



Redes En Acción

The National Latino Cancer Research Network

Report On
The Sixth Annual
Redes En Acción
National Steering
Committee Meeting

August 2-4, 2006
San Antonio, Texas

www.redesenaccion.org



Report on
**The 6th Annual
Redes En Acción National Steering Committee Meeting**
 August 2-4, 2006 • San Antonio, Texas

Redes En Acción: The National Latino Cancer Research Network is a major Community Networks Program initiative supported by the National Cancer Institute's Center to Reduce Cancer Health Disparities. 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.

Table of Contents

EXECUTIVE SUMMARY

- 3** Moving forward together: Partnering for change
- 3** Meeting Agenda

FEDERAL PARTNERS

- 4** NCI panel offers partnership ideas
- 4** Cancer centers address disparities

COMMUNITY/NATIONAL PARTNERS

- 5** Community discussion focus: Effecting change
- 5** Nonprofit panel offers collaboration insights
- 5** National panel gives partnering advice

GUEST SPEAKERS

- 6** Dr. Hawk: 'One of our highest priorities'
- 6** Dr. Reed: 'Driving down the burden'
- 6** Dr. Rios: 'Finally coming around'

RESEARCH

- 7** Reporting on pilot project findings
- 7** Success stories highlight 'Redes effect'
- 8** National Steering Committee



*Redes En Acción wishes to thank
 Susan G. Komen For the Cure, a major
 sponsor of the 6th Annual National
 Steering Committee Meeting.*



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EXECUTIVE SUMMARY

Moving forward together: Partnering for change

In *Redes En Acción's* rich and diverse history, collaboration has always been a key to our success. From the beginning, we have recognized and valued the relationships that have helped us make a difference as we strive to reduce cancer health disparities in Latinos. Our role over the years has evolved into an engine for research, a generator of data, a cultivator of knowledge and a pipeline for training young investigators.

Because none of this would be possible without partnerships, collaboration seemed the natural choice for the theme of this year's National Steering Committee (NSC) meeting. NSC members heard from a diverse group of speakers and panel participants who offered informative and enlightening overviews of their organizations and activities. Even more exciting, their presentations were often packed with inspiring ideas for partnering opportunities. We heard from our national partners, cancer centers, nonprofits, volunteer organizations and community / advocacy groups – many of whom work deep in the communities that need them the most – about searching out and fostering significant alliances, improving access to care and translating research into practice.



Dr. Ernest Hawk of the National Cancer Institute (NCI) gave the keynote address on the role of the cancer centers in addressing disparities, emphasizing that

changing the future depends on the training we are doing now.

Driving down the cancer burden for all was the focus of Dr. Eddie Reed's talk on how we can best work with the Centers for Disease Control and Prevention (CDC), keeping in mind complex issues such as race, ethnicity and biology, as well as economic, cultural and environmental factors, when addressing cancer disparities.

Once again, Dr. Elena Rios from the National Hispanic Medical Association (NHMA) gave us the view from Washington, DC in her luncheon address that provided a comprehensive overview of policy challenges in our nation's capital. We also viewed a touching tribute to our dear friend and tireless advocate Soraya,

who lost her battle with breast cancer last year.

Updates on our pilot projects had a new twist this time. In addition to traditional status reports, we heard from people on how *Redes En Acción* has helped them in their careers – what we ultimately dubbed “the *Redes* effect,” illustrating the far-reaching impact on people's lives and work.

That brings us full circle to our relationships, with one another as professionals and advocates, and with the communities that we serve.

By thinking deeply about what we can do to reduce the burden of cancer health disparities among Latinos and all citizens, by building partnerships and reaching within ourselves and out to others, by sustaining an ongoing dialogue on how we can reduce and ultimately eliminate cancer health disparities among Latinos and others, our voices are growing stronger. Together our voices will forge new and vital connections, and for that we are immensely grateful.

Amelie G. Ramirez, DrPH
Principal Investigator
Redes En Acción

6th Annual *Redes En Acción* National Steering Committee Meeting

Wednesday, August 2

6:00 – 8:00 p.m. Reception & Registration

Thursday, August 3

8:00 – 8:30 a.m.
Continental Breakfast

8:30 – 9:00 a.m.

Welcome/Meeting Overview

Amelie G. Ramirez, DrPH

9:00 – 9:30 a.m.

Redes En Acción: Looking Back, Moving Forward

Amelie G. Ramirez, DrPH

9:30 – 9:45 a.m.

Community Networks Program Initiative

Roland Garcia, PhD, Program Officer, Center to Reduce Cancer Health Disparities, NCI

10:00 – 10:45 a.m.

Keynote Address: Role of the Cancer Centers in Addressing Disparities

Ernest T. Hawk, MD, MPH, Director, Office of Centers, Training and Resources, NCI

10:45 – 11:45 a.m.

Panel: Community / Advocacy Organizations: Effecting Policy Change

Moderator: María Fernández, PhD

Panel Participants: Sylvia Garcia Rickard, Director, Utah Breast Cancer Network; Venus Gines, MA, CEO & Founder, Dia de la Mujer Latina, Inc.; Maria Carolina Hinestrosa, MA, MPH, Executive Vice President for Programs and Planning, National Breast Cancer Coalition; Lupe Salazar, MD, Acting Instructor, Oncology, Fred Hutchinson Cancer Research Center, University of Washington

12:00 – 1:30 p.m. Lunch

Washington Perspective: Policy Challenges

Elena Rios, MD, MSPH, President & CEO, National Hispanic Medical Association

1:30 – 5:30 p.m.

National Partnerships: How Can We Work Together?

1:30 – 2:00 p.m.

Working with the CDC

Eddie Reed, MD, Director, Division of Cancer Prevention & Control, CDC

2:00 – 3:00 p.m.

Panel: Collaborations with National Groups

Moderator: Gregory A. Talavera, MD, MPH

Panel Participants: Edward Zuroweste, MD, Medical Director, Migrant Clinicians Network; Armin D. Weinberg, PhD, Co-Founder, Intercultural Cancer Council; Member, C-Change

3:15 – 4:30 p.m.

Panel: Collaborations with Nonprofit Organizations

Moderator: Amelie G. Ramirez, DrPH

Panel Participants: Cheryl Y. Kidd, MPH, Director, Education, Susan G. Komen For the Cure; Jerome W. Yates, MD, MPH, National Vice President, Research, American Cancer Society; Erica Childs, MPH, Assistant Director, Evaluation and Outreach, Cancer Research and Prevention Foundation; Andy Miller, MHSE, CHES, Director of Survivorship, Lance Armstrong Foundation

4:30 – 5:30 p.m.

Panel: NCI Partners: Collaborating for Effective Outreach

Moderator: Eliseo J. Pérez-Stable, MD

Panel Participants: Diana D. Jeffery, PhD,

Program Director, Office of Cancer Survivorship, NCI; Rachel Ballard Barbash, MD, MPH, Associate Director, Applied Research Program, NCI; Ed Trapido, ScD, Associate Director, Epidemiology and Genetics Research Program Division of Cancer Control and Population Sciences, NCI; Ludmila Cofta-Woerpel, PhD, Senior Research Coordinator, NCI's Cancer Information Service

Friday, August 4

8:00 – 8:30 a.m. Continental Breakfast

8:30 – 9:30 a.m.

Panel: Cancer Centers: Partnering to Address Disparities

Moderator: Frank J. Penedo, PhD

Panel Participants: Cathy Meade, PhD, RN, Professor, H. Lee Moffitt Cancer Center and Research Institute; Electra Paskett, PhD, Professor, Ohio State University Comprehensive Cancer Center; Isabel Scarinci, PhD, MPH, Associate Professor of Medicine, University of Alabama, Birmingham

9:30 – 11:30 a.m.

Panel: Pilot Projects: Promoting a Latino Cancer Research Agenda

Moderator: Eliseo J. Pérez-Stable, MD

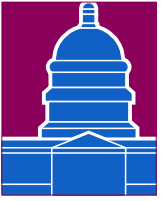
Panel Participants: New results: Concepción Díaz-Arrostía, MD; Tomás Nuño, MA (for Francisco Garcia, MD, MPH); Martha Martinez, PsyD; Debbie Salas-Lopez, MD; Wendy Lorizio, MD, MPH (for Elad Ziv, MD); Success stories: Isabel Scarinci, PhD, MPH; Ana Natale-Pereira, MD; Ana Maria Lopez, MD, MPH

11:30 a.m. – Noon

Meeting summary
Meeting evaluation

Noon

Adjournment



FEDERAL PARTNERS

NCI panel offers partnership ideas

Responding to a mandate for initiatives of the Community Networks Program to establish collaborative agreements with at least four divisions of the National Cancer Institute, panel participants answered the question, "How can we develop a specific partnership with the NCI?"

"Think big," suggested Diana Jeffery, PHD, Program Director, Office of Cancer Survivorship, NCI. "Big projects that can work on the public health of the whole country. An umbrella type of issue is to push the agenda for survivors. You can help educate us about the pressing needs in your communities to make sure we have your agenda on our agenda."

Ed Trapido, ScD, Associate Director, Epidemiology and Genetics Research Program Division of Cancer Control and Population Sciences, NCI, emphasized serving on committees, "because that's where you can have an impact on the kinds of things that happen." New directions are also on the horizon with the need "to look more globally." Impact missions by the Office of International Cancer Control to low-resource countries "are going to need people with a particular area of expertise who can make a time commitment of



(L-R) Drs. Diana Jeffery, Eliseo Pérez-Stable, Rachel Ballard Barbash, Ed Trapido, Ludmila Cofta-Woerpel

anywhere from a week to several months."

Rachel Ballard Barbash, MD, MPH, Associate Director, Applied Research Program, NCI, reiterated the global theme in describing meetings with countries in Southeast Asia and Latin America: "There is an international collaboration to identify and develop measures related to tobacco, physical activity and diet. United States investigators can help to move this forward." Closer to home, she said, "we work with a number of national organizations to improve the surveillance data in cancer control."

Ludmila Cofta-Woerpel, PhD, Senior Research Coordinator, NCI's Cancer Information Service, discussed the role of the CIS in working with *Redes En Acción* on its 2007 television public service announcement campaign that, when launched later this year, will air in target areas with a high density of Latinos. "We will provide *Redes* with call data and demographics of callers," she said. "It would be a great idea for the *Redes* regional PIs to get in touch with the CIS regional offices to see how they can best work together to address Latino cancer needs in their respective areas."

Cancer centers address disparities

"Collaborations, collaborations, collaborations," stressed Cathy Meade, PhD, RN, Professor, H. Lee Moffitt Cancer Center and Research Institute, in a panel presentation on "Cancer Centers: Partnering to Address Disparities." Tapping into "the media, local grassroots stakeholders, even the police department, would provide a much greater impact than the usual types of partners," she said. "We need to think outside the box."

Electra Paskett, PhD, Professor, Ohio State University Comprehensive Cancer Center, commended *Redes En Acción* for its hard work. "You really lead the way for community network programs."

She suggested that, when "pushing our cause to the financial decision-makers, we have to use their vocabulary. Our goals are not necessarily the same as the administration's. They have their goals and we have our goals, and we try to blend." She also urged cancer centers to "quit giving lip service and actually put the dollars behind increasing accrual of minorities to trials. The money has to come from somewhere, so why can't it come from developmental money in cancer center grants?"

"In times of lean funding," added Isabel Scarinci, PhD, MPH, Associate Professor, University of Alabama at Birmingham, Division of Preventive Medicine, "the Minority Health and Research Center is a great model for us to follow in terms of how much we can do with very limited funding." The center focuses on an integrated program of research, training and



(L-R) Drs. Frank Penedo, Cathy Meade, Isabel Scarinci, Electra Paskett

outreach. "First we serve the community and then we ask them to participate in research. We establish partnerships from grassroots to national organizations.

"At UAB," she said, "there are no boundaries between departments or centers. We work together. You need expertise in foreign language, they work with you, and that has been very helpful to us."

Collaborations "take time, patience and resources," reminded Dr. Meade. "But we can collaborate on community outreach, connecting our research to the community and sharing our models for outreach. The community is where the action is."



COMMUNITY/NATIONAL PARTNERS

Community discussion focus: Effecting change

Making sure that “voices are not left unheard” was the focus of “Community / Advocacy Organizations: Effective Policy Change” presented to National Steering Committee members.

“Breast cancer needs to become a political priority,” said Maria Carolina Hinestrosa, MA, MPH, Executive Vice President for Programs and Planning, National Breast Cancer Coalition, noting the difficulty in persuading policymakers. Coalition efforts paid off with a legislative expansion to Medicaid that offers treatment to women screened through their program. “In a year when no one thought anything could happen, this was a major success,” she said.

Lupe Salazar, MD, Acting Instructor, Oncology, Fred Hutchinson Cancer

Research Center, University of Washington, stressed the need to increase the diversity of the investigator pool. “We’re actually identifying well-known advocates with ties to different groups in our community to help build relationships with cancer patients, their families and their extended support groups.”

Venus Gines, MA, CEO and Founder, *Dia de la Mujer Latina*, Inc., offered: “We started to work with the CDC in putting together data we were getting from the women. We need someone who can run with it and put it into a funding mechanism.”

Sylvia Garcia Rickard, Director, Utah Breast Cancer Network, discussed her group’s efforts in lobbying legislators in Idaho and Utah,

including helping to write the state’s first cancer action plan. “There are so many barriers out there you have to take them one at a time, and that’s what we’ve done,” she said. “It’s not just about breast cancer, it’s about helping the disparities groups get help.”



(L-R) Sylvia Garcia Rickard, Venus Gines, Maria Carolina Hinestrosa, Dr. Lupe Salazar

Nonprofit panel offers collaboration insights

NSC members heard about the challenges of implementing innovative programs in “Collaborations with Nonprofit Organizations.”

“In the most medically advanced nation on earth, how can it happen that certain women don’t have access to the best care available?” asked Cheryl Kidd, MPH, Director, Education, Susan G. Komen for the Cure. The Komen Foundation works with dozens of its member organizations, she says, “to embrace what we call at Komen the dynamic force of many, by collaborating to accomplish what no one group can do alone.”

“These aren’t just medical problems, they are social problems,” offered Jerome Yates, MD, MPH, National Vice President, Research, American

Cancer Society. “We are trying to address the issue of a bedrock insurance plan, whether it’s Medicare, universal health, single payer, that would at least eliminate that barrier.”

“We have a lot of programs that aren’t reaching the underserved as well as they could be,” said Erica Childs, MPH, Assistant Director, Evaluation and Outreach, Cancer Research and Prevention Foundation (presenting for Carolyn Aldigé, President and Founder). The research program, however, is a “great opportunity. We have the funding for roughly 20 small grants and fellowships per year, good for fledgling researchers.”

Andy Miller, MHSE, CHES, Director of Survivorship, Lance Armstrong Foundation,

said that the LAF seeks out national partners “that we feel bring a complementary competency to the table.” Latino-focused programs include the family-oriented Wonders & Worries and *promotora* training in partnership with Texas educational institutions.



(L-R) Cheryl Kidd, Dr. Jerome Yates, Erica Childs, Andy Miller

National panel gives partnering advice

Working effectively with national partners was the theme of “Collaborations with National Groups,” a panel that gave pointed advice to NSC members about maximizing resources and techniques.

Comparing partnerships to a “two-way street,” Armin Weinberg, PhD, Co-Founder of the Intercultural Cancer Council and member of C-Change, explained that collaborations are “like any kind of relationship. They require maintenance and – being one of the partners – so will you.” Speaking with one voice, he said, is “incredibly important.”

Bringing the Collegiate Cancer Council – a group of mentored students from around the country – into the ICC was part of their effort to help

them establish national chapters. “If any of you are interested, we would be happy to help you plant those seeds in communities, because you are directly helping address how to get young people engaged.”

Edward Zuroweste, MD, Medical Director, Migrant Clinicians Network, described the network’s collaborations with CDC and NCI, as well as local programs such as health departments and migrant community health centers, in addressing the challenges of a mobile and underserved population.

He directed NSC members to the group’s Web site (www.migrantclinician.org), which has a “tool box” to help clinicians “navigate through the maze,” including a resource database with 289 links to related cancer care and 42 links for financial assistance. The bottom line, he said, is

“organizations that bring us all together will certainly help in improving the health care of the people we serve.”



(L-R) Drs. Gregory Talavera, Armin Weinberg, Edward Zuroweste



GUEST SPEAKERS

Dr. Hawk: 'One of our highest priorities'

Ernest T. Hawk, MD, MPH, is the Director of the Office of Centers, Training and Resources at the National Cancer Institute (www.cancer.gov).

"Cancer centers form the foundation of most of what the National Cancer Institute does," said Dr. Ernest Hawk in his keynote address, "The Role of Cancer Centers in Addressing Disparities." To *Redes En Acción* he added: "You're operating in an essential area, and we are very enthusiastic about working with your group."

The mission of the NCI's 61 cancer centers, said Dr. Hawk, is "first of all to foster excellence in research," while acknowledging the problematic gap between research and the application of research, especially in these times. "The fact that the population is changing so quickly and so dramatically makes cancer health disparities one of the highest priorities for the institute."

Admitting to the lack of "hard and complete data" with regard to minority participants, investigators, trainees and center activities, Dr.

Hawk said, "we don't currently collect this sort of information, but it is an important area for us to do a better job. Training," he added, "is an important part of changing the future."

The NCI's Minority Institution Cancer Center Partnership Program "speaks directly to the issues of cancer health disparities," he said. Objectives include building research capabilities, creating stable long-term collaborations, improving benefits to underserved populations, and then ultimately "exporting what we've learned across the broad network of NCI cancer centers in order to extend their effectiveness into the populations that need them the most."

"Despite the challenges presented by funding and limited data," he said, "we're moving in a positive direction."



Ernest T. Hawk, MD

Dr. Reed: 'Driving down the burden'

Eddie Reed, MD, is the Director of the Division of Cancer Prevention & Control, Centers for Disease Control and Prevention (www.cdc.gov).

"Is disparity the real issue? Or is the real issue driving down the cancer burden for all?" asked Dr. Eddie Reed in his talk, "National Partnerships: Working with the Centers for Disease Control and Prevention."

And as far as the CDC is concerned, he added, "What are we doing for Hispanic and Latino Americans?"



Eddie Reed, MD

Dr. Reed reported that the National Breast and Cervical Cancer Early Detection Program serves about a half million women a year, approximately 22 percent of them Latino. According to data, "we're reaching 14 percent of the eligible population in terms of delivering those services."

In a three-year program to screen low-income people for colorectal cancer, none of the five program sites is focused on Hispanic communities, "which is something that is going to be fixed and soon," he said. In the meantime, bilingual public service announcements will appear this year featuring actors Jimmy Smits and Morgan Freeman.

The CDC is working with national partners such as the NCI and the American Cancer Society on the Comprehensive Cancer Control program, and "we're still struggling with exactly how to define that," said Dr. Reed. The goal so far is risk reduction, early detection, better treatment and enhanced survivorship.

"*Redes En Acción* should become one of our national partners," he said.

Dr. Rios: 'Finally coming around'

Elena Rios, MD, MSPH, is President and CEO of the National Hispanic Medical Association (www.nhmamd.org).

Transforming disparities research into outreach, communicating with state leaders, and kicking advocacy to a new level were key points in Dr. Elena Rios's luncheon talk, "Washington Perspective: Policy Challenges."

"Being in Washington for 12 years now, I have seen national Latino organizations finally coming around to health care projects and policy more than ever before," she said.

Even with disturbing news in the areas of state and federal cutbacks, burdensome citizenship documentation for Medicaid patients, and the looming threat of privatized home health care, Dr. Rios believes that vigorous advocacy is the answer. "The resources, the talent and the people are out there," she said. "We just have to figure out how to go from step A to step B and keep following the connections."

"We have 14 Hispanic medical societies who are now affiliated with

(NHMA)," she noted. "In 2006, the NHMA registered as lobbyists, and the board of directors expanded to 17 members. This is our network. It's been a long time coming."

For the first time in history, a bipartisan health disparities bill is awaiting Senate introduction. "It will happen," said Dr. Rios.

NHMA projects include a campaign with the Department of Health and Human Services on diabetes and obesity, a U.S.-Mexico bi-national health insurance program, and a new Web site portal (www.hispanichealth.info) as a one-stop source for Hispanic health resources. "We welcome your input."

"If we're going to reduce health disparities, it's not just about doing the research," she stressed. "It's about getting the information out through extensive communication channels. *Redes En Acción* has those channels."



Elena Rios, MD



RESEARCH

Reporting on pilot project findings

In a research panel, five investigators presented new results from *Redes En Acción* pilot projects funded by the National Cancer Institute.

Debbie Salas-Lopez, MD, Assistant Professor of Clinical Medicine, New Jersey Medical School: *Surgical Cultural Competency Cancer Education Program*. “We use two groups of medical students. The control received the standard cancer education curriculum; the intervention group received that along with cultural competency components. We learned that there is an ethical obligation to follow up with your patient’s concerns, including the ability to get an interpreter in the health care encounter. We have begun to collaborate with local Newark policymakers and stakeholders on the importance of doing this type of training and education at all levels.”

Concepción Diaz-Arrastía, MD, Assistant Professor, University of Texas Medical Branch, Galveston: *The Natural History of Human Papillomavirus (HPV) Infection in Aging Women*. “As we know, cervical cancer incidence goes up with age, but I think this project is taking on a new meaning in the era of the HPV vaccine. Nobody has yet to figure out what the appropriate boosting of the vaccine is. I think that this population needs to be looked at in more detail as it has implications for requirement of boosting into later age.”

Tomás Nuño, MA, Research Associate, University of Arizona (for Francisco Garcia, MD, MPH): *Increasing Hispanic Enrollment onto Gynecologic Cancer Prevention Trials: The Role of Linguistic Capacity*. “There were significant differences about the language preference between Hispanics and non-Hispanic whites but no significant differences between those who previously participated in clinical research and those who had not. Our next step is a \$100,000 study on *Hispanic Participation in Clinical Trials*, a statewide project.”

Martha Martinez, PsyD, MS, MAC, CH, Investigator, University of Miami: *Latinas’ Perception of Genetic Testing on Breast and Ovarian Cancer*.



(L-R) Dr. Concepción Diaz-Arrastía, Dr. Martha Martinez, Tomás Nuño, Dr. Wendy Lorizio

“Most respondents said that if they were found to be carriers of mutations they would make some behavioral changes, including more frequent breast self-exams. This is very important because we know from the literature that Hispanic women are reported as having poor cancer screening practices. We want to use the information to ascertain the needs of this underserved group, publish our data, prepare a follow-up study, and submit a grant application to develop a culturally sensitive intervention that can address the needs of women at familial risk.”

Wendy Lorizio, MD, MPH, Associate Specialist, University of California San Francisco (for Elad Ziv, MD): *Mammographic Breast Density as a Risk Factor for Breast Cancer*. “Our goal was to understand how mammographic breast density among Latinas is affected by lifestyle and environmental factors. We plan to expand recruitment to two additional hospitals, and we are collaborating with Dr. Gabriela Torres Mejia of the National Institute of Public Health in Mexico. We are also seeking to test for association between density and genetic ancestry, and also include other hormonal and reproductive factors in analysis.”

Success stories highlight ‘Redes effect’

Everybody loves a success story. Three pilot project researchers were asked to give a reflective account of how *Redes En Acción* has helped their careers, which came to be known as “the *Redes* effect.”

Isabel Scarinci, PhD, MPH, Associate Professor, University of Alabama at Birmingham: *Cervical Cancer Primary Prevention in Latina Immigrants*. “In 2001, I was the first junior faculty member to go through the *Redes* training. I spent three months here with Amelie and her staff, and those three months changed my life. A huge lesson I learned from *Redes* is how to maximize your resources. It was very important to me to develop a scientific road map and to stay on track.”

Ana Natale-Pereira, MD, MPH, Assistant Professor, New Jersey Medical School: *A Community Intervention to Improve Prostate and Colorectal Cancer Screening among Latino Men*. “Faculty development programs, grant writing workshops, writing workshops – all of that came through relationships established through *Redes*. We can only do this by collaborating with people who have done the basic science. Collaborations are major components. To me, that was the most powerful aspect of the *Redes* effect.”

Ana Maria Lopez, MD, MPH, FACP, Associate Professor, University of



(L-R) Drs. Isabel Scarinci, Amelie Ramirez, Ana Natale-Pereira, Ana Maria Lopez, Gregory Talavera

Arizona, Arizona Cancer Center: *Ethnicity and Cancer Care*. “What’s happened since the *Redes* effect? We’re often taught in academic medicine to present and publish, present and publish. I think the point of that is because you really want to share the work with others who have some interest. That enhances your own work and process, and then you can enrich and enhance other people’s work.”



Redes En Acción 2006 NSC Meeting Participants

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