



Redes places clinical trial issues high on priority list

With the heightened emphasis nationally on increasing minority participation in cancer research, *Redes En Acción* has responded with a host of related projects in recent months. The initiative is involved in

clinical trial issues on several fronts, including studies specifically aimed at learning more about Latino and other Special Populations' knowledge, attitudes and behaviors with regard to cancer genetics.

The wide-ranging *Redes En Acción* projects include:

The National Latino Genetic Community Consultation Network

Supported by the National Institutes of Health, this project is promoting public involvement among the Latino population in the decision-making process regarding genetic research and genetic health care. A major goal is to identify methods and opportunities to increase genetic research (both basic and behavioral) and educational needs among Latinos.

Redes En Acción researchers are developing a network of Latino stakeholders in genetics issues, and inviting a cross-section of key opinion leaders from the Hispanic community to a pilot community consultation June 22-24 in Washington, D.C. Primary purpose of the community consultation will be to identify and prioritize genetics issues on research, education and health care delivery affecting the Hispanic/Latino population.

National media campaign

In 2001-02, *Redes En Acción* produced several bilingual television and radio public service announcements (PSAs) and launched a nationwide public awareness campaign informing Latinos about the availability of cancer studies and benefits of participation in cancer clinical trials.

This year *Redes En Acción* will take the campaign, which in the past has relied on non-paid airtime donations by national TV/radio media, to another level of exposure. In this phase, the initiative plans to conduct a comparison study, using combinations of paid advertising spots and public relations in selected regions and the PSAs using only donated airtime in the control area. The project will evaluate the responses to these strategies in terms of inquiry phone calls from the Latino public to the Cancer Information Service.

Evaluation of recruitment materials

A bilingual educational booklet, *Buena Vida: A Guide to Family Cancer Research*, is the focus of a collaborative project involving *Redes En Acción*, the NCI Cancer Genetics Network (CGN) and Texas Cancer Genetics Consortium (TCGC).

The project will study response in the Latino community to the TCGC-funded and *Redes En Acción*-produced publication, a 24-page magazine-format booklet designed to educate the public about cancer clinical trials and increase enrollment of Latinos in the CGN Registry.

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Inside



With this issue, we're introducing a new series: profiles of our *Redes En Acción* Co-Principal Investigators (Co-PI), written in their own words in response to questions

about their careers and philosophies. And, since we're spotlighting the *Redes* Southwest Region in this issue, it seemed appropriate to launch the new series with a focus on Greg Talavera, MD, MPH, Co-PI of the Southwest Regional Network Center, in San Diego. You'll find the News Spotlight on the Southwest Region and Greg's responses to our Q&A on page 5.

We're always excited to learn of new milestones and achievements of our National Steering Committee (NSC) members. We're pleased to report on recent awards and accolades bestowed on two individuals who have served on the NSC since the inception of the *Redes En Acción* initiative: Venus Ginés, founder of Día de la Mujer Latina, and Armin Weinberg, PhD, Director of the Chronic Disease Prevention and Control Research Center at Baylor College of Medicine. See *Honores* on page 4.

This issue also reports on a number of activities in progress or recently concluded by *Redes En Acción* researchers. We start with a summary of projects related to cancer clinical trial issues of importance to the Hispanic/Latino population. This is our lead story on page 1.

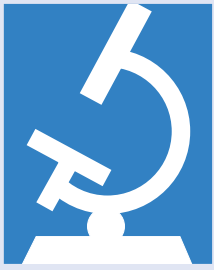
Other stories inside discuss the publication of a new bilingual educational booklet designed to raise awareness of Pap testing for Latinas and a new Cancer Information Service collaborative effort to educate Latinas in Houston about the importance of breast cancer early detection.

Amelie G. Ramirez, DrPH
Principal Investigator
Redes En Acción

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.

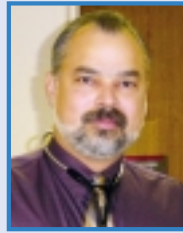
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RESEARCH

Promoting Participation

Tulio E. Rodriguez, MD
Chicago, Illinois



To receive the medical benefits we're all entitled to, participation in clinical trials by Latinos is vital, asserts Tulio Rodriguez, MD, a cancer investigator at Loyola University Chicago. Promoting greater Latino involvement in research is an issue he feels very strongly about.

"It is extremely important for all of us in the Latino community to understand that our participation in cancer research will provide us with the opportunity to receive the latest treatment options," he emphasizes. "We all deserve and should expect high-quality cancer medical care."

A native of Puerto Rico, Dr. Rodriguez has devoted much of his career to bone marrow transplantation research. He has published and lectured on a wide range of general medical and bone marrow transplantation topics, and is principal investigator in

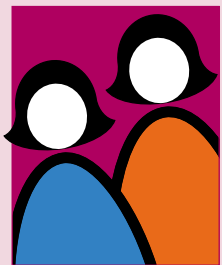
related studies.

Born in San Juan, Dr. Rodriguez earned his medical degree at Pontificia Universidad Católica Madre y Maestra School of Medicine in the Dominican Republic and completed his residency in Internal Medicine at San Juan Veterans Affairs Medical Center in Puerto Rico. He then completed fellowships in Hematology/Oncology and Bone Marrow Transplantation at the University of Texas Health Science Center at San Antonio. From 1988 to 1990, he was coordinator of health promoters for the Department of Health, Commonwealth of Puerto Rico.

He served as program director of the Bone Marrow and Peripheral Blood Stem Cell Transplantation program at Texas A&M University Health Science Center College of Medicine, where he also was co-director of the Apheresis Center for the National Marrow Donor Program. In addition to his current position at Loyola University Chicago, he has held faculty appointments in medicine at Texas A&M and Rush University College of Medicine in Chicago.

Dr. Rodriguez's current research interests include the development of post-transplant vaccines for hematological malignancies, including chronic lymphocytic leukemia, non-Hodgkin's lymphoma and multiple myeloma. He has also been working to develop safer strategies in bone marrow transplantation.

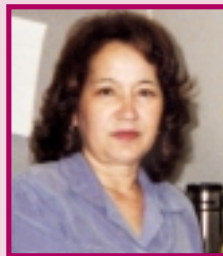
Contributed by: **Catalina Ramos, MD**
Redes En Acción Advisory Committee Member
Chicago, Illinois



TRAINING

Providing Support

Carmen Ortiz, PhD
San Francisco, California



When Carmen Ortiz, PhD, was diagnosed with breast cancer in 1988 at age 39, she couldn't have foreseen how it would change her life – and the lives of other Latina patients in the future. The experience placed her on a new career path managing and developing cancer support groups, which in turn has led to opportunities to train other survivors as group facilitators.

"I really believe in that model... training women who already have been through the experience of cancer to help other women who are experiencing a cancer diagnosis," says Dr. Ortiz. "Women in my groups often say that no one understands what they are feeling better than someone who has already been there."

For the past seven years Dr. Ortiz has been director of a Spanish-language support program in San Francisco that provides support groups, cancer information, individual counseling and advocacy services to Latina cancer patients. She also developed a support program at San Francisco General Hospital's Breast Clinic for newly diagnosed Latinas.

Dr. Ortiz, who was born in Río Piedras, Puerto Rico and grew up in Ohio, has a BA in psychology from San José State University and MA and PhD degrees from the California School of Professional Psychology. Her cancer career began as a psychotherapist at *La Clínica de la Raza*, in Oakland, where she counseled a woman newly diagnosed with breast cancer.

"What impressed me the most," Dr. Ortiz recalls, "was how much it helped her to just sit across from someone who already had battled cancer. I thought, maybe I could use my cancer experience in a positive way. Eventually, I left *La Clínica* to pursue cancer support work full-time."

She became involved with the Cancer Support Community in San Francisco and managed the support program for Latinas. She improved outreach and opened a second support group after tripling the number of Latinas attending the group.

In recent years, Dr. Ortiz's group facilitator training model has proven successful, providing the impetus for development of Spanish-language support programs in four other cities in the San Francisco Bay Area. As part of the project, she trained 10-12 Latina facilitators. She is presently pursuing funding to train additional group members, and is working on a Spanish-language facilitator training manual.

Dr. Ortiz herself was a trainee last year – mentored by **Anna Nápoles-Springer, PhD**, and **Eliseo J. Pérez-Stable, MD**, at the *Redes En Acción* Northwest Region office at the University of California-San Francisco. This year, she and Dr. Nápoles-Springer submitted a pilot research project to the *Redes En Acción* program entitled "Enhancing the Participation of Latinas in Breast Cancer Support Groups."

Contributed by: **Martha Rangel-Lugo, PhD**
Redes En Acción Coordinator
San Francisco, California



AWARENESS

Educational Focus

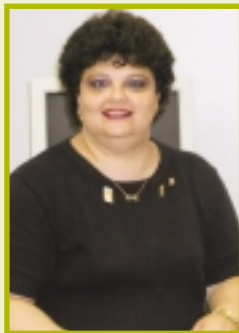
Sara Fainstein, PhD
San Diego, California

For Sara Fainstein, PhD, the prevalence of cancer has made educating Latinos in the San Diego South Bay community about cancer risks and prevention measures a priority.

“As I look around me, there are more people dealing with cancer than ever before,” she observes. For this reason she has dedicated most of her professional life to raising awareness about the benefits of regular cancer screening among Latinos.

A breast cancer survivor herself, Dr. Fainstein has experienced firsthand the traumatic effects of this disease on families such as hers. She was diagnosed with breast cancer in 1992 and again a year later. Her mother and maternal aunt also fought the disease.

Today Dr. Fainstein serves as Outreach Program Manager for the South County Satellite of the Wellness Community, a private, nonprofit organization serving the psychosocial and educational



needs of people from all walks of life, particularly Latinos affected by cancer.

She encourages patients to take an active role, in partnership with their health care team, to improve their quality of life and enhance their recovery. This proactive approach helps “patients and their families to feel empowered,” she says. It can take the form of searching for information, learning from other patients, researching the Internet, reading, asking questions and finding clinical trials – as opposed to being helpless and passive, allowing the health care team to make decisions without their input.

Through her work, Dr. Fainstein, a bilingual and bicultural psychotherapist by training, is able to provide much-needed support to cancer patients by teaching them visualization and relaxation, as well as other stress management techniques, to better cope with the ill effects of treatment.

Since the South Bay community has the highest concentration of Latinos in San Diego County, providing educational and support programs in Spanish is of the essence. “I am a true believer in educating the community,” says Dr. Fainstein. “Most people are eager to learn and get information, yet it is not always available to them in their language, or they are not familiar with the resources available in their own community.”

Dr. Fainstein deems it essential in reaching out to Latinos to provide them with the navigation tools, resources, education and support, “especially when they are journeying through the cancer experience.”

Contributed by: **Ana Talavera, MPH**
Redes En Acción Coordinator
San Diego, California

Breast health education program targets Latinas

The Hispanic Health Coalition of Houston, the Center for Research on Minority Health at University of Texas M. D. Anderson Cancer Center and the National Cancer Institute’s Cancer Information Service (CIS) South Central Region have teamed up to educate un- and under-insured Hispanic women in Houston about the importance of breast cancer early detection, including mammography.

This collaboration is the only program in Harris County (Houston) that specifically targets Latinas with breast health information.

The program uses *Health and Beauty from the Inside Out*™, a breast cancer curriculum developed by the University of Texas Medical Branch Health Care System, to train lay health educators to educate Latinas about breast health. After completing the training, the lay health educators are encouraged to provide educational sessions in their own communities to promote awareness among other Latinas about breast health.



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

The CIS provides logistical support, educational materials, give-aways and evaluation tools to support the sessions in the community. The Hispanic Health Coalition adapted and translated the curriculum, and provides the training to lay health educators. The training is provided in a culturally appropriate manner consistent with traditional Latino values and beliefs.

Since October 2001, 31 lay health educators have been trained to conduct the *Health and Beauty* education sessions in their communities. The project attained its goal of educating 200 Latinas with breast health information by the end of November 2002.

This project is funded by an American Cancer Society Making Strides Against Breast Cancer Community Partnership Grant.

For more information about breast cancer resources for Latinas, contact the CIS by calling 1-800-4-CANCER or by logging on to the National Cancer Institute’s web site at www.cancer.gov.

HONORES

Awards and Achievements

► **Venus Ginés**, a member of the *Redes En Acción* National Steering Committee, has been the focus of considerable attention lately. First, she was featured in a fall 2002 issue of *Atlanta Woman* magazine. Then, during the San Antonio Breast Cancer Symposium in December, she was honored by AstraZeneca Pharmaceuticals with their national Visions of Hope award.



Venus, founder of *Día de la Mujer Latina*, an annual health fair, was one of six individuals placed in the spotlight by *Atlanta Woman* in a section titled “How Do You Define Success?” Each received a full-page photo-and-story spread.

The article recounts, in her own words, Venus’s inspirational story of battling breast cancer and lupus, and the impact those challenges have had on her life and her aspirations for a career in law.

“I didn’t go to law school after all,” she said. “I started an annual health fair for Latina women. Success now means that every year I get to help save more and more lives.”

Recognition of her efforts has come in many forms, including the Visions of Hope award, granted by AstraZeneca Pharmaceuticals to a select group of women. In announcing the award, the pharmaceutical company told Venus she was chosen “for your outstanding contributions to the fight against breast cancer within your community.”

Redes En Acción would like to add our heartfelt congratulations to Venus for these honors and for her success with the *Día de la Mujer Latina* program.

► **Armin D. Weinberg, PhD**, *Redes* National Steering Committee member, has been honored by the American Cancer Society (ACS), the nation’s leading voluntary health agency. The ACS presented its 2002 Humanitarian Award to



Dr. Weinberg and Lovell A. Jones, PhD, co-founders of the Intercultural Cancer Council. Dr. Weinberg is a professor of medicine and director of the Chronic Disease Prevention and Control Research Center at Baylor College of Medicine. The Humanitarian Award honors individuals who have made outstanding improvements in human welfare and social reform, impacting the cancer problem in medically underserved populations.



Daniel Glimpse-Medina (center), who served an internship with the Northwest Regional Network Center last summer, takes part in a training session conducted by the Cancer Information Service (CIS), California office. The training included information about the Northern California Cancer Center Registry, the National Cancer Institute and the CIS Partnership Program, Information Service, Cancer Facts and Figures, Hispanic caller characteristics, Breast Cancer Early Detection Program and clinical trials. Shown with Daniel are **Edmundo Nevel** (left), Bilingual Information Service Supervisor, and **Titas Marquez**, Information Service Co-Manager, both of the CIS California office.

continued from page 1

Breast Cancer Genetics Survey

Redes En Acción recently completed the first phase of the Breast Cancer Genetics Education Materials and Programs Development Project, which was funded by the Susan G. Komen Breast Cancer Foundation. In this phase, researchers developed a culturally appropriate and tailored survey to collect breast cancer genetics knowledge, attitudes and behavior among Latino, African American, Asian American, Appalachian and Native American women.

In subsequent phases of the project, plans call for administration of the survey, assessment of the collected data, and design and dissemination of customized breast cancer genetic educational materials among the five minority ethnic populations.

Scientific publications

Redes En Acción researchers are working on several manuscripts. One describes the literature to date on challenges to the identification and recruitment of minority populations to cancer clinical trials. Another paper is detailing the experiences of the Cancer Genetics Network’s education activities and providing recommendations for a national education policy on cancer genetics.

Yet another manuscript will discuss Latino and non-Hispanic physician knowledge, attitudes and behaviors regarding clinical trial recruitment and their patients. Data from this paper are drawn from a national survey of physicians recently conducted by *Redes En Acción*.

Some of these cancer research projects have been reported in previous issues of the *Redes Report*. We’ll continue to update readers on these and provide greater detail on new and existing projects in future issues.

NEWS SPOTLIGHT

Southwest Region

New pilot projects

Among the recently approved *Redes En Acción* pilot research projects, a psychosocial study involving Latino cancer patients is directed by an investigator in the *Redes* Southwest Region.

Martin Alberto Perez, PhD, of the City of Hope National Medical Center in Duarte, California, is Principal Investigator of a study titled “Coping and Quality of Life in Latino Cancer Patients.” The project will explore the relationship among cancer beliefs, coping and quality of life, and help identify what styles of coping and aspects of quality of life are most important for Latino cancer patients.

From the Northeast Regional Network Center (RNC), **Ana Natale-Pereira**, MD, is Principal Investigator of “A Community Intervention to Improve Colorectal Cancer Screening Rates among Latinos.” The project, led by Dr. Natale-Pereira, of the New Jersey Medical School, Newark, NJ, aims to promote colorectal cancer screening and early detection through education and by facilitating access to screening resources.

In addition to the Southwest Region’s new pilot project, a minority supplement has been approved for funding. **Maria Luisa Zúniga**, PhD, who is serving a junior faculty mini-sabbatical with the Southwest RNC, will study “Barriers to Cervical Cancer Screening for Latina Women.”

CIS training institute

Redes En Acción’s Southwest Regional Network Center (RNC) participated in the Partner Training Institute conducted by the

Cancer Information Service (CIS) at the University of Southern California/Norris Comprehensive Cancer Center in Los Angeles. **Ana Talavera**, MPH, Southwest RNC Coordinator, delivered a presentation on the “Burden of Cancer and Barriers to Clinical Trials for Hispanic/Latinos in the United States.”

The training session also gave participants an opportunity to view public service announcements developed by *Redes En Acción* promoting involvement of Latinos in cancer clinical trials.

An interactive session, the Partner Training Institute focused on providing the latest and most accurate cancer information to CIS partner organizations that reach out to minority and medically underserved populations who traditionally don’t seek health information through the CIS.

Redes PSAs in the news

The *Redes En Acción* Southwest Regional Network Center and local partners the University of California, San Diego (UCSD) Cancer Center and Fox Television Network affiliate FOX6 recently joined forces to educate the San Diego Latino community on the importance of participating in cancer clinical trials.

The *Redes En Acción*-produced public service announcements promoting Latino cancer research involvement were the focus of a news story developed by reporter **Eric Collins** of the San Diego Fox Network affiliate.

“I had no idea Latino participation in cancer trials amounted to less than 6 percent when compared to participants from other racial/ethnic groups,” Collins said. “That eye-opening statistic made me realize how important it was to get the information out to the Latino community, especially in an area like San Diego County.”

For the piece, Collins interviewed *Redes En Acción* Co-Principal Investigator **Dr. Gregory Talavera** and **Dr. Georgia Sadler**, Associate Director of Community Outreach with the UCSD Cancer Center.



FOCUS: *Redes* Co-Principal Investigator Gregory Talavera



Gregory Talavera, MD, MPH, Co-Principal Investigator for the Southwest Region, was recently promoted to Associate Professor in the Graduate School of Public

Health, Division of Health Promotion at San Diego State University.

Briefly describe the primary project you’re currently working on.

I’m the Principal Investigator for “Project SOL: Smoking Cessation for Latinos.” This study is a randomized clinical trial exploring the effectiveness of a culturally and linguistically appropriate smoking cessation program for Spanish-speaking Latinos using the community health worker (*promotora*) model. This study takes place in the community health care setting.

What are your major areas of research interest?

I’ve focused most of my research career on managing

programs focusing on cardiovascular disease, cancer prevention and recruiting Latinos into clinical trials. During the early part of my career, I practiced medicine in the Spanish-speaking, underserved communities of San Diego’s border region. As a family practitioner, I came to understand the culture-specific beliefs that serve as barriers to quality care for Latinos. Now I am focused on documenting and addressing these culture-bound barriers among Latinos. This effort requires knowledge of the language and culture unique to our region of the country, knowledge and trust of the collaborating community, and the design and testing of innovative strategies for health promotion in the Latino community.

What do you consider your most notable achievement?

I think my most notable achievement is the number of research interventions that have become institutionalized in the organizations that we have collaborated with.

Who has inspired you most in your work – and why?

I have always been socially conscious in my work. Ever since my older brother took me in the summers to work in the California farm worker movement back in the ‘60s, I have realized the importance of giving back to the community. My brother had given up his comfortable and prestigious job with the aerospace industry to work for Cesar Chavez and the grape boycott. This act caused me to rethink my goals and motivation in life. I came to realize that making money

in a job simply for financial gain was not very rewarding. Now I try to apply my skills in the community I came from in order to improve their health and welfare.

What are the most important issues related to Latinos and cancer?

One of the most important issues that affect Latinos related to cancer is that of culture-bound beliefs. These are beliefs and practices that prevent Latinos from participating in cancer prevention and control. Many immigrant Latinos come from a health care system that does not promote clinical preventive services, so when they arrive in the U.S. they don’t usually think of prevention. In addition, many Latinos, especially women, put their family before their personal health, so they don’t take the time and resources to get clinical preventive services like breast or prostate cancer screenings.

What single piece of advice would you give a young Latino who aspires to a career in the cancer field?

The same message that was given to me when I was young boy passing out flyers in front of Safeway stores. Get the most education and skills that you can and give back to the community that you come from.

What do you hope will be your legacy?

That my work and community efforts will somehow be remembered by the students and colleagues that I have worked with.

Redes produces bilingual cervical cancer booklet

Redes En Acción researchers from the National Network Center have written and produced a new publication to educate Latinas about cervical cancer and the importance of regular Pap testing.

The booklet, *Buena Vida: Protecting Yourself from Cervical Cancer*, is a four-color, 24-page magazine-style publication presenting information in Spanish and English. The print piece was produced by the Chronic Disease Prevention and Control Research Center, Baylor College of Medicine, as a component of a Centers for Disease Control and Prevention-funded project.

In a largely graphics-oriented format, the *Buena Vida* booklet provides basic information about cervical cancer, including the risk factors, prevention, testing, treatment and support. Also included is resource information for readers who wish to learn more about the disease.

As in previous publications in the *Buena Vida* series, which cover such topics as breast cancer and clinical trial participation, the booklet presents photos and comments of “role models” – real-life Latinas who express their motivations for being tested regularly for cervical cancer.

To view the *Buena Vida* cervical cancer publication, visit the *Redes En Acción* web site at www.redesenaccion.org.



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