

Engaging Communities

Partnerships among researchers, health care providers, and patient communities are helping to bring research advances to the people who need them. **BY LAURA BONETTA**

During the 1970s, Pittsburgh football fans watched L. C. Greenwood bring home four Super Bowl victories for the Pittsburgh Steelers. Today, he can be spotted in a short video bringing home to viewers a message about the benefits of participating in clinical research studies.

Greenwood stars in the 30-minute documentary “Clinical Research: Advancing Science & Changing Lives,” produced by WQED, the Pittsburgh public television affiliate, in collaboration with the University of Pittsburgh Clinical and Translational Science Institute (CTSI), a recipient of a 2006 Clinical and Translational Science Award (CTSA) from NCRR. The film, a version of which is streamed on the University of Pittsburgh CTSI Web site (www.ctsi.pitt.edu/video/index.html), is one of the institute’s many activities aimed at engaging its community.

NCRR-funded programs like the CTSI in Pittsburgh increasingly involve communities in translational research—the process of taking basic laboratory findings and translating them into strategies to prevent or treat diseases. To achieve its purpose, translational research must engage members of racial and ethnic minority groups and people living in rural and inner-city areas, who face much higher rates of disease, premature death, and disability than other populations (see sidebar “Health Disparities” on page 8). The key to this engagement, regardless of the type of program or population served, is two-way communication that establishes partnerships among researchers, health practitioners, and their community members.

LONG-LASTING RELATIONSHIPS

In Pittsburgh, a successful partnership between the University of Pittsburgh and the community grew out of the joint efforts of two people. In 2002, Steven Reis, a professor of medicine in the Division of Cardiology at the University of Pittsburgh School of Medicine, began recruiting subjects for his Heart Strategies Concentrating on Risk Evaluation (Heart SCORE) study, a community-based protocol to identify risk factors associated with heart disease.

Because the prevalence and severity of heart disease are much higher among African Americans than other U.S. populations, Reis wanted half of the 2,000 study participants to be African American. In the Pittsburgh region, however, only 12 percent of the population is of this racial group. “We wanted to recruit a study population that had 4 times the representation in the general population,” says Reis. “That seemed like a huge challenge.”

Lee Hippi, Jr., former executive vice president and chief operations officer of the Urban League of Greater Pittsburgh, an organization that provides programs and services to about 35,000 people annually, offered to assist Reis in his recruitment efforts. Within two years, they achieved an astounding 100 percent of their recruitment goal among African Americans.

“Key to our success was the willingness of Steve and the University of Pittsburgh to listen to the community’s needs,” says Hippi. “Rather than saying, ‘We want something from you,’ we went to the community asking, ‘What can we do for

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■ Sherry Brooks, community outreach coordinator for the University of Pittsburgh Clinical and Translational Science Institute (CTSI), prepares to analyze cholesterol levels in one of the participants at a health fair held in the employees’ cafeteria of Pepsi Bottling Group, Inc., in McKees Rocks, Pa. Another member of the CTSI, Mary Fisher, provides health and wellness educational information and literature on clinical research participation. The screening is one of many outreach activities by the CTSI designed to give members of the community health information and to listen to their concerns.

you?” Hipps received resounding requests from the public for health screenings, such as for cholesterol and blood pressure. In response, Hipps says, “We started doing free screening at churches and community centers and then referred people to physicians for follow-up care.”

The university-community partnership, which has since been brought under the umbrella of the CTSI, developed into the Community PARTners (Partnering to Assist Research and Translation) Program, co-directed by Hipps and Jacqueline Dunbar-Jacob, dean of the University of Pittsburgh School of Nursing. “With the CTSI, we now have an institutional presence in the community,” says Reis, the institute’s director. “We provide a central resource for the community and for investigators.” And in light of the fact that community engagement programs require a long time to establish and sustain, Reis assures, “We expect the CTSI to be a long-term program at the University

of Pittsburgh. Therefore, we can commit to a sustainable partnership with our community.”

The CTSI has three main goals, according to Reis, that affect three communities. “We want to have a research-informed general community, research-informed practicing physicians and nurses, and community-informed researchers,” he explains.

Through Community PARTners, the CTSI continues to provide free health screenings and information in various settings and has instituted a community-oriented speakers bureau through which researchers are available to speak to churches or other groups on key health topics. Consequently, educating speakers has also become a critical component of the program. “We do not assume that just because a researcher is an expert on a topic, he or she could talk to community members,” says Hipps. “It is not about impressing people with your knowledge but rather giving people the information they need.”

FOCUSING ON WOMEN'S HEALTH

Listening to and becoming familiar with the needs of the Nashville area community has been a focus for the research at Meharry Medical College for years. “We do a lot of focus groups to assess the concerns of people in our community,” says Valerie Montgomery Rice, senior vice president for health affairs and dean of the School of Medicine.

At a recent focus group, Meharry researchers asked parents how they felt about sharing information with their children about a vaccine to protect against the most common types of human papillomavirus—a virus transmitted by sexual contact that can, in some cases, cause cervical cancer in women and other kinds of cancers in both men and women. “We learned that parents were not concerned that talking about the vaccine would make their children more likely to engage in risky behavior,” says Montgomery Rice. “Their main concern was a misapprehension that the vaccine would cause them to get the disease.” She added that it is important for clinical researchers to know their communities and not make assumptions about their needs or concerns.

To better address the community's needs, particularly those of women, Montgomery Rice spearheaded the creation of the Center for Women's Health Research—the nation's first research center devoted exclusively to understanding why African American women are at greater risk for certain diseases, such as type 2 diabetes and HIV/AIDS, and how biology, race, and economics contribute to health disparities in women.



■ Valerie Montgomery Rice (right), dean of the School of Medicine at Meharry Medical College and a professor of obstetrics and gynecology, spearheaded the creation of the Center for Women's Health Research to bring together investigators conducting research on health disparities in women. She is shown here with one of her colleagues, Dineo Khabele, director of the center's Gynecologic Oncology & Women's Cancer Research Laboratory.



■ Obesity plays an important role in many conditions affecting African American women, such as type 2 diabetes. Women who participate in studies at the Center for Women's Health Research at Meharry Medical College have access to fitness and nutrition counseling as well as the center's exercise facilities, which include cardiovascular and strength training equipment and a group exercise studio.

“The center was conceived out of the idea that lots of people at Meharry were doing research in women's health disparities, but they were not connected,” says Montgomery Rice, the center's executive director. “If you really want to focus on a bench-to-bedside effort, you need to have a physical structure to allow for basic and clinical researchers to come together.”

Funded with grants from NCRR and NIH's National Center on Minority Health and Health Disparities, the Center for Women's Health Research is a 10,000-square-foot facility, of which about one-third is dedicated to laboratory space for researchers in the areas of reproductive biology; cell, molecular, and developmental biology; and HIV. The center also includes several cores, including radiology, exercise and nutrition, hormones, and behavior.

“The behavior core is unique,” explains Montgomery Rice. “This is where we answer the hard questions, such as ‘Why do women make the choices they do that put them at increased risk for diseases?’” And because obesity is an important factor in many diseases affecting African American women, the center emphasizes nutrition and exercise. All women who participate in a study at the center have access to the center's exercise facility and to fitness and nutrition counseling.

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The Center for Women’s Health Research—one of many programs at Meharry with a strong community component—will now have access to additional resources provided by the Vanderbilt Institute for Clinical and Translational Research, which was established through an NCCR CTSA in 2007 awarded to Vanderbilt University in partnership with Meharry Medical College. The CTSA builds on a decade-old alliance between the two institutions.

One of the CTSA’s roles will be to educate more researchers about what community engagement entails. “Many researchers still think community engagement is only community-based participatory research,” says Marino Bruce, an associate professor in the department of family and community medicine at Meharry, who co-directs the community engagement core of the CTSA. “It is not just about recruiting people to a clinical trial. Translation is about people having a conversation. And just like language translation, it is not just the words that matter but also the context.”

SPEAKING THE SAME LANGUAGE

Sergio Aguilar-Gaxiola, a professor of internal medicine and director of the Center for Reducing Health Disparities at the University of California, Davis, also knows the importance of effective communication.

A growing amount of research has found that differences in language and culture, even small ones, could be one of the reasons for the nation’s persistent health care disparities. As a result, Aguilar-Gaxiola is implementing a new training effort at UC Davis’ Sacramento campus that will incorporate the Culturally and Linguistically Appropriate Services (CLAS) standards, a set of guidelines published in 2000 by the U.S. Department of Health and Human Services’ Office of Minority Health. (For more information, visit www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15.)

In addition, Aguilar-Gaxiola is leading a national program to improve the way in which hospital staff communicate with non-English-speaking patients. The program, called Speaking Together: National Language Services Network, was

launched in fall 2006 with funding from the Robert Wood Johnson Foundation and involves the UC Davis Health System and nine other collaborating institutions. “We are addressing the importance of language services,” says Aguilar-Gaxiola. “For a system whose patients sometimes have limited resources, communication plays a critical role in health care.”

The UC Davis Health System serves a diverse population in Sacramento and from counties throughout the Northern California region. “The more I work with our community, I realize there is an incredible disconnect between what researchers are doing and what is being provided to the community,” says Aguilar-Gaxiola, whose research interests are in the area of mental health. “For example, in the last decade we have learned a lot about the risks and protective factors for mental disorders, but the rates of these disorders are still significantly high.” Many people are simply not aware of what mental disorders are or how to seek treatment.



■ Sergio Aguilar-Gaxiola, a professor of internal medicine and director of the Center for Reducing Health Disparities at the University of California, Davis, is working with medical interpreters for the UC Davis Health System on a national initiative to help improve communication between health practitioners and patients from different ethnic backgrounds. Aguilar-Gaxiola co-chairs the CTSA consortium’s Community Engagement Steering Committee along with Lloyd Michener, director of the Duke Center for Community Research at Duke University Medical Center.

As a first step in increasing participation of underserved communities in health care, Aguilar-Gaxiola and colleagues are partnering with community-based organizations, providers,

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and public agencies to understand needs and concerns of diverse groups and populations. He recently completed a nine-month project funded by the California Department of Mental Health to gather information about the kinds of problems residents see in their communities and the types of services that might help prevent these problems. The report resulting from this effort will help both the agency and the counties around the state to plan programs and improve their mental health services.

These examples are just a few of the projects working toward one ultimate goal: “to develop evidence that it is possible to reduce certain disparities in health care and improve the quality of care to all populations,” says Aguilar-Gaxiola. “I believe that it is possible to do that. We need to recognize and act upon the idea and common understanding that the ultimate beneficiaries of our health research are the very communities that need it the most.”

CHANGING THE FACE OF MEDICINE

Aguilar-Gaxiola also co-chairs the CTSA consortium’s Community Engagement Steering Committee along with Lloyd Michener, director of the Duke Center for Community Research at Duke University Medical Center (see related story on page 3). “The goal of the committee is, first of all, to bring attention to the importance of reaching out to communities, to have meaningful input from community organizations, and to use them as partners,” explains Aguilar-Gaxiola. “We are finding ways to facilitate bidirectional communication by sharing knowledge, expertise, and resources.”

The committee is developing a series of workshops over the next year to share best practices among CTSA-funded institutions. The ultimate goal is to promote co-learning and collaboration across sites. The first workshop, entitled “Accelerating the Dissemination and Translation of Clinical Research into Practice,” is scheduled for May 9, 2008, on the NIH campus in Bethesda. It is jointly sponsored by NCCR and the Association for Prevention Teaching and Research. (For more information, visit www.aptrweb.org/workshops.)

The knowledge that will emerge from these workshops will benefit not only CTSA institutions but also all researchers involved in community-based programs. In addition to NCCR, several NIH institutes and other organizations, including the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Association for Prevention Teaching and Research, the Health Resources and Services Administration, and the Association of American Medical Colleges, will strive to engage all communities in biomedical research and health delivery.

“People go into medicine to make a difference,” says Montgomery Rice. “But you cannot change the face of medicine unless you impact your community. You can be the top institution in terms of research and NIH grants, but if you don’t impact the community, what is the benefit of being number one?” ■

HEALTH DISPARITIES

Health disparities refer to gaps in the quality of health and health care across racial, ethnic, and socioeconomic groups. In 2003, the Institute of Medicine published *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, a landmark report that reviewed health disparities and helped raise further awareness of this issue at the national policy level. According to the report, “racial and ethnic minorities tend to receive lower quality of healthcare than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled. The sources of these disparities are complex, are rooted in history and contemporary inequities, and involve many participants at several levels” (www.nap.edu/openbook.php?isbn=030908265X).

More recently, the Agency for Healthcare Research and Quality published the *2006 National Healthcare Disparities Report* on behalf of the U.S. Department of Health and Human Services to provide a national overview of disparities data in both quality of care and access. The report documents that racial and ethnic minorities continue to receive poorer quality of care than whites according to 22 essential quality-of-care measures. Specifically, Hispanics receive poorer quality of care compared to non-Hispanic whites in 77% of these measures, African Americans in 73%, American Indians and Alaska Natives in 41%, and Asians or Pacific Islanders in 32%.