



The National Hispanic/Latino Cancer Network

www.redesenaccion.org

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SPN genetics survey development initiated



Breast Cancer Genetics Survey Meeting participants gather for a group photo in San Antonio. The project is supported by the Susan G. Komen Breast Cancer Foundation.

In a meeting hosted by *Redes En Acción*, researchers representing the five major National Cancer Institute Special Populations Networks (SPNs) discussed plans to collect data on breast cancer genetics knowledge, attitudes and behaviors of culturally diverse women.

The June 6-7 conference in San Antonio was an initial step in forging a culturally tailored survey that will be administered to Latino, African American, Asian American, Appalachian and Native American women. The survey will be produced in the Breast Cancer Genetics Education Materials and

Programs Development Project's first phase, which is funded by the Susan G. Komen Breast Cancer Foundation.

The Breast Cancer Genetics Survey Meeting involved representatives from the National Cancer Institute, Komen Foundation and each of the national SPNs. The primary discussion areas focused on survey methodology issues (e.g., sample size and survey cost analysis), pre-testing methodology and execution, survey draft review, and identification of culturally specific items to be included in the survey instrument.

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Dr. Harold P. Freeman

Harold Freeman to speak at 3rd Annual NSC meeting

Dr. Harold P. Freeman, Associate Director of the National Cancer Institute (NCI) and Director of the NCI Center to Reduce Cancer Health Disparities, will deliver a pair of presentations at the 3rd Annual *Redes En Acción* National Steering Committee Meeting.

This year's meeting will be August 21-23 at the Plaza San Antonio Hotel in downtown San Antonio. Dr. Freeman, former Chairman of the President's Cancer Panel, will be the special guest at the opening night reception and dinner.

His presentation, *Approaches to Diminishing Cancer Health Disparities in Poor Communities*, will address outcomes of his President's Cancer

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Inside



Almost from the moment we adjourned our annual National Steering Committee meeting last summer, we've been focusing attention on this year's event — the

3rd Annual *Redes En Acción* National Steering Committee Meeting.

From the outset, one of our priorities was to bring a highly recognized, respected and renowned advocate for minority cancer health to speak to the group. When Dr. Harold Freeman of the National Cancer Institute (NCI) agreed to participate, we were extremely pleased. Indeed, we couldn't have found a stronger champion of cancer prevention and control among special populations. Details of Dr. Freeman's appearance are among our stories in this issue.

In our Winter 2002 edition, we told you about a new study that *Redes En Acción* is taking the lead on, the Breast Cancer Genetics Education Materials and Programs Development Project. In June, we hosted our first Breast Cancer Genetics Survey Meeting, with representatives from the five NCI Special Populations Networks, the Susan G. Komen Breast Cancer Foundation and the NCI. This is our lead story.

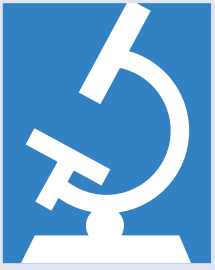
Another of our new *Redes En Acción* activities involves a collaborative effort with the NCI Cancer Genetics Network (CGN) and the Texas Cancer Genetics Consortium. We'll be evaluating a bilingual clinical trials recruiting publication, called *Buena Vida: A Guide to Family Cancer Research*, which was produced by *Redes En Acción* last year. The goal of the study is to test the publication's recruitment effectiveness in the CGN Registry. That story is on page 6.

In addition, our Regional Network Centers (RNC) have been extremely busy, and in this issue we're spotlighting the activities of one of these — the Northwest RNC, which is headquartered in San Francisco.

Amelie G. Ramirez, DrPH

Principal Investigator

Redes En Acción



RESEARCH

Target: Tobacco Industry

Joaquin Barnoya, MD, MPH
San Francisco, California

Dr. Joaquin Barnoya, of the University of California, San Francisco (UCSF), is working to impede the spread of what he considers a tobacco epidemic among Latinos.

His research on tobacco control with Professor Stan Glantz at UCSF is focusing on the role of the tobacco industry in the rise of smoking in Latino populations both in the United States and throughout Latin America.

"Latinos in Latin America and the U.S. are being targeted by tobacco industry marketing, and we need to stop (the tobacco companies)," Dr. Barnoya emphasizes.

Cancer prevention has been a longtime research interest for Dr. Barnoya. Born in Guatemala, he graduated from the San Carlos University of Guatemala Medical School in 1998. He wrote his thesis on "Cancer Prevention: A Proposal for Guatemala" and became involved in community education programs on chronic



disease prevention.

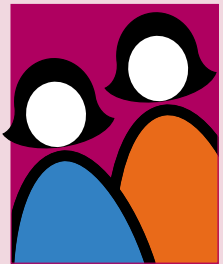
"Chronic disease prevention is relevant to Guatemala, as the epidemiologic transition is just beginning there," he says.

In 1998, the American Cancer Society (ACS) of San Francisco invited him to give a series of lectures on cancer prevention for Latinos. The ACS linked him with the National Hispanic Leadership Initiative on Cancer (NHLIC): *En Acción*, the National Cancer Institute initiative that preceded the current *Redes En Acción* program. The lectures, organized by NHLIC: *En Acción*, focused on reducing the risk of cancer through lifestyle modification.

In his research career, the major limitation that Dr. Barnoya has faced is the "curative" orientation that he received in medical school. "As a result of this orientation, the social context behind health and disease is missed," he says, "and physicians deal only with outcomes, leaving aside the causes."

To overcome this limitation he obtained a Master's of Public Health degree at the Harvard School of Public Health under the supervision of Dr. Graham Colditz. His MPH was focused on cancer prevention, and he conducted research on obesity.

Contributed by: **Marynieves Díaz-Méndez, MD**
Redes En Acción Outreach Coordinator
San Francisco, California



TRAINING

The Impact of Mentoring

Lorena Teran, MPH
Los Angeles, California

Lorena Teran, whose research studies have focused on breast cancer in Latinas, has benefited from excellent mentoring in her young career and is now returning the favor for those following her path.

Perhaps her most influential mentor has been Dr. Lourdes Baezconde-Garbanati, who introduced Lorena to cancer research when a community organization was interested in studying breast cancer screening compliance. The project, entitled Breast Cancer Rescreening, opened the door to a new research career.

"The impact was great," notes Lorena, "because I never imagined when I started this study that it would be the topic for my dissertation." Lorena, who earned her undergraduate degree in Health Psychology and a Master's in Public Health with concentrations in both Epidemiology/Biostatistics and Health Promotion, is currently working on her dissertation at the University of Southern California.

As a doctoral degree student in Medicine (Health Behavior



Research), she is also a recipient of a National Cancer Institute training grant, which "is the ideal way to conduct research by providing funding and flexibility to study breast cancer screening compliance in Latinas," she adds.

Lorena chose this area of research for a variety of reasons. "I have always had a strong desire to help people in need and to give back to the community, especially to Latinas," she says. She was also influenced by a close friend who recently died of breast cancer.

Mentorship has played a significant role in Lorena's education.

Two individuals in particular, Drs. Baezconde and Karen Belkic, are "excellent examples of outstanding mentors, because they have a genuine interest in my training and success as a health behavior researcher," notes Lorena.

"Their interest in me and their time are a great privilege, and I have learned via their exceptional example. My training would definitely be incomplete without them, and I would lack many insights that are so valuable and fundamental to becoming a good researcher and leader."

Giving something back through mentoring is important to Lorena, as well. "It has definitely been a positive experience for me as a mentor and mentee, and I wanted to give back by helping Latina students gain a better understanding of research in cancer control."

To her own mentors, Lorena's career and future are very promising. "She has an absolutely fabulous future," says Dr. Baezconde, "and she will be an outstanding and excellent soon-to-be Doctor Teran."

Contributed by: **Janel Heine, MPH**
Project Coordinator, Project SOL
San Diego, California



AWARENESS

Serving Communities

Ximena Ilabaca-Somoza, MD, MPH Kansas City, Kansas

For Dr. Ximena Ilabaca-Somoza, who heads the Hispanic and Minority Program at the University of Kansas Cancer Institute (KCI), social medicine has become a way of life.

In her work at KCI, she has developed several Latino cancer prevention initiatives and has been tireless in her efforts to educate Latinas and their families about breast cancer risk factors and the benefits of regular mammography screening. In addition, she is an advocate for helping underserved women access screening services and receive proper treatment and follow-up.

Dr. Somoza's interest in social medicine comes naturally. Indeed, it could be said that her exposure began at birth. A native of Chile, she was born into a family of physicians for whom the practice of responding to public health and social issues was the norm.

She left Chile in 1973, moving temporarily to Venezuela and Suriname. Settling in Guadalajara, Mexico, she completed her medical degree and, continuing a family tradition, pursued a



Master's in Public Health. Concerned about improving the quality of medical care, she took a position with Jalisco state, overseeing the practice of maternal and child health in many hospitals and clinics.

She came to the United States in 1995, assuming a position at the Kansas Cancer Institute, University of Kansas Medical Center the following year. Using community participatory models, she began initiating Latino cancer prevention initiatives.

Dr. Somoza founded the Hispanic Women's Coalition Against Cancer in 1996 and was recognized for this effort by the state of Kansas, the National Cancer Institute and local community organizations, including the Wizards soccer team. She has also organized local and regional conferences delivering breast health education to Latinas and promoted the establishment of culturally competent training for providers at all levels. Additionally, she has served as an advisor to the University of Nebraska Breast and Cervical Cancer Program.

Continuing her commitment to minority women, she will lead the Midwest Regional Native American Cancer Network, the first initiative joining Latino and American Indian women in Kansas and Missouri.

In her work with children, Dr. Somoza has implemented a novel approach, using puppets to facilitate cancer prevention messages. The two-year-old program was recently recognized by the Centers for Disease Control and Prevention (CDC) for its innovation.

Contributed by: **Patricia Canessa, PhD**
Redes En Acción Coordinator
Chicago, Illinois

Taking Aim at Tobacco

Tobacco use causes more premature death than all drugs of abuse combined, according to the National Cancer Institute (NCI). Although Latino smoking incidence is lower compared to other racial/ethnic groups, it is important that the health community unite to address tobacco control among the Hispanic population.

First, the tobacco industry disproportionately advertises and promotes its products in minority communities. Furthermore, the tobacco industry tries to gain credibility in the Latino community by contributing to education programs, scholarships and cultural events. In addition, studies have indicated a positive relationship between acculturation and current smoking status among Latinas. These reasons, compounded by the rapid growth of this population, validate the need to promote smoking prevention and cessation efforts among Latinas.

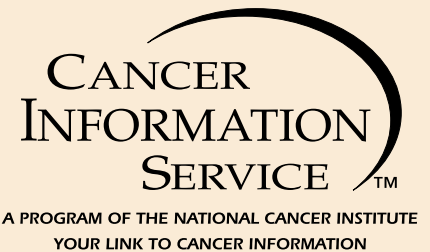
The National Latino Council on Alcohol and Tobacco Prevention (LCAT) mission is to combat tobacco problems and their underlying causes in Latino communities. LCAT, a *Redes En Acción* partner, is the only Hispanic/Latino national organization dedicated to using research, policy analysis, community education, training and information dissemination to reduce the harm caused by tobacco in the Latino community. To create a forum for representatives from local, state and national agencies as well as community-based organizations to familiarize themselves with, examine and discuss policies and strategies to reduce Latino tobacco use, LCAT sponsored the 1st National Hispanic/Latino

Conference on Tobacco Prevention and Control, "Tobacco Control Is in Our Hands" in Washington, DC earlier this year.

A component of the conference, "LCAT Hands" (Hispanic/Latino Action Network and Leadership Development Summit), was initiated by LCAT to build the capacity and leadership of local Latino communities with regard to tobacco-related health issues. LCAT Hands is a year-long fellowship that trains emerging tobacco control leaders in the fight for healthier Latino communities nationwide. The program offers skill-building courses, resources, mentoring and technical assistance throughout the year so that fellows can implement tobacco prevention and control activities locally in their Latino communities.

NCI's commitment to preventing, diagnosing and treating tobacco-related cancers began more than 40 years ago and remains one of our highest priorities. Not only was the NCI a co-sponsor of this conference, the Cancer Information Service (CIS), a program of the NCI, has joined LCAT's tobacco control efforts by affording Partnership Program staff time to attend the conference and participate in the LCAT Hands program.

By becoming part of a nationwide network working on tobacco prevention and control, the CIS hopes to make an impact on smoking to make Latino communities tobacco-free.



Promoting Cutting-edge Cancer Care

Arturo Molina, MD, MS, FACP
Duarte, California

Cancer patient care and research go hand-in-hand for Dr. Arturo Molina, whose work with the City of Hope National Medical Center in Duarte, California focuses on lymphoma and Hodgkin's disease. Many of his patients and clinical trial participants are Latinos.

"The patient population at the City of Hope National Medical Center is representative of the greater LA population," says Dr. Molina. "There is a proportionate percentage of Latino and Spanish-speaking patients at our cancer center. As a result, all eligible patients are offered enrollment in our state-of-the-art clinical trials."

Indeed, Latinos have been beneficiaries of truly cutting-edge therapies, he notes. "For example, we were one of the first centers in the world to offer autologous stem cell transplantation to patients with HIV-related lymphoma," he said.

"The first patient with this condition who received this treatment at our institution is a Latino, and he remains in remission from his lymphoma more than four years after the transplant. Historically, these patients have had a very poor prognosis with a median survival of less than a year."

Dr. Molina, who received his medical degree and Master's of Science from Stanford University School of Medicine in



California, is currently Attending Staff Physician in the Division of Hematology and Bone Marrow Transplantation and Division of Medical Oncology and Therapeutics Research at City of Hope. In addition, he is Chair of the Chronic Lymphocytic Leukemia Committee and Co-Chair of the Lymphoma Committee at the center, a Board Member of the City of Hope Medical Group and President-Elect of the City of Hope Medical Staff.

Dr. Molina's research interests focus on the treatment of lymphomas and Hodgkin's disease using standard and investigational approaches, including biological agents and autologous and allogeneic hematopoietic stem-cell transplantation. He has a large practice dedicated to the treatment of mycosis fungoides and other cutaneous T-cell lymphomas.

"My primary goal is to improve the cure rates and decrease the side effects of treatment in patients with lymphoma and leukemia," he says.

In addition, Dr. Molina has a vision for Latino cancer research, training and awareness, which includes educating Latino/Hispanic patients and empowering them with decisions regarding their health care. "We should encourage them to utilize the recommended screening evaluations for cancer prevention and make the best subspecialty care available to them when they need it," he emphasizes.

SPN Genetics Survey

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"This was a highly productive meeting," said Amelie G. Ramirez, DrPH, Principal Investigator. "The input from participants will be essential in formulating a culturally sensitive survey that will provide researchers with much-needed information regarding breast cancer genetics knowledge, attitudes and behaviors in these diverse populations."

The overall goal of the ground-breaking Breast Cancer Project is to research, design and disseminate customized breast cancer genetic educational materials among the five minority ethnic populations. While Phase 1 involves development of the survey, in Phase 2 the SPNs will administer the survey to their populations. During Phase 3, information collected will be used to develop education and intervention materials and programs tailored to each of the groups.

"After many months of working with other project members by e-mail and phone, it was invigorating to meet in person and deal with key project development issues," noted Dena L. Jackson, PhD, CHES, Grants Specialist for the Komen Foundation. "The passion the project members have for the Breast Cancer Genetics Study was evident, and the Komen Foundation is glad to be a part of the process."

Louise Wideroff, PhD, MSPH, a collaborating researcher at

the National Cancer Institute, offered her perspective on the significance of the project. She said, "Current data suggest that underserved minority populations are often less likely to access cancer genetics services such as genetic counseling and testing. They are also less likely to participate in research studies to improve such services and increase our knowledge about cancer genes. The Breast Cancer Genetics Survey is an important step toward understanding the barriers to cancer genetics care in these populations."

While the main purpose of the June meeting was to discuss key methodological issues and to review the survey draft, a secondary objective was to discuss Phase 2 activities, including future funding and considerations for the field implementation of the survey instrument. As a basis for discussion, *Redes En Acción* prepared a background paper summarizing current literature findings with regard to breast cancer genetic testing knowledge, attitudes, beliefs and behaviors for each population group.

Once the survey draft is revised, it will be distributed to the five SPNs for pre-testing. The group plans to reconvene in October 2002 to review results of the pre-test, finalize the survey instrument and the field implementation methodology, and discuss Phases 2 and 3 of the project.

Dr. Freeman

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Panel Report. On the following day, Dr. Freeman will speak at the opening regular session of the NSC meeting, providing

updates on his Center to Reduce Cancer Health Disparities and other National Cancer Institute (NCI) minority health activities.

NEWS SPOTLIGHT

Northwest Region

With a host of activities and honors, the *Redes En Acción* Northwest Regional Network Center (RNC) has been actively engaged in Latino cancer awareness, research and training in recent months.

Redes participates in CIS training institute

Redes En Acción's Northwest RNC was well represented at the Partner Training Institute conducted by the Cancer Information Service (CIS) at the Northern California Cancer Center in Union City earlier this year.

Martha Rangel-Lugo, PhD, Northwest Region Coordinator, and Marynieves Díaz-Méndez, MD, Outreach Coordinator, participated in the training, and Marynieves facilitated a small-group discussion session with Latino organization participants to help evaluate the Institute and plan follow-up activities.

The interactive two-day training focused on providing breast and cervical cancer education, information and resources to organizations serving minority and medically underserved populations. Topics included cultural competency for effective multicultural outreach and education, screening, diagnosis, treatment, clinical trials education/research and the latest breast and cervical cancer care news.

About 30 ethnically diverse participants, representing 23 organizations within the San Francisco Bay Area, attended the training. About one-third of those in attendance were of Hispanic origin and affiliated with organizations that serve Latino populations. Some of the participants were recommended by the Northwest Region staff.

Institute participants received resource binders with National Cancer Institute (NCI) breast and cervical cancer information,

and Spanish-language resource materials provided by *Redes En Acción* and NCI/CIS. Based on participant feedback, the CIS hopes to collaborate with *Redes En Acción* in developing a Partner Training Institute for Spanish-speaking partners.

The training is part of the CIS's partnership effort with organizations to provide cancer education, information and resources to medically underserved special populations who do not traditionally seek cancer information through the 1-800-4-CANCER phone line.

'Commitment, dedication and service'

Marynieves Díaz-Méndez, MD, Outreach Coordinator, and Anna Nápoles-Springer, PhD, Co-Investigator of the Northwest RNC, were honored as members of the BCEDP (Breast Cancer Early Development Program) Latina 50+ Task Force for their "years of unwavering commitment, dedication and service to the West Bay Breast Cancer Partnership and to the women of San Francisco, San Mateo and Marin County."

Latina exercise brochure

Earlier this year, the Northwest RNC participated in a press conference to introduce a new Spanish-language brochure on exercise for Latinas. The brochure, titled *¡Luzca y Siéntase Mejor Haciendo Mas Ejercicios!*, was developed by the Latina 50+ Task Force and the West Bay BCEDP Partnership.

The Northwest RNC has been a member of the Partnership since its inception in 1998. The Partnership is comprised of organizations from San Francisco, San Mateo and Marin counties in California that work together on breast cancer programs serving low-income Latinas.

Public forum participation

For the second time, *Redes En Acción*-University of California, San Francisco (UCSF), participated in a Public Forum of the American Association for Cancer Research (AACR).

The 2002 Public Forum, "Progress and New Hope in the Fight Against Cancer: A Public Forum Highlighting the Latest Discoveries," was a public education program developed during the 93rd Annual Meeting of the AACR last April in San Francisco. *Redes En Acción* also participated in the Public Forum in San Francisco in 2000.

In both events *Redes En Acción* representatives set up a booth and table with printed bilingual information about cancer and the *Redes* Latino cancer awareness, research and training initiative. This year, *Redes En Acción*-UCSF and the Cancer Information Service of California worked together in planning and developing both organizations' exhibits.



The Northwest Region's Martha Rangel-Lugo and Marynieves Díaz-Méndez (2nd and 3rd from left) participate with Pamela A. Ratliff (left) and Michelle Axel Moseley, both of the CIS, in the Partner Training Institute workshop.

HONORES

Awards and Achievements

Martha A. Medrano, MD, MPH, Co-Principal Investigator for the South Central Regional Network Center, has been selected as the new Assistant Dean for Continuing Medical Education at the University of Texas Health Science Center at San Antonio, effective September 1. She is currently clinical associate professor of psychiatry and pediatrics and Director of the Hispanic Center of Excellence.

Redes En Acción has received bronze Telly Awards for excellence in the production of two Public Service Announcements (PSAs) promoting Latino cancer clinical trial awareness and participation. The Telly is one of the most sought-after awards in the television, commercial and video industry. The award-winning PSAs were part of a *Redes En Acción* mass media campaign currently being aired on Spanish- and English-language TV and radio stations nationwide.

New study will test *Buena Vida* impact

Redes En Acción, the NCI Cancer Genetics Network (CGN) and Texas Cancer Genetics Consortium (TCGC) are collaborating on an innovative new project aimed at evaluating a bilingual cancer study recruitment publication and increasing enrollment of Latinos into the CGN Registry.

The TCGC-funded publication, called *Buena Vida: A Guide to Family Cancer Research*, was produced by *Redes En Acción* last fall to provide information about cancer risks and clinical trial participation. A 24-page Spanish/English magazine-format publication designed to serve as a cultural- and literacy-appropriate educational tool, *Buena Vida* includes photos and quotes from ordinary people, all Latinos, who serve as role models for others.

Additional objectives of the *Buena Vida* Magazine Evaluation and CGN Hispanic Recruitment Study will be to identify other potential barriers to Hispanic enrollment in the CGN Registry and help determine the amount of time, energy and resources needed to successfully recruit Latinos into such a registry. The project will be co-directed by Principal Investigators Amelie G. Ramirez, DrPH, and Alexander R. Miller, MD.

The CGN Registry is a national listing of individuals who have a personal or family history of cancer, and who may be interested in participating in studies about inherited susceptibility to cancer. The registry serves as a pool of interested persons readily available so that important research studies can progress without unnecessary delays due to participant recruitment.



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