UCSF Department of Medicine
ZUCKERBERG
SAN FRANCISCO GENERAL

Meeting Native Americans Where They Are

November is Native American month. We take this time to applaud the work that our faculty and staff are doing and their insights, that help us meet Native Americans where they are in their lives, their circumstances, and their spaces.

Expanding Access to Care

"The U.S. has a dire shortage of rheumatologists, and by 2030, demand will be double the supply," said Jennifer Mandal, MD, Assistant Professor in the ZSFG Division of Rheumatology. "The burden of this workforce shortage falls heavily on rural areas."

There are also stark racial and ethnic disparities. For example, Navajo Nation is home to more than 170,000 tribal members living on a reservation larger than West Virginia. Because of environmental and genetic factors, Navajos are five times as likely to be afflicted by rheumatoid arthritis (RA) compared with the general population. Yet there is only one full-time rheumatologist on Navajo Nation.

In 2020, Jinoos Yazdani, MD, MPH, Chief of the ZSFG Division of Rheumatology and Alice Betts Endowed Professor of Medicine, met that rheumatologist, John McDougall, MD, at a conference. "Jinoos knew I had a strong interest in health equity, access to care, and medical education, and put us in touch," said Dr. Mandal. Through that connection she met a visiting rheumatologist, Wendy Grant, MD, as well as local primary care providers and community health leaders at the Healthy Native Communities Partnership. Together they obtained a grant from the Bristol Myers Squibb (BMS) Foundation and conducted a needs assessment study. By interviewing primary care providers, they learned that many Navajo patients wait more than six months and travel more than 100 miles each way on dirt roads to see a rheumatologist off the reservation.

"Native Americans have also experienced generations of trauma and medical exploitation, including when their blood and data were taken without their consent," said Dr. Mandal. "There is often mistrust in the Western health care system, especially when they have to leave the reservation. Many patients prefer to get specialty care from their primary care provider, and those providers are highly motivated to learn more about rheumatology."

Prompt access to care is essential. "If you initiate proper treatment within the first year of symptom onset, you can usually prevent permanent joint damage, control symptoms, and restore high quality of life," said Dr. Mandal. "But if a local provider isn't comfortable prescribing rheumatologic medications, often the only option is pain medication, including opioids. These mask the pain but don't treat the underlying cause, and have serious side effects."

The Force Multiplier Effect

These insights inspired Dr. Mandal and her collaborators to create the Rheumatology Access Expansion Initiative (www.raeinitiative.org) for Navajo Nation. They created a 12-week online training program using the Extension for Community Healthcare Outcomes (ECHO) model (projectecho.unm.edu). Primary care providers across Navajo Nation attended a weekly lunchtime webinar led by a multidisciplinary team of rheumatologists, pharmacists with specialized knowledge of RA medications, and Navajo cultural interpreters.
Each week featured a short didactic on a high-yield topic in the diagnosis or management of RA, followed by interactive discussions in which participants presented deidentified patient cases. "That case-based learning is critical to the success of the ECHO model, and makes it more valuable

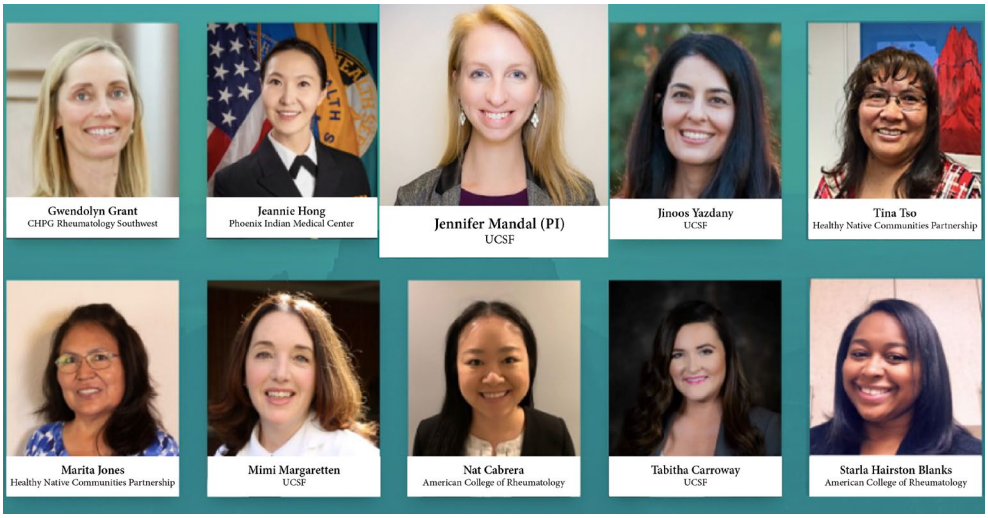
than just an online lecture series," said Dr. Mandal.

Navajo cultural interpreters provided essential context for translating evidence-based care to the community. "For example, the guidelines say if a patient's RA isn't adequately controlled by pills they should be escalated to biologics, which usually require refrigeration," said Dr. Mandal. "The cultural interpreter would say, 'About 25 percent of Navajo homes don't have electricity, and even those that do may not have a refrigerator. Before prescribing biologics, you need to check with the patient about their access to electricity and refrigeration." They also explained that many patients use a combination of Navajo and Western healing modalities.

Dr. Mandal and her colleagues also created a series of detailed videos on specific topics, such as how to perform a rheumatologist's joint exam. "In the future we hope to offer an in-person symposium for everyone who has taken the course, providing hands-on training for joint exams, aspiration and injection, as well as building community," she said.

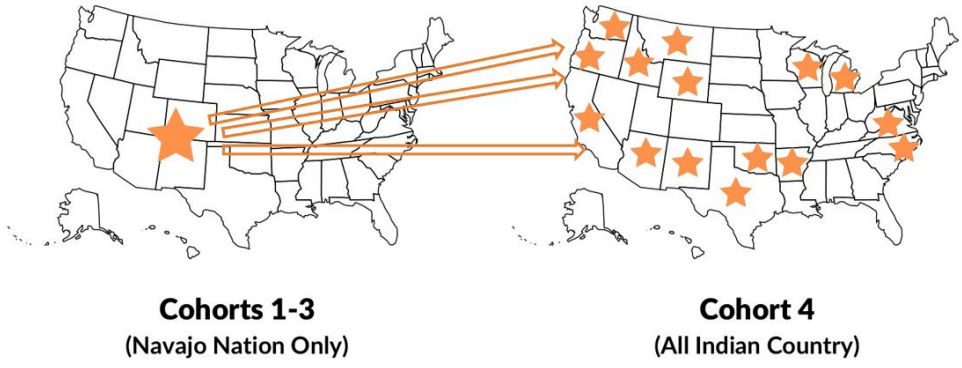
In 2023, the RA ECHO program expanded eligibility to any primary care provider in Indian Country. "The benefit is that we reach a lot more people," said Dr. Mandal. "However, Native Americans are not a monolith. These are different communities with extremely rich traditions, cultures, histories and languages. Though we've stepped away from giving Navajo-specific context, we invite a patient representative to each cohort's opening session who describes what it's like to be a Native person living with RA."

Last year Dr. Mandal and her colleagues also created an in-person joint health training program for community health representatives (CHRs). These frontline providers are a large network of mostly bilingual and bicultural health workers who provide transportation to medical appointments, deliver medications and food, and provide other essential services. "We wanted CHRs to feel more confident about talking about arthritis and recognizing warning signs suggesting an autoimmune form of arthritis," said Dr. Mandal.



Rheumatology Access Expansion Initiative Collaborators

So far, the RA ECHO Program has trained 111 primary care providers working in Indian Country. "I hope this program serves as a blueprint for others to create similar programs," said Dr. Mandal. "Rheumatology isn't the only specialty plagued by access to care issues. We've shown that this is feasible, scalable and effective. With the workforce crisis, there's often a focus on creating a few more fellowship slots that will produce a few more rheumatologists a decade from now. By contrast, the ECHO program is something you can create and implement within one year. You're training primary care providers who will hold onto these nuggets of information for the rest of their careers and spread this knowledge to their colleagues. The ECHO program calls this the 'force multiplier effect,' and it's exciting to see how the power of that knowledge is amplified."



Extension for Community Healthcare Outcomes (ECHO) Expansion

Building Trust Takes Time

Initially Dr. Mandal encountered some hesitancy from colleagues at national conferences about whether it was safe or wise to give specialist training to generalists. "Primary care providers are already providing enormous amounts of complex care for patients with rheumatologic diseases, because there simply isn't access to a specialist," she said. "It's important to find creative, logistically feasible ways to give them mentorship, support, and a place to ask questions."

She notes that most grant processes, which require patient health and outcomes data and a strict timeline for deliverables, work well for traditional clinical research but fall short for innovations in health equity. "Because of the history of exploitation in Native American communities, asking early for personal health data guarantees you will lose the community's trust," said Dr. Mandal. "The BMS Foundation was something of a unicorn, because they funded us for three years while allowing us a great deal of flexibility. We need more opportunities like that in health equity."

These long-term community partnerships are essential for advancing science and improving health outcomes. "Native American patients are incredibly underrepresented in clinical trials, and there are major gaps in basic epidemiology about why these communities are so affected by rheumatologic disease," said Dr. Mandal. "A lot of the reason is that it's very difficult to fund the time it takes to build up the trust needed to ethically seek that data."

Her advice for others engaged in similar work? "Listen more than you talk. Work in partnership with community leaders, and follow their lead. Recognize that building trust is the most important foundation for a successful intervention, and that can't be rushed."

Alex Monk, MS

Generosity and Collaboration

"My culture is maternal and collectivist, and at odds with much of what's happening in the United States – but it fits well with the public health model," said Alexandra ("Alex") Monk, MS, Women, Infants, Children and Youth Program Manager for Ryan White HIV Services within the UCSF Division of HIV, Infectious Diseases and Global Medicine.

On her father's side she is Mohawk, also known as Kanien'kehá:ka (People of the Flint) – an Indigenous people originally from a part of the Hudson River Valley where flint for making fires is abundant. Her mother, who identifies as white, grew up close to two large Ojibwe reservations in northwest Minnesota. "My dad was in the military, so I never grew up around the Mohawk culture specifically," said Ms. Monk. "I've always been in pan-Indian cultures, which is quite common in cities, where more than half the Native population lives."

When she was nine, her family settled in the Seattle area, and she witnessed the impact of the AIDS crisis as a young adult. "Two of my neighbors on our street died of AIDS, and I felt I needed to do something," said Ms. Monk, who started volunteering with the downtown Seattle needle exchange.

When she moved to San Francisco for graduate studies in linguistics, she volunteered for a similar program at Sixth and Mission Streets. Her group shared a storefront with the UCSF REACH study, which focused on marginally housed and unsheltered people at risk for HIV. She eventually joined their team as a research analyst, interviewing study participants.

"We collected laboratory and clinical data as well as information about the social determinants of health to see what factors are connected to risk for HIV," said Ms. Monk. "I loved working with this population, and the fact that San Francisco General is infused with the values of compassion, taking care of people, and working with what you have." She then worked as a grant evaluator at the Native American Health Center, a multisite health clinic focused on urban Native patients, before returning to UCSF to manage HIV-related grants and contracts.

She is proud that the Mohawk Nation was one of the founding tribes of the Iroquois or Haudenosaunee Confederacy, which sought to end intertribal conflicts and advance prosperity. "The founders of the United States asked some of our elders, both men and women, to talk about how it worked, and it became one of the founding concepts of the United States Constitution," said Ms. Monk. "I was brought up to believe that a roomful of people who reach consensus is way more important than having one leader making all the decisions."

She sees that collaborative spirit alive at ZSFG. During the pandemic, she decided to continue working on campus. "Our nurses, doctors, phlebotomists, and hospital assistants had to be here to help patients, so the least I could do was be there for them," said Ms. Monk. "I became the quartermaster, coordinating with people driving up to donate food, gloves, masks and meals. That level of generosity was a miracle. I would have expected the same thing if I'd been working on Native land."

Becoming Visible, Rebuilding Trust

There are many challenges that can accompany Native American identity. "Many people don't realize that there are about 100,000 Native Americans in the nine-county Bay Area, because we can pass as white, Black, Asian or Latin American," said Ms. Monk. "We have a very small, tight community, and can have a lot of suspicion of medicine because of the way we've been treated by doctors and researchers." For that reason, she said, it is especially important to let Native patients know they have the ability to volunteer or withdraw consent at any point in their treatment.

"We have a history with genocide and violence, including a history of [Native] children being kidnapped and sent to residential schools to 'get the Indian out of them,'" said Ms. Monk. "There's also a movement to recognize the many Indigenous women who go missing or are murdered each year…. I encourage providers to treat patients as survivors, because you never know what someone has faced or is facing."

Her graduate work in linguistics has helped her navigate sensitive topics with Native patients. "When you're collecting information, don't fill

Photo credit: John Hosteen

out the form yourself – ask them the questions," advised Ms. Monk. "That goes for pronouns and sexual orientation, but also race, culture and ethnicity. I foreshadow everything, and say, 'I have a form to fill out, and I'm going to ask you about all the different facets of how you identify. For example, the form will have seven racial and ethnic categories, and I'll ask you which one best fits you. The reason I'm doing this is so we have a better understanding of who our patients are.'"

In the past, she herself had forms in her personnel file filled out on her behalf which erroneously categorized her as white. "Now I feel we are given the agency to fill out forms ourselves, and though there's room for improvement, the culture of understanding at UCSF has definitely improved," said Ms. Monk.

Like many people of color, she experiences the difficulty of focusing at work when traumatic world events personally affect her. "When bad things happen in the Native community, such as a friend of a friend going missing, I have to shut off part of my brain because I have to do my job," said Ms. Monk. "I'm glad UCSF has places to talk about these things, like the Office of Diversity and Outreach. It's also been helpful to socialize with other Native staff, faculty and students across UCSF, which gives me a sense that we're all in this together." She is a member of the UCSF Native American Health Alliance (NAHA@listsrv.ucsf.edu), which sponsors a listserv, in-person gatherings, and a springtime ceremony and potluck to present Native graduates with blankets, a symbol of protection.

She is also passionate about cultivating the next generation. As a mentor for the Community Health Leadership Initiative, a program of the San Francisco HIV Frontline Organizing Group, Ms. Monk works with young people who are underrepresented in health care. She helps them learn about careers as a data analyst, program evaluator and grant writer. "It's nice to see how these exceptional, super motivated learners have absorbed what we have to offer, just given this small chance," she said.

"I'm really glad to be back at UCSF," said Ms. Monk. "They are always asking us for input, and inviting people to join DEI committees, which gives us ways to build UCSF.… I'm just one member of the Kanien'kehá:ka Nation, but there's so much diversity among Native Americans. We represent every part of what's now the United States, and there are so many different languages, cultures, and ways of seeing the world. It's always a struggle working in an environment where we don't see many people like us, but we're here to serve all of San Francisco."

-Elizabeth Chur

Editors: Neil Powe, Leonard Telesca, Ali Cunningham

SPOTLIGHT

Congratulations!

Jonathan Ballard, MA, BS, received a Spirit of DOM Award for his invaluable support to the Division of General Internal Medicine at ZSFG and the Primary Care General Internal Medicine Residency Program at ZSFG (SFPC).

Susan Ehrlich, MD, MPP, ZSFG CEO and General Internal Medicine faculty member, has been named a 2024 San Franciscan of the Year.

Alicia Fernandez, MD, General Internal Medicine faculty member, has received the 2024 Chancellor Award for Dr. Martin Luther King, Jr. Leadership.

Ari Johnson, MD, Division of Hospital Medicine faculty member, received the Kristof Holiday Impact Prize for his work with MUSO Health to deploy community health workers in remote places and save large numbers of children.

Call to Action:

Contribute to the **December 2024 Newsletter** by answering questions or adding photos to this Qualtrics Survey by December 6th