An $8 million project aims to change the health of this tribe’s children, who suffer an alarming rate of asthma and lack disease control.

by MARIAM MATTI

The Navajo Action Plan
Peter Nez was driving along a dusty road headed for his home in the Navajo Nation on a late summer evening in 2017, when his mobile phone beeped. The 55-year-old read the message on his screen and pulled over — just to let it sink in.

"It was a golden moment," Nez says of learning that he had helped to secure an $8.5 million grant for much needed medical care and education to improve asthma management among his people, the 174,000 residents of the vast Navajo Nation. "This is an opportunity to make steps towards change and healthier living; it's a blessing," he says today.

When it comes to asthma, the need for better patient care is enormous in the 27,000-square-mile Nation, which sprawls across a high mesa of land, crossing the clockwise corners of Arizona, Utah, Colorado and New Mexico. This is the largest Indian reservation in the United States, a territory of rich cultural traditions and scenic mountains and canyons that attract tourists. But the Navajo Nation's spread-out populace also faces difficult issues that include a high rate of poverty and an unenviable asthma problem. In fact, the prevalence of this chronic respiratory disease is estimated to be phenomenally high — at least twice the national rate of 10 percent of the population.

Nez, a community advocate who has spent most of his life on the reservation working for various government entities, says the news of the asthma-care grant from the National Heart, Lung and Blood Institute (NHLBI) is "the most exciting moment" of his career. "A new generation of Navajo kids will have the means to be a lot healthier than the kids today," he says. Getting people to focus on health needs is complicated because, even "the basic needs other people have, we don't have." Although there has been improvement, across the reservation as many as 40 percent of residents still do not have running water and a slightly smaller percentage have no electricity.

The asthma project funded by the NHLBI is a big undertaking: a six-year effort led by respiratory experts from Colorado's National Jewish Health and the University of Arizona Health Sciences Asthma and Airway Disease Research Center, in collaboration with Navajo leaders, local doctors, traditional healers, community health workers and educators. The researchers will introduce two programs that have proved successful in other settings — one offers better asthma training and equipment to health-care providers, and one that focuses on awareness at school, even involving staff assisting some students with their medication. A clinical trial involving 300 Navajo families who have a child with asthma will also be undertaken, to gain a better understanding of asthma management on the reservation.

The goal is to improve the children's health — to reduce the number of Navajo kids with poor asthma control, who suffer a range of symptoms from nagging coughs to wheezing right up to serious and breathtaking attacks. But it's also crucial that disease management becomes ingrained for the long-term. "We are trying to push at sustainability so that this program can continue to help children even after we are out of there," says Dr. Bruce Bender, the program's co-principal investigator and head of the division of pediatric behavioral health at National Jewish.

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To arrive at this large asthma project, Bender spent a year traveling to a few of the Navajo communities before applying for the grant alongside co-principal investigator, Dr. Lynn Gerald of the University of Arizona Asthma and Airway Disease Research Center. Just getting to the Navajo Nation is an undertaking, since there are no commercial airports in the vast territory. Bender would fly from Denver to a city a reasonable distance from his reservation town destination, and then drive. On one trip it was a two-hour flight to Phoenix, and then a 3½-hour road trip to Tuba City. There are three Navajo towns in total involved — Tuba City, Fort Defiance and Chinle.

Amid these remote populations, some outreach clinics and specialists have worked for years to help asthma patients, and gained a sense of the scale of the disease. While the reasons for the high incidence of asthma has yet to be well studied, there are factors unique to life on this reservation that may set the stage for developing the respiratory condition. And several environmental triggers for asthma flare-ups are plainly in evidence.

Navajo Nation, which is about the size of West Virginia, is a desert area of sparse vegetation. In spring, dust storms are a regular occurrence. The wind picks up a lot of particulates from the loose sand, which then get into the air. Bus trips to school often last an hour or two, rides on which students with asthma are exposed to both dust-laden air and diesel exhaust.

When winter arrives, so do respiratory viruses, and doctors report seeing a rise in asthma symptoms and attacks among children. A likely contributor is that "many families rely on wood- or coal-burning stoves to keep their homes warm that can create air pollution issues," says Dr. Aaron Kobernick, who spent four years working in the town of Chinle at the Indian Health Service (IHS) facility and became the local head of pediatrics.
Such stoves release particulates and chemicals known to aggravate airways and set off asthma exacerbations.

Outdoors, the towering smokestacks of the coal-fired Navajo Generating Station release a steady stream of emissions into the air, which locals often blame for breathing issues. NGS officials contend the stacks at the massive plant are fitted with modern pollution-control technology. But carbon emissions remain problematic, with the Environmental Protection Agency pegging the station as the sixth largest industrial carbon-emitting facility in the United States as of 2017. The precise impact on respiratory health of creating electricity through coal-burning is not well-assessed. But the haze will disappear sooner than later—this is an industry winding down, with NGS slated to close in 2019, and taking about 800 jobs with it.

There’s also an extensive history of uranium mining in the Navajo reservation. While uranium mines no longer operate, there are hundreds that are abandoned and still need to be cleaned. Radiation has been linked to cancer and respiratory health, while studies associate carbon dioxide with triggering asthma symptoms such as shortness of breath, wheezing, chest tightness or coughing.

In 2015, Kobernick and his colleagues examined the quality of asthma care for Navajo children, including medications prescribed and spirometry, and identified areas for improvement. In analyzing electronic medical records, they also noticed that the prevalence of asthma was significantly higher than the U.S. national average. Bender says that such data sources showing a significant rate of asthma “offered essential information” toward winning the grant.

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There are high hopes that this project can make a real difference in asthma management. “I’ll be training the teams at the IHS to follow the current evidence-based guidelines [for asthma],” says Bender. “Dr. Gerald will be present in all the school-based programs to educate school staff, children and families.” Bender will employ National Jewish Health’s well-regarded Asthma Toolkit, which has been used to instruct physicians across Colorado on how to diagnose and manage asthma. The toolkit will provide physicians with training manuals and portable spirometers.

“Spirometry is one of the cornerstones of the evidence-based guidelines,” Bender notes. While currently used by IHS centers, it’s not always employed consistently. “We are going to make sure everyone has a solid understanding of what asthma is and how it should be managed,” he stresses.

For the school component, Gerald and her team will collaborate with educators on ways to improve students’ asthma care, including the American Lung Association’s Open Airways for Schools program that’s designed to teach young children about disease self-management. “We will have workshops for staff on asthma so they know how to help children prevent asthma symptoms and what to do if they have asthma attack in the classroom or school bus,” says Gerald. “We want to help them understand what to do if a child with asthma needs help.”

There’s another strategy she will consider that has had great success at other schools: supervising daily treatment for children who have significant issues with asthma or who struggle to stick with their medication routine. “[The student] gets a dose of medicine every morning when they come into school, so we can ensure they’re taking it,” Gerald explains. She has seen this improve asthma management. “We won’t be asking schools to do that for every child, but if they have one or two who seem to always have symptoms or going to the ER a lot, the school may want to consider supervising therapy,” she says.

The research team expects some special considerations in working with the Navajo population. Dr. Wayne Morgan, a pediatric pulmonologist at the University of Arizona and a senior investigator on the project application, has been traveling to work in the Navajo Nation for 30 years, and explaining to children and parents how to reduce exposure to triggers, use devices like inhalers and spacers and improve children’s medication routines. One consideration is that air quality issues are different from those in a big city. For instance, “many of the parents complain their children have more [asthma] symptoms on windy, dusty days,” says Morgan.

Just getting to a clinic to get medication refills can be a problem, notes Kobernick, as many families don’t have access to transportation or must travel a long distance. “There are unique challenges on the reservation, so maybe kids with asthma may not do well
Dr. Bruce Bender (left) credits Peter Nez (right) for connecting the medical team with local leaders for the asthma project. Miss Navajo Nation, Crystal Littlebrown (center), will be helping to promote the program within the community.

wants to make sure educational materials are culturally appropriate for both literacy levels and manner of communication, mindful that the Navajo have an oral history tradition. "At formal meetings, a lot is handled in their language," says Bender. "At the schools, it's all in English, but the adults all speak Navajo fluently."

Another unique aspect is working with traditional healers, who have been a community fixture for thousands of years. If Navajo children have breathing problems or asthma-related symptoms, the traditional healers have their own remedies and medicines for treatment. The IHS hospital employs traditional healers so patients have both Western medicine and traditional Navajo medicine. "We are planning to utilize our traditional healers and community leaders to communicate the same message to the people," says Nez.

Bender credits Nez for helping bring together the outside team and the local population on this project. "He's the one who leads the way on the reservation," he says. Nez helped to facilitate meetings, developing collaborations among state, regional and local leaderships and overall community advocacy. "During meetings, Peter will speak to representatives in Navajo -- they capture nuances better with it than they do in English." The reception from the community has been welcoming and focused on helping children with asthma. "We've had an incredible response in terms of engagement," says Gerald. "People have been driving long distances -- up to two hours -- to attend meetings with us."

The doctors will build the program, then implement it in the communities year-by-year, stepping back in the fifth year to gauge whether the program is becoming self-sustaining, whether the tools and resources are working. Then they will go back in the sixth and final year to get feedback and resolve any issues.

One thing that's evident in speaking to everyone involved is how passionate they are about improving the health of the Navajo children, and showing them that asthma, while a chronic condition, can be managed even in a remote, vast and dusty nation.