

Redes helps children find state-of-the-art therapies

Redes En Acción is spearheading a new National Cancer Institute-supported effort to boost enrollment of Latino children in leukemia clinical trials.

Based in the Lower Rio Grande Valley of Texas, the project will seek to increase recruitment of patients from the heavily Hispanic United States-Mexico border region into pediatric hematology / oncology studies.

"We have an opportunity to help the underserved and disadvantaged Latino population in the Lower Rio Grande Valley attain cutting-edge therapies," said Amelie G. Ramirez, project principal investigator. "We anticipate boosting recruitment rates for critical childhood and adolescent leukemia clinical trials by 20 percent or more."

Dr. Ramirez is principal investigator of *Redes En Acción* and Director of the Institute for Health Promotion Research (IHPR) at the University of Texas Health Science Center at San Antonio (UTHSCSA).

Leukemia is the most common cancer in children and adolescents in both the United States and Texas. About 30 percent of all childhood cancers are leukemia.

In South Texas, the incidence of childhood and adolescent leukemia is higher than in the rest of Texas and in the nation, according to the IHPR's *South Texas Health Status Review*, which identifies health disparities affecting whites and Latinos. In South Texas, the incidence of childhood and adolescent

leukemia is higher for Latinos (59 / million) than for non-Hispanic whites (48.7 / million).

In addition to guiding more Latino cancer patients to new therapies, the project is helping researchers gain important new information.

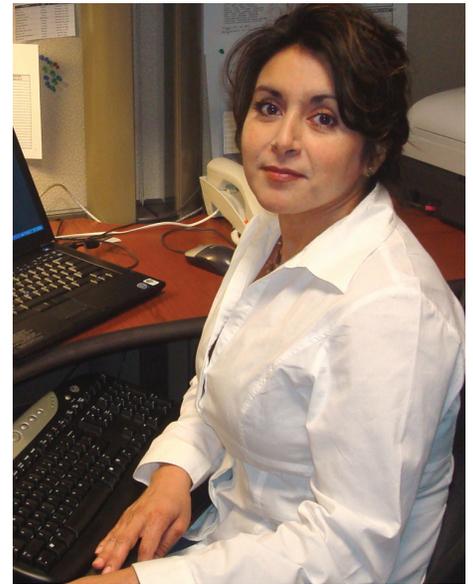
"Knowledge about risk factors for childhood and adolescent leukemia is limited," Dr. Ramirez emphasized, "and participation of disadvantaged populations and groups with higher incidence in clinical trials is absolutely critical."

The focal point of the project is development of a patient navigation (PN) program at UTHSCSA's Regional Academic Health Center in the Lower Rio Grande Valley to open new opportunities to offer clinical trials to more children and adolescents.

The navigator, Cynthia Wittenburg of the IHPR, is making patients' families and physicians aware of clinical trials and helping overcome barriers to participating in them. The PN program will allow investigators to improve enrollment in both therapeutic trials and cancer control studies.

In addition to working with medical and nursing staff and assisting patients and their families, Wittenburg is acting as a liaison with area pediatricians and other clinicians, providing information about pediatric clinical trials.

The intervention is also developing culturally sensitive, bilingual educational brochures for patients' families. The print materials, tested for readability, attractiveness, and message comprehension



Patient Navigator Cynthia Wittenburg

with the intended audience, will serve as an educational tool providing critical information about child and adolescent clinical trials.

Serving as co-principal investigators on the project are Luis Velez, MD, PhD, MPH, and Anne Marie Langevin, MD. Dr. Velez is an Assistant Professor of Epidemiology and Biostatistics at UTHSCSA and member of the IHPR team, and Dr. Langevin is an Associate Professor of Pediatrics at UTHSCSA and a principal investigator in the South Texas Pediatric Minority-Based Community Clinical Oncology Program.

The project, supported by a one-year NCI grant administered through *Redes En Acción*, could be extended if results appear promising.

Redes En Acción: The National Latino Cancer Research Network is a major Community Networks Program 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.

The *Redes Report* is produced quarterly by *Redes En Acción*: The National Latino Cancer Research Network, NCI Grant No. 1 U01 CA114657-01

T R A I N I N G

Evelyn Gonzáles, MA, Philadelphia, Pennsylvania

The value of partnership

For the past 10 years, in her role with the NCI Cancer Information Service's Partnership Program, Evelyn Gonzáles has been involved in individual and organization training efforts. She now directs the Partnership Program for the Atlantic Region, which serves Pennsylvania, New Jersey and Delaware.



The program provides training and technical consultation in program planning, implementation and evaluation to regional, state and local organizations striving to reach the medically underserved and ethnic minority communities with evidence-based cancer programming.

"We work collaboratively with institutions / organizations such as state health departments, cancer centers, NCI-funded

Community Networks Program partners like *Redes En Acción*, and other organizations that address the needs of the medically underserved and ethnic minority audiences," says Evelyn.

For the past 30-plus years, the Partnership Program has provided a network for NCI to disseminate the latest cancer research findings to communities in an effort to improve health care outcomes.

"Perhaps the most unique aspect of our program is the tailored consulting we provide to the organizations / institutions we partner with to implement and evaluate programs," Evelyn notes. "Our staff are highly trained public health advocates who are often brought in to assist with technical support in program planning efforts."

Organizations have a keen understanding of their clients and the barriers they face when seeking services, she says.

"The role of the CIS Partnership Program is to provide a new lens through which to view programs and services that target these clients. We offer resources (such as www.cancer.gov/espanol) and consultation to improve programmatic outcomes by using evidence-based approaches."

A W A R E N E S S

Marisa R. Mir, Houston, Texas

The voice of experience

As a fundraiser for the American Cancer Society, Marisa Mir was speaking at a colon cancer committee meeting when she noticed that some of the unusual symptoms she had been experiencing were listed in a colorectal cancer education brochure.

She scheduled a colonoscopy, where her doctor discovered a suspicious polyp, subsequently found to be a malignant tumor.

Five years later – and now in complete remission – Marisa is making the most of her experience with this terrible disease. As a program coordinator for the Anderson Network, a patient and caregiver support program of the Department of Volunteer Services at M.D. Anderson Cancer



Center, she oversees the institution's employee cancer support group and is currently developing support programs for caregivers of adult and pediatric cancer patients.

"As a survivor myself, the return I get from the work I do is immeasurable and at times a bit therapeutic, too," says Marisa.

"It is an overwhelmingly rewarding feeling to be able to offer and provide hope by connecting patients to others who have been through a similar experience and who can be their source of encouragement and knowledge through their dark journey."

She lists her most significant achievement as the inclusion of Spanish-language educational breakout sessions in the annual patient and caregiver conference.

"Because of this added component to our conference, we have opened the door to the Latino cancer community to learn from and ask questions of world renowned cancer experts," says Marisa, "arming them with information about new treatments, research findings and clinical trials that I hope will help create more open dialogue with their health care providers."

RESEARCH

Ana Navarro, PhD, San Diego, California

‘We need to ramp up our efforts’

In a research career dedicated to addressing cancer disparities, Dr. Ana Navarro has developed innovative community-based health interventions targeting San Diego’s Latino population, who represent both a low socio-economic level and a low level of acculturation.

She sees progress in the battle against disparities, particularly the increase in quality programs and in health professionals addressing disparities over the past two decades.

“Nevertheless, we need to ramp up our efforts, given the complexity of the issue and the evolving challenges,” she says. “Part of that ‘ramp up’ effort must include attracting and supporting more underrepresented scientists to conduct cancer research.”

Dr. Navarro, an Associate Professor in the Department of Family and Preventive Medicine at the University of California, San Diego (UCSD), has participated in research and community projects in the area of cancer prevention and control,



in particular early detection, tobacco-free communities, and nutrition cancer control.

Currently, she is UCSD principal investigator of the Comprehensive SDSU-UCSD Cancer Center Partnership, an innovative project to address cancer disparities through research, training and outreach. The five-year project is supported by the National Cancer Institute through the Minority Serving Institution-Cancer Center Program.

“This project will make inroads in cancer disparities research, increase the number of underrepresented scientists conducting cancer research, and directly benefit the health of our communities,” Dr. Navarro says.

During her career, Dr. Navarro, who received her doctorate degree from the University of Valencia in Spain, has received numerous awards for her contributions to the Latino community as a scientist and as a community volunteer.

NEW PROJECTS / NUEVOS PROYECTOS

Redes En Acción researchers will explore the knowledge, attitudes and behaviors of Latina women with regard to breast cancer genetic testing. The goal is to develop and pretest a survey that accurately assesses the factors that go into Latinas’ decision-making process.

Leading the project is Amelie G. Ramirez, DrPH, *Redes* principal investigator and Director of the Institute for Health Promotion Research (IHPR) at the University of Texas Health Science Center at San Antonio (UTHSCSA). Her team includes IHPR researchers Drs. Luis F. Velez, Patricia Chalela and Jennifer Salinas. José A. Pagán, PhD, Professor

of Economics and Director of the Institute for Population Health Policy at the University of Texas-Pan American (UTPA), is project co-leader.

Researchers will recruit Latina women in Texas’ Lower Rio Grande Valley to participate in a series of focus groups to evaluate their current knowledge, attitudes and behaviors related to breast cancer genetic risk and genetic testing. In a later phase, investigators will pretest a survey instrument to be developed based on focus group results to assess factors associated with breast cancer genetic testing among Latinas.

Because a clear understanding of Latinas’ knowledge, attitudes and

behaviors regarding breast cancer risk assessment and genetic testing is needed for the development of culturally appropriate interventions, this project is expected to meet a critical research need in this population. Researchers expect to use the findings to submit a National Cancer Institute (NCI) proposal utilizing the survey instrument for larger-scale studies and interventions.

The study is one of three pilot projects funded by NCI fostering cancer research in the Rio Grande Valley in a UTHSCSA and UTPA partnership. Dr. Susan L. Naylor, professor in the Department of Cellular and Structural Biology, is principal investigator of the UTHSCSA grant.



Latinos less likely to seek cancer info

Finding health information can be overwhelming. We have access to many, sometimes conflicting, sources of medical information that is constantly changing and coming at us from all directions.

There are more than 20,000 Web sites dedicated to health information alone. And, while there is much information out there, many wonder about its accuracy and how available it is to everyone.

Just because cancer information is available doesn't always mean it is accessible, especially for underserved populations such as Latinos. Numerous barriers and cultural factors can make seeking cancer information more challenging for this population than for others.

According to the latest data in the 2005 *Health Information National Trends Survey* (HINTS), which routinely collects nationally representative data about the American public's use of and access to cancer-related information, Latinos are less likely to seek cancer information than non-Latinos. About 37 percent of English-speaking Latinos and 17 percent of Spanish-speaking Latinos say they have looked for cancer information at least once, compared to 52 percent of non-Latinos.

HINTS also notes that language is a cultural factor that impacts the cancer information-seeking behaviors of Spanish-speaking Latinos; they are less likely to feel confident that they can obtain health information. If a person is not comfortable speaking English, it can be especially frustrating when searching for health information in a predominantly English-language health care system.

The HINTS 2005 results showed that, among Latinos who did seek cancer information, the vast majority experienced dissatisfaction with their search. Specifically, 67

percent of Spanish-speaking Latinos reported that their last cancer information search took a lot of effort, 55 percent said the information was difficult to understand, and 58 percent had concerns about the quality of the information they found.

To help overcome these barriers, the National Cancer Institute (NCI) has developed resources in Spanish for the public. If a family member, friend or neighbor is primarily Spanish-speaking, you can guide them to the NCI Web site in Spanish, www.cancer.gov/espanol.

There, individuals can find accurate, reliable, up-to-date cancer information they can trust. Whether you're seeking information about a cancer topic or doing background research on a health decision for yourself or someone close to you, the experience should be an easy and positive one.

Sometimes, though, what people want more than a Web site or booklet is to talk with someone who can answer their questions. The NCI Cancer Information Service (CIS) is available for patients and their families and the public toll-free at 1-800-4-CANCER (1-800-422-6237).

CIS is a source for accurate, personalized and confidential cancer information. Information specialists are available to answer questions in Spanish and English between 9 a.m. and 4:30 p.m. local time, Monday through Friday. You may also contact the CIS in Spanish by sending an email to nciespanol@mail.nih.gov.

The information specialists can also assist in finding appropriate materials and publications available online or by mail. Go to <https://cissecure.nci.nih.gov/ncipubs> to begin your search.

Empower and inform yourself, your family and others by using the resources NCI has to offer.

Tele-Workshop: Latinas & breast cancer



CancerCare will offer a free Telephone Education Workshop titled *El cáncer de seno y las mujeres hispanas* (Breast Cancer and

Hispanic Women) on June 9 from 1:30 to 2:30 p.m. ET.

The teleconference, to be conducted entirely in Spanish, is presented in collaboration with a host of organizations, including *Redes En Acción*. The workshop is **free** – no phone charges apply.

Expert speakers will discuss breast cancer in Latina women, current standard of care and new treatment approaches, Latinas and clinical trials, symptom and pain management, concerns of Latina women living with breast cancer, and more.

The program is made possible by an educational grant from Novartis Oncology. To register, click [here](#).

Reuters spotlights study led by Redes investigator

An article with Dr. Maria E. Fernandez as first author focuses on the effectiveness of using *promotoras de salud* to increase breast and cervical cancer screening among Latinas. Dr. Fernandez is *Redes En Acción* co-principal investigator for the Central Region.

The article, published ahead of print by the *American Journal of Public Health*, received attention from Reuters, a worldwide news agency.



Home visits from peers trained as health workers may encourage more low-income Latina women to get screened for breast and cervical cancers, suggests the new study led by Dr. Fernandez of the University of Texas Health Science Center in Houston.

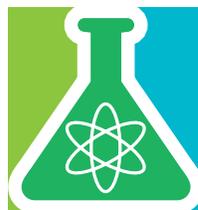
The Reuters Health article noted that “several studies have now shown the value of lay person health workers, according to the researchers. The programs may work because the information is tailored to specific groups, or because people have greater trust in peers from their own community.” Click [here](#) for the article.

Save the date for 2010 Latino Cancer Summit

The second National Latino Cancer Summit convened by *Latinas Contra Cancer* and co-sponsored by *Redes En Acción* is scheduled July 27-29, 2010 in San Francisco, California.

The summit will address cancer issues in the Latino community, including prevention, intervention and innovation. Participants will hear from experts, network with researchers, and speak with health care providers and community agency leaders and educators.

The successful inaugural National Latino Cancer Summit – *Science Meets Service, Moving Forward Together* – drew 325 registrants from across the United States. Participants included scientists, physicians, nurses, educators, community agency administrators, outreach workers, students, cancer survivors, and others.



For information about *Latinas Contra Cancer* and the 2008 Summit, click [here](#).

NHMA Web forum: health care reform

The National Hispanic Medical Association has been invited to participate in developing health care reform legislation and submit recommendations on reforming the system for inclusion into congressional bills by June 1.

To participate in one or more of four discussion groups, join the *NHMA Hispanic Provider Community Forum on Health Care Reform* [here](#), click on “create new account” and follow the instructions. For problems registering or logging on, call the help desk at 212-992-8706.

LAF SurvivorCare offers free services en español

The Lance Armstrong Foundation has made its *SurvivorCare* program available to the Spanish-speaking public. *LIVESTRONG SurvivorCare* is a free service that offers professional assistance with the everyday physical, emotional and practical challenges of cancer.

The service, available online or via telephone, offers one-on-one counseling service and help with financial, employment or insurance concerns, as well as information about treatment options and connecting to new treatments in development.

Getting one-on-one assistance from *LIVESTRONG SurvivorCare* is easy and confidential. Those interested may call 866-927-7205 or request help online at this [link](#).

AROUND REDES

Dr. Lucina Suarez, a *Redes En Acción* consultant since the program's inception in 2000, has been named Section Director for the Environmental Epidemiology and Disease Registries Section of the Texas Department of State Health Services (DSHS). She began her career with DSHS in 1983 and has served in various capacities within the epidemiology field.



Dr. Amelie G. Ramirez, *Redes En Acción* principal investigator, has been recognized for her achievements in addressing Latino health disparities:

► Honored by *Hispanic Business* magazine for her three decades of outreach, research and student training in working to eliminate health disparities, Dr. Ramirez was one of the "Women of Vision" spotlighted in the April 2009

issue.

► She was recently appointed to the Scientific and Prevention Advisory Council for the new Cancer Prevention and Research Institute of Texas (CPRIT). The advisory council is to provide strategic guidance on the development of cancer research in Texas.

► Dr. Ramirez was named one of the 2009 "Health Care Heroes" by the *San Antonio Business Journal*. She was honored in the Journal's Health Care Provider (non-physician) category.

Central Region

Dr. Maria Fernandez, co-principal investigator for the *Redes* Central Region, has been promoted to Associate Professor and received tenure. She serves on the faculty of the School of Public Health at the University of Texas Health Science Center at Houston.

Northwest Region

Dr. Anna Nápoles, program coordinator for the *Redes* Northwest Region, gave a presentation on *Advances in the Science and Art of Community Engagement* at the recent annual meeting of the Resource Centers for Minority Aging Research (RCMAR) in Birmingham, Alabama. The RCMARs are six centers funded by the National Institutes of Health, National Institute on Aging, National Institute of Nursing Research and the Office of Research in Minority Health to decrease health disparities among older, ethnically diverse adults by focusing research on health promotion, disease prevention and disability prevention.



The *Redes Report* is produced quarterly by *Redes En Acción*: The National Latino Cancer Research Network, NCI Grant No. 1 U01 CA114657-01

National Network Center

Principal Investigator

Amelie G. Ramirez, DrPH
University of Texas Health Science
Center at San Antonio
8207 Callaghan Rd. Ste. 353
San Antonio, Texas 78230
Phone: 210-562-6200
Fax: 210-348-0554
E-mail: ramirezag@uthscsa.edu

Regional Network Centers

Northeast RNC

J. Emilio Carrillo, MD, MPH
Co-Principal Investigator
Weill Medical College,
Cornell University
New York, New York
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

Central RNC

María Fernández, PhD
School of Public Health
University of Texas
Health Science Center
at Houston
Houston, Texas
Phone: 713-500-9626

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

We welcome your news items,
story ideas and suggestions.

Please send them to:

RedesEnAccion@uthscsa.edu

Visit us online at www.redesenaccion.org