



The National Hispanic/Latino Cancer Network

www.redesenaccion.org

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Redes conference emphasizes current issues, future directions

Redes En Acción's National Steering Committee of leading authorities on issues related to cancer among the country's 35 million Latinos recently gathered to discuss the *Redes* initiative's past, present and future efforts to promote Latino cancer research, training and awareness.

Special guest and speaker Harold P. Freeman, MD, Director of the National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities, summarized the challenge for *Redes En Acción* and other programs designed for special populations:

"The challenge...is to understand the fundamental causes of health disparities related to cancer and develop effective interventions to reduce these disparities and facilitate them to the patient."

Addressing the 3rd Annual *Redes En Acción* National Steering Committee Meeting at an opening-night dinner and again at the initial session the following day, Dr. Freeman placed the NCI's efforts to address disparities in context.

"Poverty and cancer are a lethal combination," he said. "It's bad enough to

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Hispanic/Latino cancer and health authorities gather for the 3rd Annual *Redes En Acción* National Steering Committee Meeting.

Redes survey of physicians examines practices, attitudes

A lack of consensus exists among physicians, particularly Latinos, that clinical trials are good for their patients. That was among the findings of a nationwide *Redes En Acción* survey of Latino and primarily non-Hispanic white family physicians comparing attitudes and practices regarding cancer.

Among the physicians surveyed, only 53 percent of Latinos and 63 percent of non-Hispanic whites agreed that sufficient scientific value and benefits exist for them to refer patients to clinical trials. Forty-three percent of Latino respondents and 32 percent of non-Hispanic whites reported that they had never participated in clinical trials.

- ▶ A summary of the survey results was presented at the 3rd Annual *Redes En Acción* National Steering Committee Meeting by Eliseo Pérez-Stable, MD, Co-Principal Investigator of the *Redes* Northwest Regional Network Center.
- ▶ Of the 2,000 surveys mailed, completed responses were returned by 744 physicians - 304 Latinos and 440 others. The target audience, drawn from the American Medical Association master file, included internal medicine (40%), family medicine (40%) and gynecology (20%) specialists from California, Texas, New York, New Jersey, Florida and Illinois.

The questionnaires sought information about demographics, medical background, type of patients and language use in their practices, smoking cessation treatments, cancer screening practices, genetic testing and clinical trials.

Inside



To borrow a line from an old TV commercial, when Dr. Harold Freeman talks, people listen. At our recent National Steering Committee meeting, we had the opportunity –

and the good fortune – to listen to Dr. Freeman, a true champion of the disadvantaged in this country and a leading force in combating cancer among minorities and the underserved.

His presentations at our opening-night dinner and during the initial session of the meeting the next morning were a true highlight of the conference. For all that he has done for the underserved, he richly deserves the *Redes En Acción* Cancer Research Leadership Award. See the story and photos of Dr. Freeman, as well as our other honorees, singer/survivor Soraya and the family of the late educator Dr. Miguel Medina, on pages 1 and 5.

The steering committee meeting was also the setting for the presentation of the *Redes En Acción* Latino Physicians Survey results summary. The story of the survey, which looked at, among other things, cancer attitudes and practices of physicians (both Latino and non-Hispanic white), can also be found on page 1.

Redes En Acción researchers have been busy on other fronts, as well. On page 6 is an item on a new collaborative effort with the Susan G. Komen Breast Cancer Foundation. In this project, funded by the Komen Foundation's San Antonio Affiliate, the experiences of Latina breast cancer survivors will be described in their own words for an educational book designed to help other Latinas cope with the spectrum of breast cancer issues.

Also inside this issue are stories of other new publications available to help Latino cancer patients, survivors and their families: a how-to guide for support groups and a Spanish-language book addressing issues relevant to Latina cancer survivors.

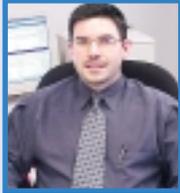
Amelie G. Ramirez, DrPH
Principal Investigator
Redes En Acción



RESEARCH

A Behavioral Approach

Frank Penedo, PhD
Miami, Florida



During his career working with older Latinos who have cancer and other chronic disease, Frank Penedo, PhD, has come across many characteristics of Hispanic/Latino culture that can both facilitate or prevent health promoting practices.

“There is a lot we still have to learn about Hispanic culture so we can identify what characteristics of our cultural values and our cultural identity may interact with health behaviors,” says Dr. Penedo, Assistant Professor in the Department of Psychology, University of Miami at the Sylvester Cancer Center, Division of Cancer Prevention and Control.

His current research is investigating the efficacy of group-based psychosocial interventions designed to improve quality of life and physical functioning in cancer patients. His work focuses on older prostate and head and neck cancer patients, and how stress can lead to further declines in immunity that we already see in older individuals.

Dr. Penedo started his research career in 1991 as an undergraduate student at the University of Miami working in studies

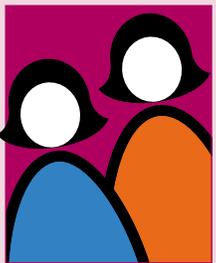
examining how stress can impact disease progression in HIV and cancer populations. The large Latino population in South Florida offered an opportunity to begin examining how Hispanic/Latino culture may influence these diseases. In 1999 he received his PhD from the University of Miami in Clinical Health Psychology, focusing on stress, coping and disease, with an emphasis on how psychological factors can impact immune function and overall health.

Along with other researchers in his field, Dr. Penedo believes that if we can show chronically ill individuals how to cope with stress - from very mild daily hassles to more severe events - we can then prevent further declines in immune function and aim to maintain a relatively healthy immune system, a condition that is particularly desired among cancer patients.

“We help patients understand that psychosocial interventions that help individuals cope with stress can be of great benefit to anyone living with a chronic condition such as cancer,” he says. “Advertising our work for what it is, a stress management program for individuals with cancer, generates more acceptability in the community. In fact, many participants tell us that our groups offer them the first opportunity to openly and comfortably speak about the challenges of being diagnosed and treated for cancer.”

Dr. Penedo firmly believes in the goals of *Redes En Acción*, advocating development of research opportunities at all levels for future generations of Latinos. “Assuming responsibility and mentorship of trainees at all levels that may be interested in Hispanic/Latino research, as well as identifying ways to engage Latinos in clinical trials are critical in order to increase the number of Latinos conducting cancer research,” he says.

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



TRAINING

Stressing Cultural Sensitivity

Maritza De La Rosa, MD
Brooklyn, New York



Cultural sensitivity is an issue that is vital in the practice of medicine, believes Maritza De La Rosa, MD, Acting Chairperson of Family Practice and Residency Program Director at The Brooklyn Hospital Center (TBHC). “No one can relate to you as well as someone who can speak your language and understands your culture,” the physician says. “Of course, there are even greater needs when one of my patients is facing a diagnosis of cancer.”

Dr. De La Rosa attended medical school in Puerto Rico, and later completed her family practice residency training in New York, where she eventually decided to remain. She joined TBHC in 1992, and since that time has been seeing patients in family practice. In addition, she is responsible for supervising a number of residents and medical students from Cornell and St. George Medical School as they rotate through the Department of Family Practice at TBHC.

During training, in addition to participating in medical evaluations, lectures and case presentations, students and residents go with Dr. De La Rosa on home visits. To provide a hands-on experience, she assigns her students a number of patients to interview and evaluate. In addition, residents, students and faculty participate in health fairs in the community throughout the year. “This helps us recognize problems and needs the community has in order for us to develop projects in which we can improve their health,” she says.

The medical students and residents that take part in Dr. De La Rosa’s training are at an advantage. Not only do they have an opportunity to work among a well-trained, devoted faculty and encounter cancer and a variety of other illnesses, but they’re exposed to an immense ethnically diverse population.

Dr. De La Rosa, who serves as a mentor to some residents, points out that the most prominent obstacle in providing Latino patients with the care they need is not being able to attract more Spanish-speaking physicians.

“You can teach people to be open-minded about many things, such as alternatives and approaches that different cultures may have, but patients ultimately prefer a physician with whom they can culturally identify,” she says. “If you are not familiar with the culture, you may not be able to understand the patient’s concerns and motives, especially if there is a diagnosis of cancer.” With this challenge in mind, she works to recruit more Spanish-speaking residents and encourages them to remain at TBHC.

Contributed by: *Erica Soto*
Redes En Acción Intern
Brooklyn, New York



AWARENESS

Speaking the Language

Steven Tobias, MA
San Antonio, Texas



When visitors stop by the American Cancer Society's Community Outreach Office on San Antonio's West Side, they notice something different: the sign over the door is entirely in Spanish.

The American Cancer Society (ACS) recognized that, for the predominantly Hispanic population in San Antonio, a barrier to accessing cancer information might be language. "This makes a big difference," says Steven Tobias, Program Manager for the Community Outreach Office. "Our sign in Spanish says to the community that we are here to help, that we have answers, that we provide hope."

A decade ago, the ACS had few materials or public service announcements (PSAs) in Spanish and few Latino employees, and struggled to do outreach to the local Hispanic community. Now the local chapter has expanded the Community Outreach Office in the primarily Latino neighborhood; 60 percent of the staff are Hispanic; and visitors can select numerous bilingual print and audio-visual materials.

"We have produced media campaigns, PSAs and a Spanish-only web page to target Hispanics, not only in San Antonio but

throughout Texas," Tobias says.

Tobias, who received his BA and MA from Southwest Texas State University in health education and health research, worked at the Texas Department of Health, Texas Health Network and Humana, Inc. before joining the local ACS office. In his community outreach position, he has been creative in disseminating cancer information and raising awareness. He goes to local churches, workplaces, health centers and community-based organizations to educate mothers, daughters and grandmothers about the importance of early-detection screenings, such as breast self-exams, clinical breast exams, mammograms and Pap tests. The information is given to them along with cancer information about proper nutrition, tobacco use, prostate cancer and other subjects.

For Tobias, the job allows him to create messages that will primarily be read and seen by Latinos. He has engaged in community outreach with individuals who, years after their exposure to a cancer prevention message, have come to his office for information about support groups and patient services such as wigs, prostheses and transportation services.

"It makes me feel like I help these people twice - once when they hear the message through the media or group presentation and the second time when they come for assistance."

Tobias is a member of the *Redes En Acci3n* South Central Regional Network and is involved with other cancer-related organizations in San Antonio.

"Working with cancer patients means more than just fulfilling a request for information," he believes. "It means being optimistic. If someone is diagnosed with cancer, we do have the answers, and we do have the progress and we have hope."

Contributed by: *Sylvia Castillo*
Redes En Acci3n Coordinator
San Antonio, Texas

Aiding Spanish-Language Callers

In 1978, with only a few bilingual staff members, the National Cancer Institute's Cancer Information Service (CIS) began taking calls in Spanish. Today, nationwide three Spanish Calls Centers - located in California, Florida and Texas - provide callers with the help they need in a language they understand.

As the source for the latest, most accurate cancer information for patients, the public and health professionals, the CIS and its trained information specialists respond to English- and Spanish-language callers via the toll-free telephone service (1-800-4-CANCER).

Last year more than 6,200 callers self-identified as Hispanic. Of these calls, 65 percent were conducted in English and 35 percent in Spanish. Compared with their English-speaking counterparts, the Spanish-speaking Hispanic callers:

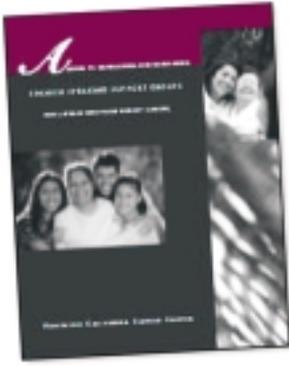
- ▶ Are members of the general public, as opposed to being a patient, family member or friend of a patient with cancer



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

- ▶ Call to request a referral to medical services instead of seeking general information about cancer
- ▶ Are usually high school graduates, as opposed to having some college education
- ▶ Find the CIS phone number from various print resources rather than from the Internet

For more information, data or statistics about callers to the CIS, including demographics, call the CIS at 1-800-4-CANCER, Monday through Friday, 9 a.m. to 4:30 p.m., and ask to speak to the research coordinator or partnership program manager.



Latina support group guide available

Research shows that women with breast cancer cope better when they receive emotional support in addition to medical treatment. Unfortunately, there are too few Spanish-speaking

breast cancer support groups available for Latinas.

To address this need, the Northern California Cancer Center (NCCC) recently published *A Guide to Developing and Sustaining Spanish-Speaking Support Groups for Latinas Who Have Breast Cancer*. In a comprehensive and practical reference publication, NCCC offers culturally sensitive how-to information, including guidelines on group facilitation issues and agency support concerns. The guide is intended to help develop additional and long-lasting support groups for the Latino community.

Designed for use by group facilitators and community organizations, this guide addresses the purpose and benefits of cancer support groups, including the importance of mutual support and understanding, and reducing emotional trauma, loneliness and isolation. It also includes guidelines for providing a safe and non-judgmental setting, communicating

effectively, helping with treatment side effects, and instilling hope and confidence.

This is a hands-on guide, formatted for sharing. The two parts are easily separated for ready access to the respective group.

Part I: The Guide for Support Group Facilitators addresses various aspects of developing and running Spanish-language cancer support groups, offering insights and skills for effective facilitation. Topics include the basics (infrastructure, location, time, eligibility), stages of group development, facilitator and group models, assessments, crisis counseling, and issues involved with death and dying.

Part II: The Guide for Community Organizations addresses the growing need for bilingual cancer support and the considerations and guidelines for starting a cancer support group program. Topics include infrastructure development; fund development; hiring and supervising group facilitators; building community partnerships; strategic planning, outreach and marketing; and recruiting and retaining group members.

To obtain a copy of the publication, contact the Northern California Cancer Center at 1-888-315-5988 or education@nccc.org, or visit www.nccc.org.

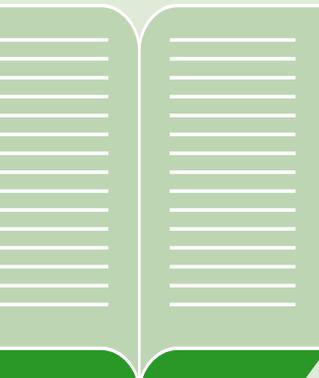
NCI book for survivors available *en español*

A new Spanish-language book for cancer survivors, developed by the National Cancer Institute (NCI), highlights issues relevant to Latinos, such as effective communication during follow-up care and the use of alternative medicines.

The publication, "*Siga adelante: la vida después del tratamiento del cáncer*," is a Spanish version of "Life After Cancer Treatment," which is part of a new series created by NCI for cancer survivors, their families and health professionals. The Facing Forward Survivor Series addresses what happens after cancer treatment, combining scientific information from health professionals with coping tips from cancer survivors.

The Spanish and English versions of the "Life After Cancer Treatment" publication address various concerns, including issues related to medical care, potential physical and emotional changes, social relationships, and life in the workplace.

To order books in the Facing Forward Survivor Series, call 1-800-4-CANCER (1-800-422-6237) or visit the web site at www.cancer.gov/publications.



New *Redes Co-PI* named in SE region

Edward J. Trapido, ScD, *Redes En Acción* Co-Principal Investigator for the Southeast Region, is taking a new position as Associate Director, Epidemiology & Genetics Research Program in the National Cancer Institute's Division of Cancer Control and Population Sciences.

During Dr. Trapido's absence, Frank J. Penedo, PhD, Clinical Health Psychologist and Assistant Professor at the University of Miami Department of Psychology and the Sylvester Comprehensive Cancer Center, is assuming the *Redes En Acción* Southeast Region leadership role.

Dr. Penedo, who has extensive experience in working with chronically ill older populations, teaches courses in the Psychology of Adult Development and Aging and is a member of the Geriatrics Research and Education Center at the Miami Veterans Administration Medical Center.

The Southeast Region of *Redes En Acción* is coordinated by the University of Miami in Miami, Florida.



Edward J. Trapido, ScD

Redes conference emphasizes current issues, future directions

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have cancer, but if you also are poor, which means you don't have knowledge, you don't have access, you don't have support systems, it makes it even more complex to have a lethal disease and have social problems that prevent you from obtaining possible solutions."

Dr. Freeman is also Associate Director of NCI as well as former chairman and present member of the President's Cancer Panel.

Another guest speaker, U.S. Congressman Ciro D. Rodriguez, commended *Redes En Acción's* leadership role in the war against cancer among Latinos and "for continuing to grow and develop...educating yourselves and

educating us (Congress).

"I want to congratulate you for your efforts in being right there in the war front," said Representative Rodriguez, who serves as Honorary Chairman of *Redes En Acción*. "You've done a great job and I want to personally thank you."

During the meeting, *Redes En Acción* Principal Investigator Amelie G. Ramirez, DrPH, presented a report on the initiative's achievements to date in promoting cancer research, training and awareness among the Latino population. Small-group breakout sessions then focused attention on possible courses of action *Redes En Acción* should follow in these efforts and in educating national

leaders on the initiative's activities as well as the need for addressing cancer issues of particular importance to Latinos.

Meeting participants also heard panel presentations by Gwendolyn Clark, Deputy Director of the Office of Minority Health, Health Resources and Services Administration (HRSA), and Robert Robinson, DrPH, Associate Director for Program Development, Office on Smoking and Health, Centers for Disease Control and Prevention (CDC). The presentations included overviews of HRSA and the CDC Office on Smoking and Health activities, as well as potential opportunities for future partnerships with *Redes En Acción*.

Redes awards presented for research, training, awareness

For the first time, *Redes En Acción* has presented awards to individuals who have made outstanding contributions to the fields of cancer research, training and awareness. The honors were bestowed during the National Steering Committee meeting.

Cancer Research Leadership Award

For his long-time commitment to special populations - America's medically underserved - in the war against cancer, Harold P. Freeman, MD, was presented the *Redes En Acción* Cancer Research Leadership Award. Dr. Freeman is Associate Director of the National Cancer Institute (NCI) and Director of the NCI Center to Reduce Cancer Health Disparities. He also is former chairman and present member of the President's Cancer Panel. In the award presentation, his vision for the American health care system - access to the best care available, regardless of race, income or social status - was cited.

Cancer Training Award

The late Miguel A. Medina, PharmD, was honored for his lifetime of service as a mentor, role model and tireless advocate for Latino students, scientists and health professionals. Dr. Medina was a retired Associate Dean and Professor Emeritus at the University of Texas Health Science Center at San Antonio, where he founded the Hispanic Center of Excellence and helped scores of young people seek and navigate the medical school system. His wife, Johnnie Word Medina, and family accepted the *Redes En Acción* Cancer Training Award.

Cancer Awareness Award

Soraya, who has made her mark in the entertainment field as a singer and songwriter, is also becoming well known for her efforts to spread the word to Hispanic women about the dangers of breast cancer. For these efforts, she received the *Redes En Acción* Cancer Awareness Award. The Colombian-born entertainer, a breast cancer survivor, is the Latina spokesperson for the Susan G. Komen Breast Cancer Foundation. She emerged from her own personal battle with the disease not only as a survivor but as a powerful and dedicated advocate.



(Top) Dr. Amelie Ramirez presents the *Redes En Acción* Cancer Research Leadership Award to Dr. Harold Freeman. (Bottom) Family members of the late Dr. Miguel Medina join Latina singer/survivor Soraya in accepting awards for cancer training and awareness, respectively. From left to right are Amy Medina, Johnnie Word Medina, Dr. Ramirez, Soraya, Sarah Medina-Pape and Brian Pape.



Redes, Komen work together on Latina breast cancer book

Redes En Acción National Network Center researchers and the San Antonio Affiliate of the Susan G. Komen Breast Cancer Foundation are teaming to develop a culturally sensitive, bilingual booklet of stories of Latina cancer survivors.

The publication will provide breast cancer educational information to underserved low-income Latina breast cancer patients and survivors, including anecdotal information about the spectrum of challenges: diagnosis, treatment, support, and coping physically and emotionally.

The project, titled *Nuestras Historias: Mujeres Latinas Sobreviviendo el Cáncer del Seno* (Our Stories: Latinas Surviving Breast Cancer), is funded by the Komen Foundation, San Antonio Affiliate. Amelie G. Ramirez, DrPH, Principal Investigator of *Redes En Acción*, will oversee development of the publication.

The project stems from a need for culturally relevant cancer educational materials, and specifically for materials that offer insight to the Hispanic/Latino experience. Hispanic/Latina survivors or patients recently diagnosed with breast cancer typically lack information regarding the challenges faced by women similar to themselves.

The booklet will offer emotional, spiritual and cultural support to help Latinas cope with and overcome breast cancer - from initial diagnosis to survivorship. Each story will examine the issues that confront Latinas from the perspective of women who have experienced breast cancer.

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