it is vital to capture information on every case and have accurate data that will support so many other areas in the battle against cancer.

“The patient is the bottom line here,” she says. “They are the ones who benefit from the work we do. That’s why we owe them to make sure we don’t miss even one.”

More than 22 years ago, Martha was asked to help a community organization called *La Liga Contra el Cancer* (The



League Against Cancer), a private, non-profit organization that provides free medical care to needy cancer patients who otherwise would not receive care.

“I started organizing the tumor registry, the patients’ files and the statistics of the organization,” says Martha. “But it also gave me more contact with the patients.”

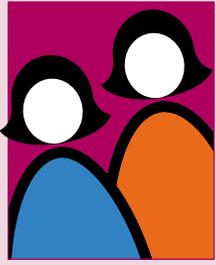
She recalls with deep emotion a patient who went to *La Liga* for an X-ray but couldn’t be touched because the pain was unbearable. This and similar experiences over the years motivate her to continue marching alongside other volunteers and health professionals in the battle against cancer.

She believes major barriers for Latinos are fear and lack of emphasis on prevention. We need to find better ways to transmit the message that with prevention there is a cure, she emphasizes.

Martha was the first Latina president of the National Cancer Registrars Association, and has been working with the International Union Against Cancer on the Hospital-Based Cancer Registries and the Cervical Prevention and Detection of Cancer project that helps countries in Central and South America develop and adequately manage their cancer registries. She developed a curriculum to train young professionals from other countries at Jackson Memorial Hospital, where they work alongside her at the registry over a 15-day period.

For Martha, transmitting her knowledge to future generations is essential. “We are helping patients when we share our experience with others who will someday replace us,” she says. “Besides, there’s nothing more delightful than to share what you know.”

Contributed by: **Martha Oliveros**
Cancer Information Service Coordinator
Redes En Acción Southeast Region



TRAINING

Lifetime mentoring

Sara Souto Strom, PhD
Houston, Texas

Sara Souto Strom, PhD, Assistant Professor at the University of Texas M.D. Anderson Cancer Center, has spent countless hours mentoring her students, many of whom are interested in cancer research careers. To her this is a long-term commitment.

"I believe that no matter what career level an individual is in, you always need a mentor to give you guidance," she says. "I think that the mentoring relationship should go on forever."

Perhaps one of the reasons Dr. Strom believes so strongly in the value of mentorship is that she has benefited from mentors herself. One of those who has had a major impact on her career is Dr. Margaret Spitz, who leads a team of Department of Epidemiology researchers at M.D. Anderson. "Our relationship has been a positive one, and this experience has taught me to be a good mentor as well," says Dr. Strom.

Dr. Strom's career path began as a marine biologist after earning a BS in zoology from the University of Buenos Aires. In 1973 she moved to the United States. She raised her family and taught part-time while obtaining her PhD in Public Health in 1988 from the University of Texas, School of Public Health at Houston. She continued her post-doctoral work with Dr. Louise

C. Strong, and joined Dr. Spitz's team.

Dr. Strom's dissertation research introduced her to cancer epidemiology. Concerned citizens in a small Northeast Texas community approached the School of Public Health about the high incidence of cancer in their area and the need for a study. She took on the challenge. Since then, she has been engaged in cancer research, primarily involving prostate cancer and hematopoietic cancers (leukemias and lymphomas).

She has mentored students at different levels in their careers, including graduate students wishing to gain basic experience in

epidemiology/cancer prevention studies, as well as doctoral and postdoctoral students interested in expanding their knowledge in cancer research. These students spend from three months to several years learning the ropes in cancer research from Dr. Strom.

Currently, she is mentoring several M.D. Anderson students, as well as others from the University of Puerto Rico, where she has an adjunct appointment. Having limited time for each student is a challenge, but she enjoys this side of

her work, and continues to dedicate as much time as possible.

When asked what single piece of advice she would offer a Latino student aspiring to a career in research, Dr. Strom says, "They have to understand how competitive and demanding a research career is, and they have to accept that they would have to become not only good or excellent researchers but also role models for others."

"I hope that my students remember me as someone who taught them something valuable, not only in research but in human values. I want them to remember that I gave them tools to use for the rest of their lives."

Contributed by: **Sylvia Z. Castillo**
Redes En Acción Coordinator
San Antonio, Texas



Latinos needed for National Lung Screening Trial

Lung cancer is the leading cause of cancer death among Hispanic men and second among Hispanic women, according to the American Cancer Society.

Researchers have discovered that cigarette smoking is by far the most important risk factor in the development of lung cancer, accounting for nearly one-third of all cancer deaths in this country each year. Unlike some other cancers, there is no screening test available to detect lung cancer early – when there are more treatment options and higher survival rates.

To determine whether certain screening tests can detect lung cancer early and reduce lung cancer mortality rates, the National Lung Screening Trial is now available to current and former smokers. The trial, sponsored by the National Cancer Institute (NCI), aims to provide evidence needed to determine whether spiral computed tomography (CT) scans are better than the standard chest X-ray in reducing a person's chance of dying from lung cancer. The National Lung Screening Trial, which began in September 2002, will enroll 50,000 participants at 30 sites across



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the United States.

Too few of the trial's current participants are from minority ethnic groups. For example, Hispanics only account for about 3 percent of the patients that have been recruited at M.D. Anderson Cancer Center, the only National Lung Screening Trial site in Texas. For study results to be translated equally across diverse populations, all

racial/ethnic groups should be adequately represented in clinical trials such as this.

To qualify for the lung trial, participants must be:

- Healthy men and women age 55 to 74
- Current or former smokers who have smoked heavily or who now smoke heavily or who have smoked for many years
- Individuals who have never had lung cancer and who are currently not being treated for any type of cancer

For more information about the National Lung Screening Trial, call the NCI's Cancer Information Service at 1-800-4-CANCER, Monday through Friday, 9 a.m. to 4:30 p.m., local time.

NHMA NEWS

Addressing cancer disparities

The National Hispanic Medical Association (NHMA) has been participating in the first U.S. Department of Health and Human Services (DHHS) Disparities in Health Progress Review Group (PRG) focused on cancer. The major purpose is to help develop, through a national roundtable meeting, recommendations for DHHS agencies to work together to best address these disparities.

The three-stage process involves 1) Recommendation – and the leadership meeting that occurred in June in Maryland; 2) Implementation – and the establishment of work groups and the objectives and measures of progress, as well as a response meeting scheduled for August in Chicago; and 3) the Reporting stage to develop an implementation plan to be announced in early 2004.

The PRG is hosting a roundtable discussion in which participants include *Redes En Acción* Principal Investigator **Amelie Ramirez**, DrPH, and individuals from the *Redes* Executive Committee and National Steering Committee, as well as board members of the Hispanic-Serving Health Professions Schools, Inc.

The framework for the activities of the federal government has been described as discovery, development of interventions and delivery of evidence-based interventions. A major outcome of this process will be to identify new interagency partnership

opportunities – both public and private – that can facilitate elimination of disparities in cancer health.

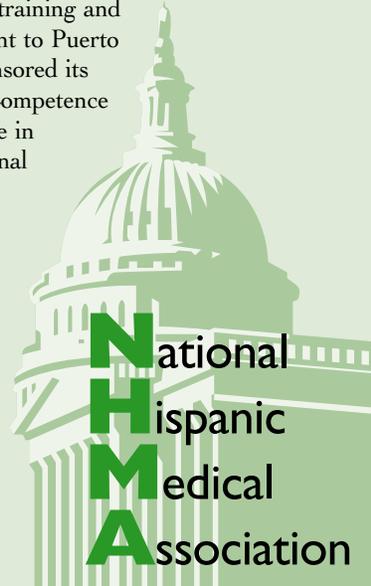
Medicare Reform

NHMA also has been discussing Medicare reform with Congressional conferees, along with the National Hispanic Health Coalition, and its impact on Hispanics. Proposed recommendations involve coverage of legal immigrants for Medicaid, the importance of data collection of ethnic identifiers, increased Medicare access to low-income individuals with raised DSH payments to hospitals, incentives to physicians who work in underserved areas, reimbursements to clinics and teaching hospitals for language services as well as cultural competence training and other services, and higher reimbursement to Puerto Rico and other territories. NHMA sponsored its first Capitol Hill Briefing on Cultural Competence and discussed issues related to Medicare in July for an audience of 100 Congressional staffers. For further information, call NHMA at 202-628-5895.

New Web Site

NHMA announces its new web site (www.nhmamd.org). The site aims to provide information to improve health care delivery for Hispanics and other underserved populations.

Elena Rios, MD, MSPH
NHMA President and CEO



Physician explores access-to-care issues

Francisco Garcia, MD, MPH
Tucson, Arizona

For Francisco Garcia, MD, MPH, an intense concern for the health and wellness of women along the U.S.-Mexico Border has motivated his service and outreach efforts, as well as his professional accomplishments. Although he has dedicated his career to cancer research, particularly in the areas of breast and cervical cancer screening in rural and immigrant communities along the Border, Dr. Garcia feels that “access to care for Hispanic populations is the biggest issue that needs to be ameliorated.”

“The issue of access to care overrides other issues like cultural competency and quality of care,” he says, “because if a patient cannot even access screening services or other treatments, the quality of care or the language in which it is provided is irrelevant in terms of the health outcomes for, or benefit to, that patient.”

An Associate Professor and Director of the Division of General Obstetrics and Gynecology in the Department of Obstetrics and Gynecology at the Arizona Health Sciences Center, Dr. Garcia also serves as Medical Director of Obstetrics and Gynecology Outpatient Clinic at the University Medical Center. In addition, he has assumed the role of Principal Investigator for the Arizona Hispanic Center of Excellence and



serves as a board member for the Arizona Coalition on Adolescent Pregnancy and Parenting and for the Hispanic-Serving Health Professions Schools, Inc.

Upon receiving his medical degree from the University of Arizona in Tucson, he completed a residency in the Department of Obstetrics and Gynecology. It was during both a two-year fellowship in Women’s Reproductive Health and his masters degree studies in Public Health Policy and Management at Johns Hopkins University that he began to extensively publish his cancer research.

Dr. Garcia’s research not only focuses on premalignant gynecological disease, human papilloma virus infection, and the evaluation of new technologies and therapeutics for cervical cancer precursors, but also on areas that involve screening behavior determinants and barriers to care for Latinas.

He recognizes the complexity surrounding the utilization of and access to cancer screening services for Latinas. Dr. Garcia encourages those interested in women’s health and wellness to champion integrated and involved partnerships with the Hispanic/Latino community and to explore this complex issue to better understand it as an essential component to health care for Latinas, especially those residing in the U.S.-Mexico Border Region.

Contributed by: **Elizabeth Collins**
National Hispanic Medical Association

Genetics summit

continued from page 1

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."

Judith H. Greenberg, PhD, Acting Director of the National Institute of General Medical Sciences (NIGMS), said the community consultation summit "exceeded my wildest dreams...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."

More than two years in the planning, the summit meeting brought together 120 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, served as a participatory model for involving Latinos in identifying and discussing genetic issues and examining those that are of greatest significance to the Hispanic/Latino population.

The 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



Amelie G. Ramirez, DrPH, *Redes En Acción* Principal Investigator, second from left, joins members of the National Institutes of Health panel at the HLGCCN summit: (l-r) Francis S. Collins, MD, PhD, Director of the National Human Genome Research Institute; Judith H. Greenberg, PhD, Acting Director of the National Institute of General Medical Sciences; and Andrew C. von Eschenbach, MD, Director of the National Cancer Institute.

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).

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

For a report of the HLGCCN summit meeting, visit the *Redes En Acción* web site: www.redesenaccion.org. A scientific proceedings report of the meeting will be published by the NCI.



HONORES

Awards and achievements

► **Amelie G. Ramirez**, DrPH, Principal Investigator of *Redes En Acción*, has been selected to receive the American Cancer Society's 2003 Humanitarian Award. The presentation will be made November 15 in Atlanta.

The American Cancer Society (ACS) annually presents the Humanitarian Award to individuals who have made

outstanding improvements in human welfare and social reform, impacting the cancer problem in medically underserved populations. "Your selection to receive this award is indicative of the high esteem in which your peers and colleagues hold you," noted Harmon J. Eyre, MD, ACS Chief Medical Officer and Executive Vice President for Research and Medical Affairs.

Dr. Ramirez is Associate Professor and Deputy Director of the Chronic Disease Prevention and Control Research Center, Department of Medicine, at Baylor College of Medicine.

► **John F. Alderete**, PhD, a member of the *Redes En Acción* National Steering



Committee, has been named Co-Chair of the Health Sciences Advisory Council of the Hispanic Association of Colleges & Universities (HACU).

Dr. Alderete, a Professor in the

Department of Microbiology and Immunology at the University of Texas Health Science Center at San Antonio, is a longtime advocate for the entry of young Latinos into graduate programs in the health sciences.

Redes pilot studies approved by NCI

Six new National Cancer Institute-supported pilot projects approved for funding through *Redes En Acción* are researching wide-ranging aspects of cancer among Hispanics, focusing attention on a variety of cancers. The new studies bring the total number of *Redes En Acción* pilot projects to 11, with approval pending on another after resubmission.

The latest pilot research projects are as follows:

- ▶ *Colorectal Cancer Screening: Identifying Barriers to Screening in the Latino Population*; Principal Investigator (PI) Monica Yepes-Rios, MD, of the Southwest Regional Network Center (RNC)
- ▶ *Enhancing the Participation of Latinas in Breast Cancer Support Groups*; PI Anna Nápoles-Springer, PhD, Northwest RNC
- ▶ *The Feasibility of Telecolposcopy in a Gynecology Clinic*; PI Ana Maria Lopez, MD, MPH, Southwest RNC
- ▶ *Prostate Cancer Diagnosis Treatment Among Latino Men*; PI Thomas Denberg, MD, PhD, Northwest RNC
- ▶ *Perception of Risk of Skin Cancer in Hispanic Students*; PI Robert Kirsner, MD, Southeast RNC
- ▶ *Barriers to Colorectal Cancer Screening Among Hispanics*; PI Mark S. Johnson, MD, MPH, Northeast RNC



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