Improving Health Through Engagement and Expertise

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” —Margaret Mead

THE UC DAVIS CLINICAL AND TRANSLATIONAL SCIENCE CENTER (CTSC) has just such a group. The Community Engagement program helps ensure that communities and researchers have the capacity to consult on research priorities, working together as full partners with respect and reward for their time and expertise. Through implementation and dissemination of effective community-based strategies, the goal is to increase public trust in and support for research, and ultimately improve the health and well-being of communities.

**Program of national repute**

Established with the first Clinical and Translational Science Award (CTSA) in 2006, Sergio Aguilar-Gaxiola has led the CTSC Community Engagement effort. Over the ensuing 13 years, he developed and honed successful community-engaged programs and models to improve health at the community level (see insert). His team teaches community engagement skills, reaches out to populations in need, conducts research on their healthcare gaps, and then works to address them by integrating existing community health resources with new culturally appropriate strategies.

“Whatever research we do, it is grounded in the community, and whatever we find, we give back to it,” says Aguilar-Gaxiola, who also directs the UC Davis Center for Reducing Health Disparities. His efforts have led to health gains associated with a multitude of diverse projects he has led, including tackling health/mental health and comorbidity needs in communities throughout California’s Central Valley, Mexico, and Central and South America as well.

One such project is currently underway with the Solano County Behavioral Health Division, whose leaders asked for his help to address inequities in healthcare services among three groups: Latinos, Filipinos, and the LGBTQ community. In response, the team embarked on a multi-year, multipronged translational strategy. “We are now at the third and last phase of implementing interventions developed by county and community members themselves,” says Aguilar-Gaxiola. “We are evaluating access to and utilization of mental health services, patient and provider experiences, healthcare delivery costs and health outcomes, and we anticipate finding improvements in those areas.”

CTSC Community Engagement in practice

- Research Education and Community Advisory Board
- Science Cafés
- Community Engagement Studios
- Community Engagement Speaker Series
- Science Communication Fellowship

For more information about these programs, visit https://health.ucdavis.edu/ctsc/area/engagement.

To join the mailing list, send an email request to Elizabeth Vasile (evasile@ucdavis.edu).

Sergio Aguilar-Gaxiola, M.D., Ph.D. (standing), keynote speaker for the 2019 Symposium on Immigration and Family Separation

praise from national organizations and leaders for developing and implementing a model of successful community engagement, such as the Solano County Cultural Transformation Model. With this success comes the opportunity to grow and demonstrate impact. For example, a short video describing the Solano County Model and its outcomes to date was recently created by and broadcasted at the “American Public Health Association 2019 Annual Meeting,” in Philadelphia, Pennsylvania (November 2-6, 2019) under its “Thought Leadership Film Series” (https://youtu.be/1ki81Z7LUK0).

Expanding leadership

Luis Carvajal-Carmona, who serves as associate director for basic science in the UC Davis Comprehensive Cancer Center, recently joined the CTSC Community Engagement program as co-director. Carvajal-Carmona brings...
rich experience in genetic and genomic approaches to cancer research in diverse populations, setting the stage for addressing health disparities. He also has a strong interest in community engagement and with support from the Office of the Provost and the Cancer Center, he recently established the Latinos United for Cancer Health Advancement (LUCHA) Initiative staffed with two bilingual and bicultural health educators who are developing plans for cancer awareness, education, prevention, and research participation of Latinos from the Cancer Center’s catchment area. “As part of LUCHA, nearly 200 Latinos from Sacramento and the surrounding area have been interviewed with questions about cancer awareness, education, prevention and participation in research and clinical trials. The results from such survey will be used by the Cancer Center and collaborating partners – such as the CTSC – to develop better strategies to address the cancer burden in the region and develop research initiatives that focus on local cancer-related issues among the local community,” explained Carvajal-Carmona.

Carvajal-Carmona’s research focuses on the genetics and epidemiology of cancer among Latinos for which he developed long-standing alliances with researchers in Latin America and collaborations with physicians and scientists in the UC Davis School of Medicine and Colleges of Biological Sciences and Agricultural and Environmental Sciences. His projects include developing large animal disease models and investigating the genetics and function of DNA repair genes that are involved in cancer risk in humans. In addition to his passion for bench to community and back research, Carvajal-Carmona is a strong advocate for research and training opportunities of under-represented minority students and carries out local and national work to promote their careers at UC Davis and beyond.

**An ethnographic approach**

The newest member of the team is Elizabeth Vasile who serves the dual role of associate director of the CTSC Community Engagement program and manager for the CTSC Community and Special Populations Engaged Research (CASPER) program. Her office connects investigators, professional staff, and community partners to build capacity and infrastructure for clinical and translational research inclusive of a broad spectrum of stakeholders with the shared aim of improving the scientific enterprise and community health. With a doctorate in geography from UC Berkeley and two decades of experience managing and conducting qualitative research in underserved and hard-to-reach communities in the United States and abroad, her areas of expertise include ethnographic field methods, community and regional development, program evaluation, and research management.

**What is CASPER?**

Further expanding the idea of community engagement is the addition of a focus on “special populations.” The National Center for Advancing Translational Science (NCATS) defines these by lifespan, ethnographic, demographic, and geographic characteristics (see insert).

### NCATS Special Populations

- Children
- Older people
- Survivors of formerly lethal childhood diseases
- Adults with chronic health conditions that originated in childhood (either due to the disease process itself or its treatment)
- Minority, under-served or health disparity populations based on race, ethnicity, and/or gender
- Differences in socio-economic status or in a rural versus urban environment
- Pregnant women, people with disabilities, and geographically isolated or other “hard-to-reach” groups that are often impacted by health disparities

The newly formed CASPER program is led by two former CTSC scholars – Kathleen Angkustsiri and Oanh Meyer. Both participated in the CTSC Mentored Clinical Research Training Program, and subsequently received CTSC KL2 awards. Meyer was also awarded a 4-year K01 Mentored Research Scientist Career Development grant from the NIH National Institute on Aging.

In conjunction with their academic credentials, subject matter expertise, and career development training, Angkustsiri and Meyer were selected to assume leadership roles within the CTSC in response to a national CTSA mandate to ensure that breakthroughs are quickly translated to the benefit of society and all subpopulations, also known as special populations.

### Rare childhood disease

Kathleen Angkustsiri, a researcher at the MIND Institute, specializes in diagnosing and treating children with neurodevelopmental disorders, such as autism spectrum disorder and attention deficit hyperactivity disorder (ADHD). She has a specific interest in chromosome 22q11.2 deletion syndrome (22q), a rare genetic disorder associated with severe physical, cognitive, and psychiatric problems. Through her research, she has found that unlike many other pediatric neurodevelopmental disorders in which...
IQ predicts long term outcomes such as independent living skills, anxiety is a more important predictive factor for children with 22q.

However, identifying anxiety is not always straightforward for these children, making it difficult to determine appropriate treatments and evaluate their effectiveness. They often have poor verbal skills and may be unable to complete the standardized testing tools used to evaluate mental health in typically developing children. To address such problems, Angkustsiri is currently testing novel ways to assess anxiety in children with severe neurodevelopmental problems, such as heart rate variability and other physiological biomarkers.

With relevant research expertise in a special population, Angkustsiri is primed to create a community of practice. “We are putting together a clearinghouse of investigators who are focused on special populations, which encompasses not only underserved minority groups but also children with special needs,” Angkustsiri explains. “The CTSC has a long history of building research relationships, and we aim to expand on that with this unique focus.”

A focus on aging

Oanh Meyer, who leads the Research Education component at the UC Davis Alzheimer’s Disease Center, provides expertise from the other end of the lifespan. Her research currently focuses on examining social contextual determinants of cognitive decline and supporting family caregivers of Vietnamese patients with Alzheimer’s disease, an area she knows intimately as she watches her own mother, a Vietnam War refugee, struggle with dementia. Meyer conducted a 6-week pilot study in Sacramento evaluating an intervention she designed that educates caregivers about the disease, provides information on community resources, and teaches culturally-appropriate stress management techniques.

Results showed that participants significantly increased their knowledge and felt more confident in utilizing support services after the intervention compared to before they started the intervention. The group experience was so successful that after the study was over, participants continued to support one another on their own. Meyer recently extended the study to the Vietnamese community in San Jose and will be analyzing data from the pilot randomized controlled trial soon.

In addition to pursuing her own investigations, Meyer also shares her capacity to improve research at UC Davis and at the state level where she was recently appointed to the California Governor’s Alzheimer’s Prevention and Preparedness Task Force. “In all my efforts, I aim to give a voice to groups with reduced access to healthcare because of language, stigma, or other social determinants,” she said. “Thanks to CTSC support, I am now on the front lines of these critical issues.”

Established expertise

Complementing the CTSC expertise, is Moon Chen, Jr. Chen is associate director for Population Sciences and Community Outreach/Engagement for the UC Davis Comprehensive Cancer Center and a recognized local and national leader in public health efforts.
to mitigate cancer disparities among high-risk minority groups. Brought up with a foot in two worlds, he devoted his career to forming bridges between underserved communities and western medicine. "Seeing life from two vantage points has given me an unusual awareness," said Chen.

"By integrating underserved populations into the medical system, the CTSC goal to engage communities is realized and public health is improved." Initially focusing on the Chinese-American community with which he shares language and ethnicity, he has expanded his efforts to help Hispanic, Native American and other Asian communities in the region. Chen has spearheaded multiple successful community projects, including:

- A mobile mammography unit, known as the "Mammo Van," which serves the Native American tribal health clinic, K'ima:w Medical Center, in Humboldt County’s Hoopa Valley. In addition to providing mammograms, the annual two-day van visit leads talking circles focused on breast cancer risk reduction. The project has increased mammography visits by 20% in the area.
- Initiating and overseeing multiple community-based, randomized controlled trials that have demonstrated the effectiveness of various interventions to increase cancer-related screenings and the value of bilingual/bicultural lay health educators.
- Leading efforts to spare the next generation of Health and Life Organization (HALO) patients from hepatitis B, the leading cause of liver cancer among Asian Americans.

**Small but mighty**

Remember that small but committed group? The CTSC team serves the community through engagement and expertise. "We have attracted exceptional professionals to help lead our program, reflecting the success of the groundwork we laid over the years," says Aguilar-Gaxiola. "I look forward to the next decade of engagement with local and worldwide communities, and continuing to make a real impact on health."