



Redes Report



Cancer Awareness • Research • Training
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Redes NSC meeting to spotlight key elements of program efforts

As plans proceed for the 2nd Annual *Redes En Acción* National Steering Committee Meeting, some of the fruits of the initiative's first-year labor will be unveiled. Headlining the program for this year's conference, scheduled August 15-17 in San Antonio, will be the premiere of *Redes En Acción's* media PSA (public service announcement) campaign. English and Spanish versions of the seven TV and radio PSAs, which promote Latino participation in cancer clinical trials, will be distributed to stations nationwide for airing, beginning this fall. The media campaign, a major component of the *Redes* overall Latino cancer awareness effort, represents a collaboration with the National Cancer Institute's Cancer Information Service.

Several speakers and panels are on this year's National Steering Committee (NSC) meeting agenda, covering a host of topics involving the *Redes* goals promoting Latino cancer research, training and awareness.

Serving as Honorary Chair of the National Steering Committee is U.S. Congressman Ciro Rodriguez, who will provide meeting participants with an update on the National Hispanic Caucus's Health Task Force. In addition, speakers include Texas Legislature Representative Irma Rangel, who is a breast and ovarian cancer survivor, and Dr. Francisco Cigarroa, President of the University of Texas Health Science Center at San Antonio and the first Latino head of a health science center in the country.

Discussing the new National Center on Minority Health and Health Disparities will be

continued on page 4



Inside



If you think something looks different about this *Redes Report*, you're right. Our new banner at the top of this page was inspired by

the design of *Redes En Acción's* new web site, which will be online (redesenaccion.org) by the time this issue is published. See the story on *Redes's* inaugural Internet presence on page 6.

For the *Redes* staff and investigators, August is a busy time. Our 2nd Annual National Steering Committee Meeting will be conducted August 15-17 at San Antonio's Plaza Hotel. More than 50 participants representing a cross-section of Latino cancer and health fields, community-based organizations and federal agencies will attend this year's conference. A highlight of the meeting, discussed in our lead story, will be the debut of our new nationwide media PSA (public service announcement) campaign promoting Latino participation in cancer clinical trials.

Inside this issue, you'll find the always-inspiring stories profiling Latinos who are serving as role models in cancer research, training and awareness around the country. As usual, these brief articles spotlight some of the fascinating work Latinos are doing to help ease the cancer burden among Hispanic/Latino populations.

We're also pleased to announce in this issue approval of the NCI for funding the first Latino cancer pilot research project submitted through the *Redes* review process. We're confident many more will follow over the next four years. For more information about these pilot projects, see the story discussing eligibility and research requirements on P. 3.

Amelie G. Ramirez, DrPH
Principal Investigator
Redes En Acción

First pilot project approved by NCI

The first cancer pilot study application submitted through *Redes En Acción* has received approval for funding by the National Cancer Institute. The one-year project, titled South Carolina Partnership for Cancer Prevention, will be directed by Principal Investigator Deborah Parra-Medina, PhD, Assistant Professor in the School of Public Health, University of South Carolina.

With an emphasis on cervical cancer prevention among Latinas, the project will cultivate development of a community-based partnership for cancer prevention as part of the South Carolina Hispanic Health Coalition. Dr. Parra-Medina is a *Redes* Southeast Regional Network Center partner and formerly trained in San Diego, where she worked with the National Hispanic Leadership Initiative on Cancer: *En Acción*.



RESEARCH

Open-Door Policy

Dr. David M. Gustin
Chicago, Illinois

Dr. David M. Gustin believes in a “no strings attached” approach to recruiting Latinos into cancer clinical trials. This is particularly applicable in the case of uninsured and undocumented patients, he notes.

“Participation in studies improves quality of care and appears to affect cancer outcomes,” he says. “Poverty and lack of entitlements should not be barriers to treatment. Immigration status should not be a necessary part of physician assessments.”

To succeed in recruiting Latinos into studies, Dr. Gustin believes it is essential that they have access to a full menu of sophisticated cancer studies and services. Clinicians who can clearly communicate in Spanish will motivate Latino



participation, he believes.

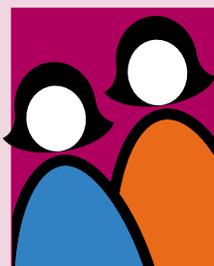
A clinician and researcher, Dr. Gustin was drawn to cancer work while completing his internal medicine residency at Chicago’s Michael Reese Hospital. He studied medicine at Universidad Central de Venezuela.

Excited about developments in molecular biology, he pursued a fellowship in hematology/oncology at the University of Iowa. There he developed an interest in

evaluating the effects of natural agents in chemoprevention and translational cancer control research.

At the University of Illinois at Chicago (UIC) Department of Hematology/Oncology since 1997, Dr. Gustin is taking leadership in Phase I chemoprevention trials. He is the principal UIC investigator of the STAR tamoxifen-raloxifen study and the upcoming SELECT prostate cancer chemoprevention studies.

Dr. Gustin is a co-investigator with the Minority Based Community Clinical Oncology Program. At both UIC and Mt. Sinai Medical Center, he attends to Latinos with cancer. He works in partnership with UIC Latino Health Research Center and belongs to the National Steering Committee of *Redes En Acción*, as well as the Regional Community Advisory Committee of *Redes*’ North Central Region.



TRAINING

Promoting Diversity

Dr. Regina Otero-Sabogal
San Francisco, California

As a bicultural cancer investigator, Regina Otero-Sabogal, Ph.D., knows the importance of recruiting students into educational programs that lead to increased involvement of Latinos in cancer research. And as co-training director, faculty and mentor for the National Cancer Institute-funded Minority Training Program for Cancer Control Research (MTPCCR), she’s helping make the goal of ethnic diversity in cancer research a reality.

In collaboration with Dr. Rena Pasick from the Northern California Cancer Center, Dr. Otero-Sabogal has partnered with faculty from the San Francisco Bay Area to train minority students in cancer control research. The goal of this program is to increase ethnic diversity in the field of cancer control research by encouraging minority students in masters level programs to pursue a doctorate.

In comparison with more affluent non-Hispanic whites, there is excess cancer incidence and/or mortality among minorities and the underserved. Yet the field of cancer control research is itself notably lacking in ethnic diversity. This directly reflects student demographics in the doctoral programs that prepare members of this field. For all disciplines in U.S. schools for 1995, the distribution of doctoral degree recipients significantly underrepresented the general population for Latinos compared with non-Hispanic whites.

“If we need to reduce the disproportionate burden of cancer among Latinos,” notes Dr. Otero-Sabogal, “Latino investigators who are best equipped to address the needs of our communities must be involved in

the research.”

The MTPCCR consists of three components:

- ▶ **Careers in Cancer Control Workshop.** This five-day summer workshop is designed to inform trainees of the need for minority researchers in cancer control and the opportunities available.
- ▶ **Student Internships.** Students who participate in the summer workshop can apply for paid full-time summer or part-time academic year internships.
- ▶ **Doctoral Incentive Awards.** Private donor-funded doctoral incentive awards are designed to assist students in offsetting the costs of applying to doctoral programs and visiting campuses.



“The main barrier that I have faced in this program is to recruit Latino master students from collaborating institutions,” says Dr. Otero-Sabogal. “Eleven Latino students participated in past programs, but this year only one Latino student has applied. The few Latino students who make it to the master level have few role models and often have family and work obligations that deter them from applying to programs. Our plan is to improve the recruitment of Latino students by working closely with schools with higher concentration of Latinos.

“The most significant impact of the program,” she adds, “has been empowering Latinos and students of other ethnic groups with low expectations of pursuing a doctoral program to apply and get accepted into graduate schools. From 50 students who took part in the summer institute, about eight participants are currently enrolled in doctoral programs and 10 report concrete plans for applying in the next one to two years.”

Dr. Otero-Sabogal is an Associate Professor at the University of California, San Francisco, Institute for Health and Aging in the School of Nursing. Originally from Colombia, she is a bicultural psychologist who has focused her research on identifying and measuring the cultural aspects related to cancer control among Latinos and on developing, implementing and evaluating cancer control interventions at the community level to improve access to cancer screening.



AWARENESS

Advocating Change

Sylvia Garcia-Rickard
San Diego, California

Sylvia Garcia-Rickard's breast cancer diagnosis in 1993 left her with an immediate need to become an informed consumer. The same breast lump she had found years before but was repeatedly told not to worry about was suddenly forcing her to make decisions: finding the right medical provider, asking the right questions, requesting treatment as an individual and not just another case.

After her surgery and her experiences with the health care field, she recognized the need for help from breast cancer coalition organizations and other support groups. The more involved she became in her treatment and recovery, the more she realized that the system had failed her – and was failing other Latinas as well.

“Changes were needed at both the state and federal level if they were to have a real impact in saving women’s lives,” Sylvia recalls. “This became my passion – to find a way to help Latinas and others in the struggle against breast cancer.”

Educating herself through programs such as the Advocacy Conference, Legislative Team Leader Training and Project Lead, and by serving on executive boards and committees (e.g., the National Latina Advocacy Network Committee), Sylvia has found

various avenues to channel her passion:

- ▶ She is serving her seventh year as Legislative Team Leader for the National Breast Cancer Coalition (NBCC), a grassroots advocacy organization dedicated to eradicating breast cancer, and currently serving as the Utah Field Coordinator.
- ▶ She is co-founder of *Juntos Contra El Cancer*, an advocacy group that supports cancer awareness activities and education for Hispanics in the area.
- ▶ She participates in the Utah Comprehensive Cancer Control Initiative, serving as an active advocate on behalf of all women.
- ▶ Through the American Cancer Society Chapter in Salt Lake City and the Cancer Control Program, she provides support and education to Latinas in need of guidance and assistance as they face the realities of breast cancer diagnosis.



Last fall, Sylvia helped pass the Breast and Cervical Treatment Act, a Medicaid Optional Treatment Bill, which will improve access and support awareness activities in Utah. Also, she lobbied for appropriation of treatment funds for underserved women in Utah, a successful effort that takes effect this month.

Today, in addition to her many other activities, Sylvia is an active member of *Redes En Acción*, Regional Community Advisory Committee for the Southwest Regional Network Center.

“Sylvia is the most energetic woman I have ever worked with,” says Maritza Arce-Larreta, A.P.R.N, Clinical Coordinator of the Utah Cancer Control program. “She legitimately cares for all women, especially those who are Hispanic and underserved.”

NSC to review concept papers for pilot projects

At the August 15-17 National Steering Committee (NSC) meeting, members will review concept papers for proposed cancer-related pilot research projects. Deadline for filing the one-page concept papers was August 1.

Redes En Acción serves as an avenue for National Cancer Institute funding for pilot research involving cancer issues related to Latinos. Maximum funding, including direct and indirect costs, is \$50,000 per project.

To be eligible, the pilot study must be led or co-led by an individual associated with an academic institution. The Principal Investigator must be Latino, with a doctoral degree and be at the junior faculty level or a postdoctoral fellow.

Proposed studies must have the strong potential of leveraging the results into an ROI NIH type proposal or other peer-reviewed funding. In addition, projects must address one or more of the following cancer sites: breast, cervical, lung, colorectal or prostate.

After review by the NSC, full proposals will be due October 1. Following a review, proposals may be revised and returned to Baylor College of Medicine no later than November 1. All pilot research proposals are due at NCI December 1.

A principal indicator of success for the pilot projects is the

research career development of Latino investigators as measured by publication of the results and subsequent grant applications and funding. Funded investigators will be assisted in developing and submitting an independent research proposal based on data collected from the pilot studies.

As part of the research experience, Latino investigators will have the opportunity to interact with investigators on the *Redes En Acción* parent grant and enhance their research skills and knowledge of cancer prevention and control among Latino populations.

Applications for pilot projects are accepted twice a year. In addition to the current proposal schedule, funding for pilot research will also be provided each spring. The deadline for concept papers for that funding period will be December 1, 2001.

Pilot project guidelines, application schedules and contact information may be obtained from the Regional Network Centers or the National Network Center at Baylor College of Medicine. Inquiries regarding the submission process, feedback and concept development should be addressed to the Regional Network Centers. Contact information may be found in the box on the back of this newsletter.

CULTURE-CANCER CONNECTIONS

Dr. Sylvia M. Ramos
Albuquerque, New Mexico

For Sylvia Ramos, MD, patient care and research go hand-in-hand. Her private practice and her role as president of People Living Through Cancer, a grassroots support organization, offer exposure to patients with diverse backgrounds. And this exposure provides a unique opportunity to better understand how different cultural and ethnic groups view cancer.

“What may be different is how groups respond to a cancer diagnosis, make choices about treatment options and adjust to life as survivors,” she notes. “It would be interesting to see if indeed there are differences and how, if present, these differences affect the quality of life and survival outcomes of patients diagnosed with cancer.”

Dr. Ramos comes to her interest in cultural diversity naturally. Born in Puerto Rico, she moved to New York at an early age and later attended Herbert H. Lehman College, where she was a Thomas Hunter Honor Scholar. She graduated from Albert Einstein College of Medicine in 1974 and stayed for her residency training in general surgery.

In 1990, she moved to Albuquerque and opened a private practice in general surgery. Because of her interest and involvement in the care of patients with breast diseases, including breast cancer, since 1995 she has devoted her practice entirely to patients with these ailments.

Throughout her career, Dr. Ramos has been involved in clinical research and has published numerous articles in medical publications. Her research focuses on “looking at my group of patients to identify significant differences in risk factors for breast cancer, determine their stage at diagnosis, and choices about treatment modalities and their outcomes.”

Her research projects have studied ultrasound for diagnostic procedures including biopsies, post mastectomy lymphedema, and most recently, the role of peer support on the quality of life and outcomes of cancer survivors.

Dr. Ramos was selected to participate in the Class of 2000 National Hispanic Medical Association Leadership Fellowship Program.



NEWS FROM NHMA

A group of Senators and Congressmen recently called on President Bush to rescind several Executive Orders signed into law by the previous administration. One of the orders on the list called for translators, signs and information for Limited English Proficient Persons (LEP persons), as a clarification of the Civil Rights Act of 1964, targeted at states/agencies/health facilities that receive federal funding. The Act prohibits denial of federal services by national origin, which was upheld by the courts to mean LEP persons. The Department of Health and Human Services Office of Civil Rights issued a Guidance on LEP in August to clarify how hospitals, clinics and medical practices could become compliant.

At the National Hispanic Medical Association (NHMA) Conference in March, presidents of the American Medical Association, American Academy of Family Practice, American Academy of Pediatrics, Society of General Internal Medicine, National Medical Association and Association of American Indian Physicians, and an American College of Physicians representative addressed the 700 participants and explained their position. All except NMA and AAIP had signed a letter requesting a moratorium on the Guidance based on cost to individual physicians who would drop Medicaid.

The Congressional Hispanic Caucus, the Congressional Asian Caucus, NHMA and other Hispanic organizations, Asian organizations, legal and immigrant organizations have written letters to the White House and Secretary Tommy Thompson about the need for quality health care to include language services for LEP as mandated by the Civil Rights law and a request for expansion of strategies to reimburse translators. According to the *New York Times* (May 2, 2001), after a meeting on LEP with immigrant groups the White House said there are no plans to repeal the order at this time.

NHMA has requested a meeting with Secretary Thompson to discuss current reimbursement policy for language and expansion of it, including requiring data collection on language preference in federal programs that can lead to a better understanding of the need. As the country becomes more diverse, it is unacceptable to ignore the language needs of Americans.

Elena Rios, MD
President, NHMA

NSC Meeting

continued from page 1

Center Director Dr. John Ruffin. Also, Dr. Armin Weinberg, Director of the Chronic Disease Prevention and Control Research Center at Baylor College of Medicine, will provide insight into national cancer dialogues and initiatives.

A pair of panel discussions will involve collaborative relationships with *Redes En Acción*. One will explore how these linkages should take shape in the future, and the other will examine opportunities for collaborations with non-profit organizations. A third panel discussion will focus on the *Redes* training mission of developing Latino cancer researchers.

Yet another highlight of the conference will be a *Redes* NSC Town Hall Meeting titled “Thinking Outside the Box in Developing Latino Cancer Awareness, Research and Training Activities.”

The NSC membership includes a cross-section of renowned cancer experts and authorities from various fields, including scientists, academicians, and leading Latino health and communications experts. Members also represent governmental agencies, including the Department of Health and Human Services, National Cancer Institute, and Centers for Disease Control and Prevention. Organizations represented include the National Council of La Raza, American Cancer Society, Latino Council on Alcohol and Tobacco, Susan G. Komen Breast Cancer Foundation, Grant Makers in Health, and Hispanic Nurses Association.



The *Redes En Acción* Northeast Regional Network Center was well represented at the recent ribbon-cutting ceremony for a new American Cancer Society Resource Center at The Brooklyn Hospital Center in Brooklyn, New York. Participants in the ceremony included Jose Marti, MD, and Helen McCarthy, RN, OCN, MPA. Dr. Marti is *Redes* Co-Principal Investigator while Helen serves as Project Manager/Research Associate. The new ACS Resource Center will give cancer patients and their families access to electronic, print and video information on the latest treatment, prevention, research and services.

Spotlight

Redes En Acción partner and National Steering Committee member Venus Ginés was the focus of a recent article in TWA's Ambassador Magazine. Venus, a TWA flight attendant, was profiled in a story titled "An Inspiration at 35,000 Feet." She is a breast cancer survivor and Hispanic Cancer Awareness Coordinator for Día de la Mujer Latina. In her role as advocate for Latina cancer awareness, she works to address the need for improved cancer education efforts in Latino communities. "She has won a number of awards for her work on behalf of Latino women and recently addressed a congressional panel on the subject," according to the TWA article.

A panel presentation moderated by Helen McCarthy, Project Manager/Research Associate for the *Redes* Northeast Regional Network Center, is available online. The presentation, "The Influence of Culture on Palliative Care," took place at the Oncology Nursing Society Congress in San Diego in May and includes a discussion of the mission of *Redes En Acción*. The panel presentation was taped and can be found on the Internet at ons.org-virtual-congress for the next year.

Cancer report card published in JNCI

The Journal of the National Cancer Institute (JNCI) has published the Annual Report to the Nation on the Status of Cancer (1973 through 1998) in its June 6 issue. The report represents a collaboration of the NCI, American Cancer Society, Centers for Disease Control and Prevention, and North American Association of Central Cancer Registries.

The purpose of the report is to provide the latest information about progress in cancer and to update cancer incidence and mortality trend data. The main finding this year is that U.S. cancer incidence and death rates overall are declining. The report contains updated cancer incidence/mortality rates by site and race/ethnicity (1992-98), including those for Latinos.

A copy of the article can be found on the NCI web site at:

<http://www.jnci.oupjournals.org>

Cancer Information Service

A PROGRAM OF THE NATIONAL CANCER INSTITUTE
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get the latest, most accurate
cancer information.

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www.cancer.gov

National Cancer Institute's Web site



A PROGRAM OF THE NATIONAL CANCER INSTITUTE
YOUR LINK TO CANCER INFORMATION

One of a series of new print-media PSAs (public service announcements) produced by the NCI Cancer Information Service.

Redes En Acción makes online debut

The *Redes En Acción* web site is now online and can be found at <http://redesenaccion.org>.

Although elements of the site are still under development, several components and resources are available now. The site currently contains information about the *Redes En Acción* program activities, mission, objectives and timeline. Included are a map of the program's six nationwide regions and pdf files of *Redes* newsletters and other publications.

Upon completion, the web site will enable members of the *Redes* National Steering Committee, colleagues and consultants, Regional Network Center personnel, and members of the media to communicate with the National Network Center and with one another. The site will also provide an online means for anyone engaged in Latino cancer research, training or public education to join the *Redes* network.

In many ways the site will remain a work-in-progress, with continuous revisions, updates and additional resources. It will include FAQs (frequently asked questions), information about Latino cancer training opportunities and pilot research project availability, and a host of helpful links to relevant online resources.

Watch future issues of the *Redes Report* for announcements of further *Redes* web site developments.



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