



Redes Report



The National Hispanic/Latino Cancer Network

www.redesenaccion.org

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Redes En Acción celebrates 5th anniversary

Redes En Acción celebrated a major milestone – its fifth anniversary – with the recent 5th Annual National Steering Committee Meeting, attracting about 70 participants, including several National Cancer Institute (NCI) leaders and other cancer health authorities.

“This meeting provided us an opportunity to recognize and celebrate the *Redes En Acción* achievements of the past five years as an NCI Special Populations Networks initiative and look ahead to future opportunities for continuing our momentum and exploring new and exciting collaborative partnerships,” said Amelie G. Ramirez, DrPH, *Redes En Acción* Principal Investigator.

“We certainly can take pride in the excellent progress *Redes En Acción* has made with regard to Latino cancer research, training and awareness, and it’s extremely important that we maintain the focus on these vital issues.”

Among highlights of the conference was a presentation by Mark S. Clanton, MD, MPH, Deputy Director, NCI, for Cancer Care Delivery Systems, addressing the changes in cancer treatment and care stemming from technological advances. NCI has expanded its focus in examining health care delivery systems in the overall context of “discovery, development and delivery,” he said.

Delivery of care is a vital component tied

2000–2005

¡MIL GRACIAS!

Redes En Acción would like to thank the many individuals and organizations who have helped us achieve our goals in Latino cancer research, training and awareness over the past five years. Special thanks for the support and contributions of the National Cancer Institute, members of the National Steering Committee and the Susan G. Komen Breast Cancer Foundation.



National Steering Committee meeting speakers: NCI Deputy Director Dr. Mark Clanton (right), OMH Acting Deputy Assistant Secretary Dr. Garth Graham (far right), NCI leaders Mary Anne Bright, Lenora Johnson and Dr. Diana Jeffery (below)

to the entire host of related issues, including access to care, economics of care, information systems and dissemination, quality of care, and clinical trials – “the system is interactive,” he emphasized. As advances in discovery and development occur, he said, systems for delivery of cancer care must keep pace with “technology changes in prediction, detection

and treatment.”

The meeting’s speakers also included Garth Graham, MD, MPH, Acting Deputy Assistant Secretary of the Department of Health & Human Services, Office of Minority Health; Holly L. Howe, PhD, Executive Director of the North American Association of Central Cancer Registries; and Elena Rios, MD, President of the National Hispanic Medical Association.

A panel of NCI leaders was composed of Mary Anne Bright, RN, MN, Associate Director of the Cancer Information Service; Diana D. Jeffery, PhD, Project Director of the Office of Cancer Survivorship; and Lenora E. Johnson, MPH, Director of the Office of Education and Special Initiatives.

A second panel, discussing potential collaborative projects among the major SPNs, included Moon S. Chen, Jr., PhD, of the Asian American Network for Cancer Awareness, Research & Training, and Stephen Wyatt, DMD, of the Appalachia Cancer Network.

Other panel discussions included principal investigators of eight of the 16 pilot research projects funded by NCI through *Redes En Acción* and three of the 131 junior faculty, pre/post doctoral candidates and student interns who have benefited from the initiative’s training program over the past five years.

A major sponsor of the annual meeting, for the fifth year in a row, was the Susan G. Komen Breast Cancer Foundation, which has provided support for several *Redes En Acción* projects over the years.

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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AWARENESS

Empowering the public

Evelyn Rojas, MSW
Brooklyn, New York



The innumerable disparities experienced by ethnic minorities inspired Evelyn Rojas's deep commitment to empowering others. As Partnership Program Coordinator for the National Cancer Institute's Cancer Information Service (CIS) and *Redes En Acción*, she has had the opportunity to aid the public by providing necessary resources and skills development.

On her own path toward self-empowerment, Evelyn has made choices in life that seemed unattainable. "As the first in my family to go to college, attending Yale to pursue my bachelor's degree seemed more like a dream than a reality," she says.

After graduating, she observed social services as an insider. In the process, she became concerned with systemic issues that negatively impacted clients. To learn more about how to combat these issues, she decided to pursue a Master of Science in Social Work degree in administration and planning from Columbia University.

Her position with CIS and *Redes En Acción* – and the opportunity to explore collaborative relationships with community-based organizations and public agencies – has given Evelyn new perspective. "Partnering with multiple cancer and health

organizations gives me a bird's-eye view of what is and is not working," she says. "Being able to positively impact disadvantaged communities from a systems approach strengthens my hope that an equal playing field for all people is possible."

Working with health and human service organizations to increase cancer awareness allows Evelyn to continue addressing issues of empowerment. While conducting a clinical trials education pilot study – a joint project of *Redes En Acción* and CIS – it became clear that Latino audiences felt a deeper sense of responsibility to join the fight against cancer if the information was provided in a discussion-style format rather than a lecture format.

"Helping organizations develop culturally, linguistically and developmentally appropriate cancer resources and programs provides a venue to drive home the idea that each one of us has a personal responsibility to manage our own health," Evelyn noted.

One way she effectively reaches the public is by educating health professionals that provide services to underserved communities. A recent project involved developing a full-day training seminar for oncology nurses that addressed the barriers leading to low participation in cancer studies by minority and medically underserved populations.

"Don't be discouraged if you don't see immediate results from your awareness efforts," she advises. "We all have different paths we need to take before we can truly become the empowered individuals we are meant to be. Just keep driving the point home – you will have an impact."

(Editor's Note: Evelyn recently assumed a new position, that of Director of Media Policy for the National Hispanic Media Coalition in Los Angeles, California.)

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



RESEARCH

Community connections

Carlos Roberto Jaen, MD, PhD, FAAFP
San Antonio, Texas



When Dr. Carlos Jaen founded and directed the Center for Urban Research in Primary Care (CURE PC) at the University of Buffalo (New York), the Center conducted a health needs assessment that led to a redesigned health care delivery system for a predominantly Puerto Rican community in Buffalo. As a result of his collaboration with local community-based organizations, a new health care facility was created and previously unavailable health services were introduced to local residents.

"This was work that needed to be done to know the community and for the community to gain your trust," he says. The experience has served him well in his ensuing career.

Now a Professor and Chair of the Department of Family and Community Medicine at the University of Texas Health Science Center at San Antonio (UTHSCSA), Dr. Jaen has devoted considerable effort to participatory research in cancer prevention, tobacco cessation, policy

development and primary care practice issues. He has also trained junior investigators in these research areas.

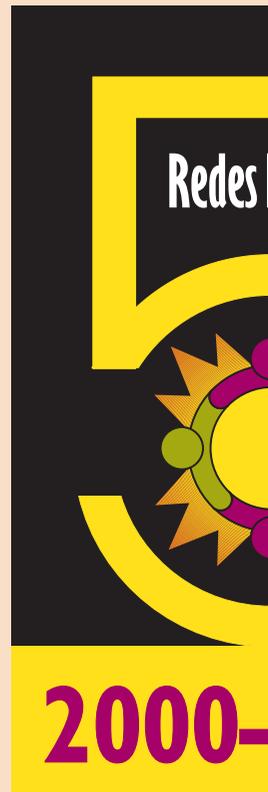
Dr. Jaen is recognized as a leader in smoking cessation research and is Chairman of the National Advisory Committee of the Robert Wood Johnson Foundation's Addressing Tobacco in a Managed Care Program. The program was designed to increase the adoption of smoking cessation clinical practice guidelines in managed care organizations. In 1996 he served on the panel of experts that published smoking cessation guidelines and was a member of the panel that published the U.S. Public Health Service Clinical Practice Guidelines: Treating Tobacco Use and Dependence in 2000.

At UTHSCSA, Dr. Jaen is Co-Director of the Center for Research in Family Medicine and Primary Care, one of only three Centers of Excellence funded by the American Academy of Family Physicians. Over the past 10 years, his work has focused on exploring the competing demands of primary care practice. Recently, he reported that in 25 percent of office visits to primary care offices, there are competing demands that override the need for smoking cessation counseling.

Dr. Jaen has excellent advice for young students and junior physicians: "Embrace the wisdom of the community – they know best about their problems and their resources. Connect with people who have similar interests, even if they are far away, and work hard at maintaining these relationships. They will sustain you through difficult times. Go at it with passion; don't let your commitment to change our broken health care system wane. Too many are dying early or suffering unnecessarily. We must act."

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

Redes En Acción's 5th Anniversary: Regional Coordinators look back



Nereida Borrero, MSN Northeast Region



Nereida Borrero is the Coordinator for the Northeast Region at the Brooklyn Hospital Center in Brooklyn, New York, where she is also associated with the Department of Internal Medicine, working as a Geriatric Nurse Practitioner. She has a Bachelor of Science in Nursing degree from The College of Staten Island, New York and a master's degree in nursing with concentration in geriatrics from Hunter College.

“As the Program Coordinator in New York, I have had the opportunity to reach over 10,000 people in this area with messages of cancer awareness. I have also had the opportunity to collaborate with more than 300 community members who have joined the *Redes En Acción* partnership program. Perhaps the most challenging part of our effort has been the establishment of *Redes En Acción* as a source of information, guidance and responsibility for participation in pilot research projects. We received submissions from young Latino researchers from a broad region in the Northeast. The quality of their work is exciting and it has been great guiding them and sharing in their joy in their success. Working with Latinos in New York City is a complex process in that we share the same language, but our origins are varied. Although Dominicans and Puerto Ricans dominate in numbers, we have specific communities of Mexican Americans as well as immigrants from many Central and South American countries. Outreach programs are designed with a knowledge of the specific community involved. Working with churches and local health centers has been essential. Radio messages and community bulletin boards have been good vehicles for the dissemination of information for health care events. One-to-one messages are still the most effective way to get the message across, so our outreach workers are a key link to the community. I feel that the community has discovered *Redes* and it has become a resource of information in vital areas of concern for Latinos in the Northeast Region. I'm very proud of the achievements of *Redes En Acción*, and I look forward to continuing to work with the professionals and public in this area.”

Sylvia Z. Castillo South Central Region



Sylvia Z. Castillo graduated from Interamerican University of Puerto Rico with a BS in Biology. She has been working at the University of Texas Health Science Center at San Antonio since 1995, and is planning to pursue her Master's in Public Administration degree in the fall of 2005 at the University of Texas at San Antonio and continue her work with minority and underserved groups.

“*Redes En Acción* has provided me with tools to train students to go into the community and talk to Hispanics about the importance of cancer prevention and their involvement in clinical trials. This experience has been particularly rewarding when I hear feedback from community- and faith-based organizations we've conducted presentations and health fairs with; their thirst for knowledge is clear when they request our participation in future activities. Also, *Redes En Acción* has provided me the opportunity to work with Hispanic junior faculty regarding training and research, and encourage them to participate in pilot projects targeting disparities in communities that represent their own roots. I know we've planted a seed that will grow strong with time. I am very thankful for this opportunity, which has helped me grow professionally and personally. *Redes En Acción* has also provided invaluable resources and networking not only in San Antonio but all over South Texas. I am also thankful for the camaraderie and friendships created among our regions over the last five years, friendships that I know will last forever. Thank you and good luck to you all!”

Haydee Encarnación-García, PhD North Central Region



Haydee Encarnación-García holds a PhD in Health Behavior; with a major in public health education and a minor in health promotion and higher education awarded by the School of HPER, Indiana University. She obtained her MS in health promotion from Indiana University. She was born in San Juan, Puerto Rico, where she obtained an MPH with a major in epidemiology at the Medical Sciences Campus of the University of Puerto Rico. She is also a Certified Health Educator Specialist (CHES).

“*Redes En Acción* has played a vital role in the North Central Region cancer research, training and awareness efforts among the partner organizations that serve the Latino community in the region. To achieve these goals, partnerships and alliances have been the key to what is really needed in order to assure the health and well-being of our Latino community and to integrate culturally competent cancer education messages. The augmentation of the capacity-building efforts in cancer prevention and control and the development of culturally competent professionals will ultimately improve the health status and health care delivery for the Latino and other minority communities. Building a research training infrastructure has involved considerable effort and resources. The

Redes En Acción North Central Regional Cancer Center has made significant progress in building the necessary professional staff to implement its cancer research, training and awareness agendas.”

Angel Loor, MA Southeast Region

Angel Loor is in the process of attaining his Master's of Science in Public Health degree at the University of Miami (UM) Miller School of Medicine. He obtained an MA in liberal studies in 2000 from UM and has a BA in business administration from Florida International University.



“ The three main goals of *Redes En Acción* are to promote cancer research, training and awareness among Latinos. Under the research umbrella, I've learned that there is a great need for more diversity in the scientific research fields. More Hispanic/Latino researchers are needed to understand and design culturally competent research models that will guarantee larger numbers of minority participation in research

studies. While mentoring Hispanic students during the summer internship programs, I've seen eager students learning about cancer research and the disparities that Hispanics face when trying to attain treatment. I have literally witnessed a maturing process and helped foster confidence in their personal abilities to acquire their educational endeavors. Personally, this has been the most rewarding aspect of my *Redes En Acción* duties. However, there is a lack of training opportunities for young Hispanics and there is a need for more role models in science and the medical fields. Finally, under my awareness responsibilities, I've found there is a great diversity of Hispanic/Latinos. Interventions and educational materials need to be specially tailored and targeted for the specific sub-population and community. Also, there is a lack of educational resources in Spanish. My experience at *Redes En Acción* has been extremely positive and I hope to continue making a difference in reducing cancer health disparities affecting the Hispanic/Latino community.”

Martha Rangel-Lugo, PhD Northwest Region

A native of México DF, Martha Rangel-Lugo has a BS in human nutrition and food science from Universidad Iberoamericana and an MS and doctorate in poultry/animal nutrition from Cornell University. She has been conducting Latino health research at the University of California, San Francisco since 1998.



“ *Redes En Acción* is well known within the Latino cancer-related community organizations network in San Francisco and the Bay Area through the many educational talks which have been delivered at

community centers and through the creation of Latino cancer research collaborations between community and academic centers. *Redes En Acción* has helped co-create a cancer support group for Latinas in San Mateo County and a coalition of agencies in Alameda County, both to serve and to do community-based participatory research for Spanish-speaking Latinos. Community agencies are open to increasing awareness about cancer prevention, diagnosis and treatment among Latinos. However, there is a very limited amount of cancer educational material in Spanish at a literacy level appropriate for the population served, and some Latinos prefer not to know about difficult issues such as cancer. I look forward to working with doctors who clearly have a great deal of influence with their patients, health care delivery places where friendly, supportive staff can make a real difference, and friends of cancer patients who often provide important information and encouragement. Finally, I hope our work will be supportive of the medical and public health professionals who are working to improve the health care of the people we serve.”

Ana Talavera, MPH Southwest Region

Ana Talavera completed her undergraduate studies and her MPH at San Diego State University. A bilingual/bicultural native of Nicaragua, she has over 10 years experience managing research projects at the Center for Behavioral and Community Health Studies.



“ As the Program Coordinator for the Southwest Regional Center housed in the Center for Behavioral and Community Health Studies at San Diego State University, I have had the benefit of significantly expanding my professional and personal growth. My experience with the National Network has also motivated me to become a better educator and communicator in the Latino community regarding cancer prevention and control issues. *Redes En Acción* has provided me with the opportunity to develop rewarding relationships with a significant number of community partners at the local, regional and national level. It has been a great honor to have met and worked alongside such a talented and committed group of Principal Investigators and project staff. I have been touched by the dedication of the various investigators to mentor young trainees as they eagerly learn and apply new skills in their daily work in the community. Working with trainees and feeling that I have made a difference in shaping the students' career goals have been among the most rewarding experiences of my *Redes* responsibilities. Equally important has been writing touching role model stories of individuals working tirelessly and selflessly to raise cancer awareness, train new investigators and conduct research to improve cancer prevention and control issues in Latinos. In addition, with the continuous support of *Redes En Acción*, I have improved my managerial, grant writing and community advocacy skills. I am very grateful for the opportunity and honor to be part of a program that promotes and supports community linkages and collaborations as well as community-based research opportunities.”

Clarifying clinical trial participation barriers

Ana Maria Lopez,
MD, MPH, FACP
Tucson, Arizona

Low health literacy and poor health care access pose major barriers to representation of underserved populations in cancer clinical trials and early disease prevention and detection, according to Dr. Ana Maria Lopez. As a medical oncologist, she warns that “without improved recruitment of minority participants, the generalizability of the clinical research findings can be called into question and the specific needs of minority participants cannot be identified or met.”



Dr. Lopez is an Associate Professor of Clinical Medicine and Pathology at the Arizona Cancer Center, University of Arizona College of Medicine, where she

focuses on the prevention and treatment of women’s cancers. She also serves as the Medical Director of the Arizona Telemedicine Program, focusing on outreach and education to patients and providers in rural and underserved areas via telecommunications technology.

Dr. Lopez is currently involved in various studies designed to increase access to prevention and early disease programs and to address the barriers to Latinos’ involvement in cancer clinical trials. One study, Examining Barriers to Minority Participation in Cancer Clinical Trials, serves to advance cancer care by clarifying the specific facilitating factors and barriers to patient enrollment in cancer clinical trials. At the core of the study, the beliefs of ethnically distinct populations affect the accrual of minority participants to these trials.

Another of Dr. Lopez’s studies, Patient Navigators in Cancer Care for Latinos and American Indians, seeks to improve access to breast, cervical and colon cancer screening, diagnosis, treatment and

survivorship care. Her primary goal is to uncover significant findings that will result in policy change that effectively contributes to the end of health care inequities. To achieve this, she believes that improving health literacy among underserved communities is crucial to improving their health care outcomes.

“Although literacy is an important barrier for many societal activities, health literacy can be a matter of life and death, and it is not overcome by simply speaking the same language,” she says.

As a devoted physician in clinical medicine, Dr. Lopez believes strongly in perseverance because “a positive outlook interwoven with the goal to improve, enhance and ameliorate is important.” She believes these qualities are exemplified in Thomas Edison’s quote, “I have not failed 2,000 times. I have found 2,000 that did not work.”

Contributed by:

Vicente Samaniego, MPH

National Hispanic Medical Association

Bilingual phone line helps smokers quit

Through the Smoking Quit Line of the National Cancer Institute, the Cancer Information Service (CIS) offers free, personalized help in English and Spanish to callers who want to quit.

Specially trained staff provide tailored information, counseling and confidential support to fit each caller’s needs. The CIS assesses callers’ smoking behavior, provides brief informational messages and written materials, and helps develop personalized action plans for quitting.

In collaboration with the CIS, Drs. David Wetter, Patricia Daza and Carlos Mazas, from the University of Texas M. D. Anderson Cancer Center’s Behavioral Science Department, conducted a study to evaluate the feasibility and cost-effectiveness of various media approaches to increase Spanish-speaking smokers’ use of the CIS’s smoking cessation service.

The study, called *¡Adiós al Fumar!*, also evaluated the efficacy of delivering an enhanced smoking cessation counseling program to smokers who called the quit line. A total of 355 Spanish-speaking smokers in Texas contacted the CIS’ 1-800-4-CANCER line for help in quitting smoking, and 306 participated in the study.

For more information about Spanish smoking cessation resources from the CIS, call 1-800-4-CANCER, Monday through Friday, 9 a.m. to 4:30 p.m., local time.

Free phone workshops offered to survivors

A free telephone education workshop series is offering cancer survivors and loved ones practical information to help them deal with concerns and issues after treatment ends.

The National Cancer Institute (NCI), in collaboration with CancerCare, the Lance Armstrong Foundation (LAF), Intercultural Cancer Council, Living Beyond Breast Cancer and the National Coalition for Cancer Survivorship, is presenting the 3rd Annual Cancer Survivorship Telephone Education Workshop Series, Cancer Survivorship: Living With, Through & Beyond Cancer. The program is funded by an educational grant from NCI and LAF.

Information provided during the telephone workshops is designed primarily for survivors who have recently completed cancer treatment, but may be helpful for long-term survivors as well. The workshops, which are free and have no telephone charges, take place from 1 to 2 p.m. (Eastern Time) on April 12, May 24 and June 14.

To register, go the CancerCare Web site: www.cancercare.org and click on the CancerCare Connect icon.

Latinas needed for sister cancer study

Researchers are encouraging Latinas and women in other underserved populations to join the Sister Study, a national research project studying 50,000 sisters of women diagnosed with breast cancer.

The Sister Study, conducted by the National Institute of Environmental Health Sciences (NIEHS), part of the National Institutes of Health, is investigating environmental and genetic causes of breast cancer. This is the largest study of its kind to look at breast cancer risk factors.

“By studying sisters, who share the same genes, often had similar experiences and environments, and are at twice the risk of developing breast cancer, we have a better chance of learning what causes this disease,” said Dale Sandler, PhD, Chief of the Epidemiology Branch at NIEHS and Sister Study Principal Investigator. “That is why joining the Sister Study is so important.”

The study will take the most detailed look ever at how women’s genes and things women come in contact with at home, at work and in the community may influence breast cancer risk. The landmark project will stay in touch with the volunteers for 10 years and compare those who develop breast cancer with the majority who do not.

Women of all backgrounds and ethnic groups are eligible for the study if they are between the ages of 35 and 74; live in the United States; have never had breast cancer themselves; and have a sister – living or deceased – who has had breast cancer.

To volunteer or learn more about the Sister Study, visit the Web site <http://www.sisterstudy.org> or call toll free 1-877-4SISTER (877-474-7837).

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National Network Center

Principal Investigator

Amelie G. Ramirez, DrPH
Baylor College of Medicine
8207 Callaghan Rd. Ste. 110
San Antonio, Texas 78230
Phone: 210-348-0255
Fax: 210-348-0554
E-mail: aramirez@bcm.tmc.edu

Regional Network Centers

Northeast RNC

Jose R. Marti, MD
Co-Principal Investigator
The Brooklyn Hospital Center
Brooklyn, NY
Phone: 718-250-8394

Southeast RNC

Frank J. Penedo, PhD
Co-Principal Investigator
Sylvester Comprehensive
Cancer Center
University of Miami, Florida
Phone: 305-243-3981

North Central RNC

Aida L. Giachello, PhD
Co-Principal Investigator
Midwest Latino Health
Research Center
University of Illinois at Chicago
Chicago, Illinois
Phone: 312-413-1952

South Central RNC

Martha A. Medrano, MD, MPH
Co-Principal Investigator
Medical Hispanic Center
of Excellence
University of Texas Health Science
Center at San Antonio
San Antonio, Texas
Phone: 210-567-0963

Northwest RNC

Eliseo J. Pérez-Stable, MD
Co-Principal Investigator
University of California,
San Francisco
San Francisco, California
Phone: 415-476-9933

Southwest RNC

Gregory A. Talavera, MD, MPH
Co-Principal Investigator
Graduate School of Public Health
San Diego State University
San Diego, California
Phone: 619-594-2362

National Hispanic Medical Association

Elena Rios, MD, MSPH
Washington, DC

Program Consultants

Alfred L. McAlister, PhD
Lucina Suarez, PhD

www.redesenaccion.org

Redes En Acción
Baylor College of Medicine
8207 Callaghan Rd. Ste. 110
San Antonio, Texas 78230

