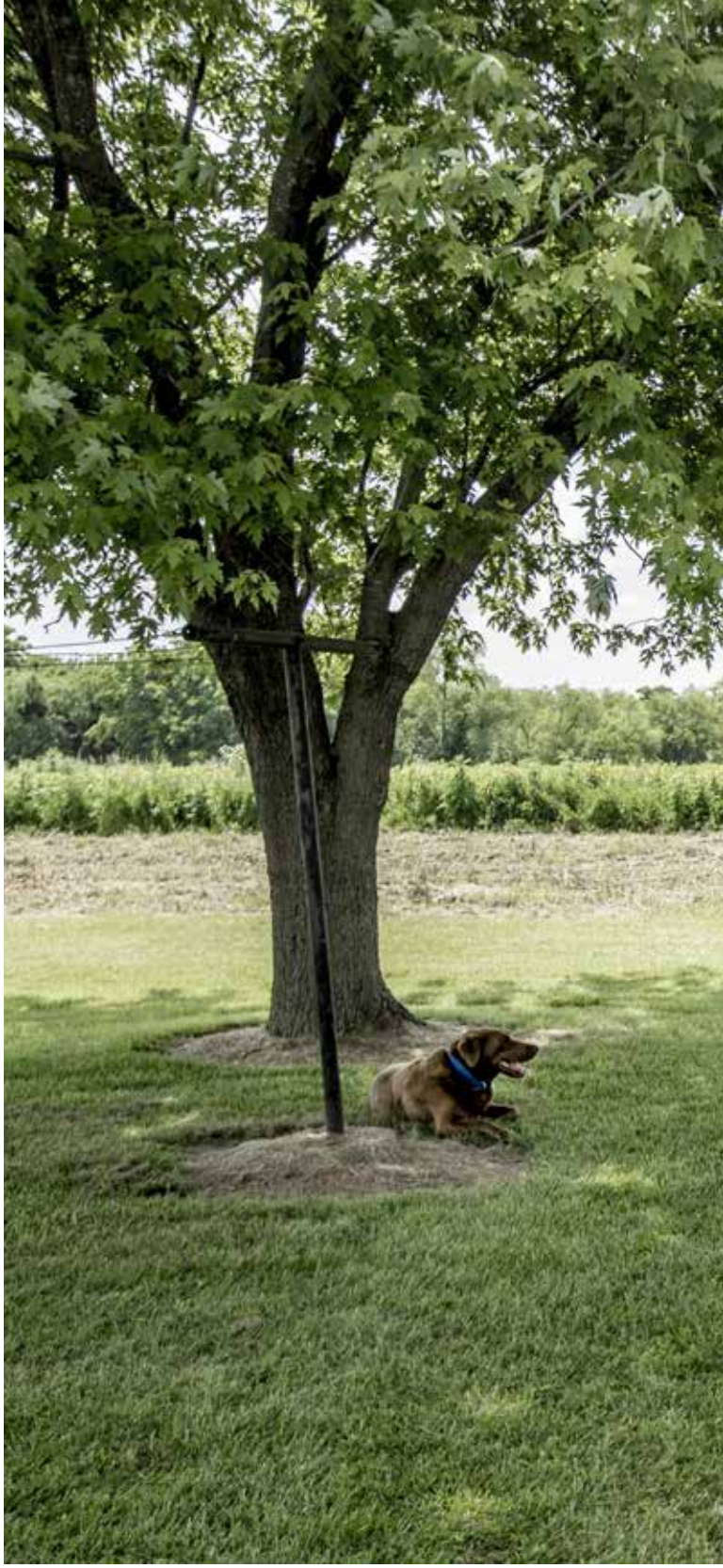
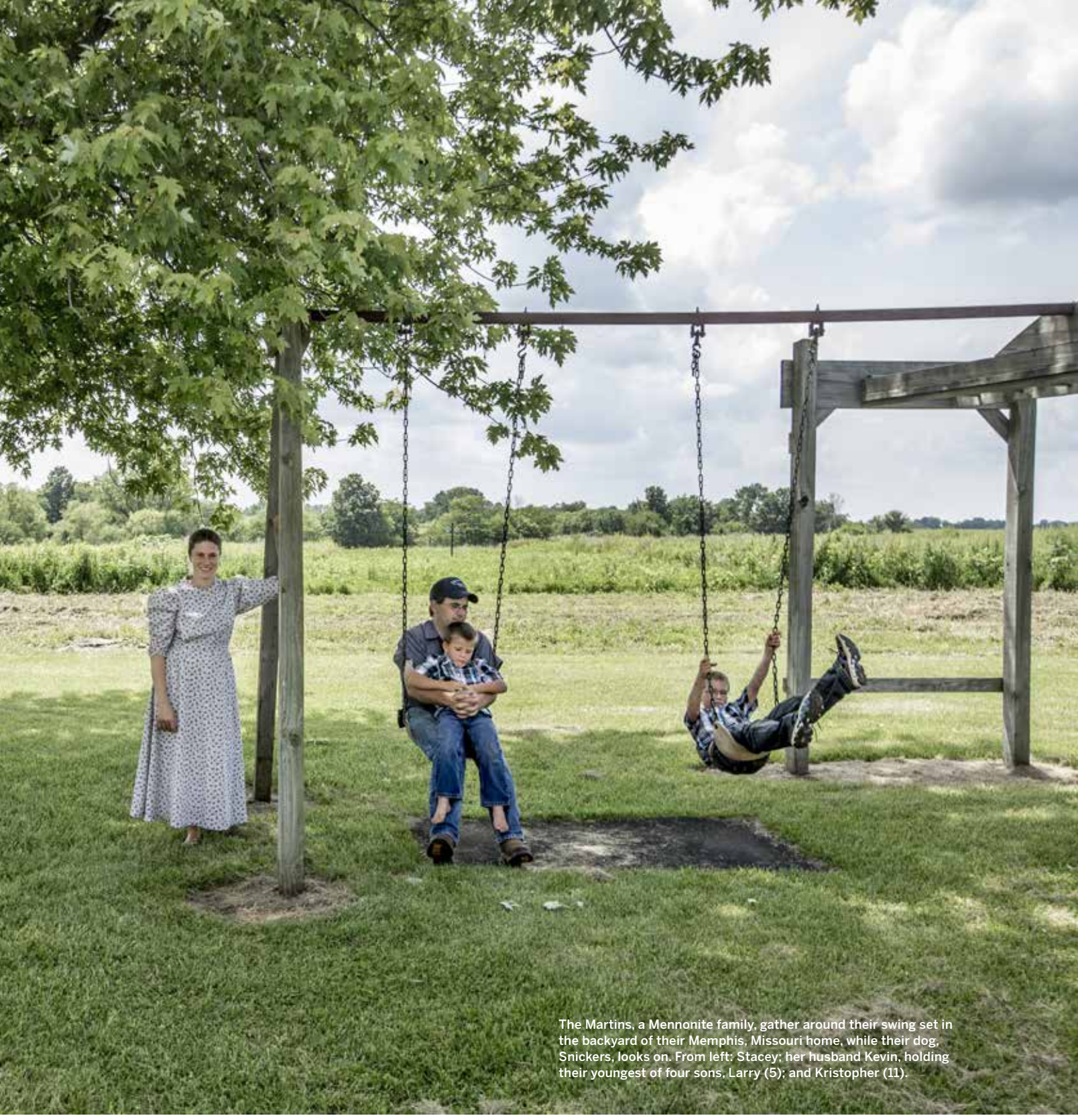
SEEKING COMMON GROUND

UMHS works with Amish and Mennonite communities toward a culturally sensitive approach to burn treatment

By Sara Talpos Photography by Jennifer Silverberg



When an Amish child is burned, perhaps by liquid in a canning pot or flames in the home's wood-burning stove, the family often turns to community healers. These trained men and women apply an ointment that looks like spun honey. In fact, honey is one of its main ingredients, along with olive oil, wormwood, myrrh and other plant-based substances. After the ointment is applied, the wound is wrapped in simmered burdock leaves, which are then secured with gauze. When it's time to change the dressings, someone might hum or sing to soothe the child while the leaves are removed piece-by-piece to minimize the pain of an open wound exposed to air. Parents will assist, sometimes holding the scissors or unrolling the gauze. When it comes to burn care, the Amish and similar communities like Old Order Mennonites value gentleness, community and their faith in God's will.



The Martins, a Mennonite family, gather around their swing set in the backyard of their Memphis, Missouri home, while their dog, Snickers, looks on. From left: Stacey; her husband Kevin, holding their youngest of four sons, Larry (5); and Kristopher (11).

Occasionally, the injury is so severe that a hospital is needed to stabilize the child. In the hospital, burn protocol is different. The patient receives a large dose of pain medication. To maximize speed and efficiency, the dressings are removed all at once. Nurses scrub the wound with soap, water and a washcloth before applying FDA-approved Silvadene, which prevents infection but slows the body's healing. This slowing is permitted because patients usually undergo skin grafting: a procedure that provides rapid wound closure, shortens hospital stays and accelerates return to function — outcomes that reflect the values of modern medicine.

"I just want to tell you how diametrically opposed these things are," says Stewart Wang, M.D., Ph.D., Endowed Professor of Burn Surgery, professor of surgery and director of burn

surgery at University Hospital, when comparing the Amish approach to burn treatment with that of the medical community. Despite good intentions on both sides, opposing expectations have created conflict at medical centers throughout the United States, including at UMHS.

For Wang, it is important to provide culturally sensitive care for a religious community that has historically avoided burn units. Yet some professionals question whether delaying standard protocol might put a patient's life in danger. Wang concedes that it isn't easy to find a middle ground that satisfies both sides.

"But," he adds with conviction, "we're trying."

A Burned Child

Wang recalls his first encounter with an Amish patient, a young girl in the pediatric intensive care unit at C.S. Mott Children's Hospital. The girl was unconscious with deep open wounds on her lower legs. A heart-lung machine was keeping her alive. Wang explained the hospital protocol to the girl's parents, and they refused it.

He tried again, and they refused again.

The girl's family belonged to the Plain community, which consists of Christian groups, including the Amish and Old Order Mennonites, who choose to live a simple, plain lifestyle separated from the rest of the world. The Amish and Old Order Mennonites often settle in the same regions of the country, where farmland is available for growing food and raising families. They have their own stores, leather shops, construction workers and healers. Individual members do go out into the wider world, but on the whole, the Plain community is highly self-sufficient.

The Amish use modern technology sparingly (unlike Mennonites who own cars and cell phones). Many forgo electricity, relying on wood-burning stoves and kerosene lamps. This may explain why they have a higher incidence of burns than the general population. Over time, the Plain community has developed its own regimen for the treatment of burn wounds: the use of a salve called Burn and Wound, or B&W, ointment with dressings of wild burdock leaves simmered to make them pliable. Plain community members would like to use this treatment in the hospital while minimizing the use of pain medication and skin grafting.

After the girl's family refused care for the second time, Wang thought, "I'm a surgeon. I'm busy. I'm here to offer a service. They've refused. I'll go away." He was polite but ready to help his next patient — until the pediatric intensive care specialists stopped him.

There had been reports of burned Amish children dying at home from shock and dehydration. The Mott team wanted Plain community families to feel comfortable seeking help. They wanted parents to bring injured children to the hospital sooner when the likelihood of positive outcomes is highest. Most of all, they did not want to file a child protection order, which would allow the delivery of potentially lifesaving medical care, but would also take custody away from engaged and loving parents. This could erode a family's already fragile trust in the medical staff. In the future, the Plain community might be even more hesitant to seek help.

So Wang returned to the room and spent time — a lot of time — talking with the family. They explained the core tenets of their faith; he explained their daughter's medical condition. The young girl wasn't yet stable enough for skin grafting. In the meantime, Wang wanted to treat her wounds with Silvadene. The family insisted on B&W.

"And my background is I'm an immigrant," Wang says. "I came to the United States. By the time I was 7 years old, I had seen every single major world religion. I had lived in different parts of the world." He was reluctant to dismiss a community's religious and cultural practices. And yet, he also needed to ensure the child's safety.

He carefully examined the wounds. They did not appear infected, and he could monitor them.

"So I said, okay, why not?"

Ancient Remedy

Though the B&W and burdock leaf regimen was new to the Trauma Burn Center staff, it has been widely used throughout the Plain community for years. It was developed in the early 1990s after an Amish toddler was injured in a kitchen accident involving a kettle filled with boiling water. The boy survived. His father, John Keim, became determined to create a better burn regimen for his community, one that would relieve pain and stimulate healing. Keim honed his product, eventually settling on the current iteration of B&W. He estimates that over a 25-year period, he treated a burn a week without once having a patient die. Keim gathered a wealth of experience, but his evidence remains anecdotal. There are no official records of his work, no randomized control trials.

Wang closely monitored his young burn patient. Over time, and to his surprise, the regimen seemed to aid in the healing process.

"I don't know why it works, but it works in many ways," Wang says. Standard treatments like Silvadene delay healing

Kristopher Martin, 11, who suffered severe burns from an outdoor trash fire in 2012, looks out the window in the living room of the Martin family home.

and require aggressive debridement — the removal of dead, damaged or infected tissues, which tend to dry onto the wound. The B&W regimen keeps the wound wet. "You begin to notice the living tissues separating from the dead tissues," Wang explains, "whereas when we use standard treatment, the tissues stick." The separation of tissues eliminates the need for vigorous scrubbing, thereby allowing new tissues to grow.

Still, the possibility of infection remains. The Plain community's healers report that infections occur rarely, if at all, when the B&W regimen is followed properly. Wang, who also trained as an immunologist, speculates that this might have something to do with the honey. Honey contains antimicrobials and has been used medicinally since Ancient Egypt. One of the earliest medical texts, known as the Edwin Smith Papyrus, details the use of honey on a wound.

The nurses also noticed B&W's effects. Lori Pelham, nurse manager for the Trauma Burn ICU, is impressed with how well B&W has worked on Plain community patients. She suspects that if the regimen were scientifically proven effective, it would be used by the general public. However, in the absence of such evidence, the burn unit staff must navigate the competing demands of evidence-based medicine and family-centered, culturally sensitive care.

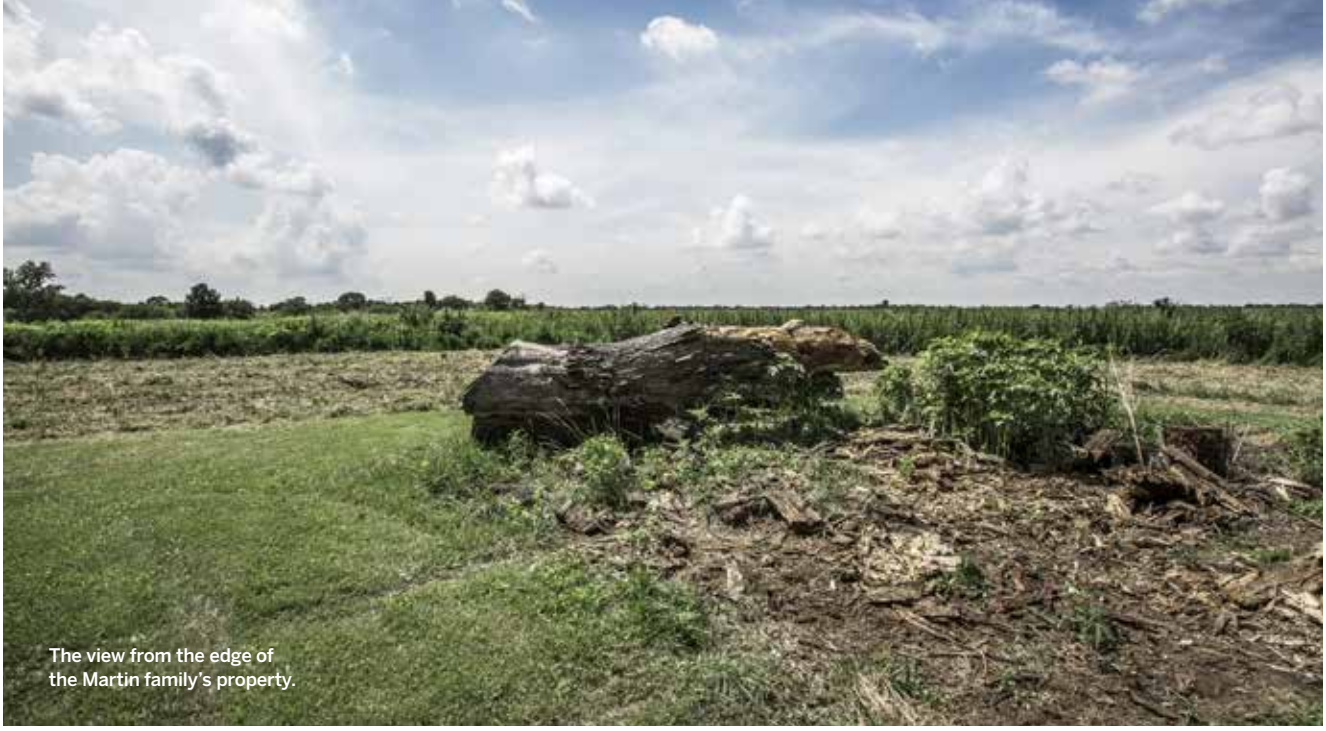
Further complicating matters, "Word went out that I would consider the use of B&W," says Wang, chagrined that generalizations were being drawn from his work with a single individual. What's more: Plain community families began to arrive with the expectation that U-M surgeons would do no grafting.

Controversy and Conversation

Thomas Bardwell, a Mennonite who lives among Plain settlements in Michigan's Thumb, explains, "In the Amish community in the United States, if something happens today, within 24 hours or less, everybody will know." Many Amish families have access to a communal phone shack or they may use a neighbor's phone. Still others receive news from Bardwell himself. A former hospital administrator, he currently operates a crisis hotline for families seeking medical advice. He also serves as an intermediary between families and treating physicians.

"The Plain community needs a major hospital," says Bardwell, adding that families will pay a driver to transport them a thousand miles, bypassing other medical centers to receive care from someone they trust. "I've heard it said they only trust Dr. Wang. They may not agree with what he says, but they trust him. That's a big step in the Plain community." Bardwell praises the U-M nurses and describes Wang as "caring and compassionate." He would like to establish the U-M as a preferred center for Amish burn patients, though he knows this could be difficult given that not everyone at the U-M wants to negotiate with families.

Many support negotiations within the burn unit, but, Wang explains, others wonder, "Why are we bending over backwards?" This internal conflict creates a stress on the system. Criticism has also arrived from other facilities when patients have requested transfer to the U-M. The burn unit's preference is for a seriously burned child to be taken to the nearest American Burn Association-verified center. But families will then request transfer if told that B&W is prohibited. Wang has received phone calls from skeptical colleagues. One prominent burn surgeon even accused the U-M of enabling malpractice. (It's worth noting that for religious reasons, the Plain community doesn't sue.) "You have to understand," Wang says, "we surgeons all think we are the best. All of a sudden, you have these very reputable surgeons who are being told that they need to send [patients] to Dr. Wang at the University of Michigan."



The view from the edge of the Martin family's property.

Some even accused Wang of never doing surgery on his Amish patients.

"I don't avoid surgery," Wang says. "I just spend the time working with the family so that I get us all to the point [where surgery is an option]. Now, you can argue about whether I was endangering the child by spending an extra week or 10 days talking to the family and their community ... But my view is that I was very careful — it was extra work on our end to monitor. I don't think I ever put the patient in jeopardy."

In his earliest conversation with the pediatric intensivists, Wang began to suspect that optimal care may be different for the Amish than for the general population. In Plain communities, responsibility for a sick child belongs not just to the parents, but to the whole group. They arrive with multiple family members, healers and elders. They bring homemade sandwiches and other food in 5-gallon pails. "You have to take care of them in that context," Wang says.

For this reason, he initiated a series of meetings to determine how to convey optimal protocols — to staff at UMHS, to the Plain community and to outside medical centers.

Baby Steps

One of several outcomes of the meetings was to establish a physician's right to oversee the use of B&W, which is considered an herbal supplement. Traditionally, herbal supplements aren't used in the hospital, but the Health System has a policy specifying that patients who want a particular supplement can discuss it with the treating physician. If the physician believes that the potential benefit outweighs the risk, then the supplement is allowed and its use is documented in the medical record.

Beyond this, the meetings established a protocol for Plain community wound care. The protocol states, in part, that "The U-M Burn Center will provide a foundation of standard medical care to ensure the safety of burn patients while incorporating Plain community approaches to burn care to the extent possible." The protocol outlines relevant cultural differences, including divergent attitudes toward medication, grafting and infection prevention. It notes the ways in which B&W has been effectively used at the U-M and presents guidelines for wound care. The role of the Plain community is also clarified: Healers and parents may apply B&W in areas designated by the burn surgeons. Other hospitals have contacted the U-M to request and implement the protocol. Most notable is Lehigh Valley Health Network's Regional Burn Center, which is a 90-minute drive from Lancaster County, home of the second largest Amish settlement in the country.

As the meetings progressed, Plain community patients continued to arrive at U-M from across the Midwest, as well as from Pennsylvania and Canada. Pelham, the nurse manager in Trauma Burn, saw a need to educate staff about these patients and their culture. She invited Bardwell to the hospital to give a presentation about the history and beliefs of Plain people. It drew a large audience, including staff from outside the burn unit.

These educational efforts, along with the new protocol, have already benefited patients, including Kristopher Martin, a Mennonite boy from Missouri who was burned by an outdoor trash fire in 2012. A community healer assessed the severity of the boy's burns and recommended that the parents, Kevin and Stacey Martin, request treatment at U-M.

Kristopher was initially transported by ambulance to a community hospital, where he was relatively calm and comfortable, having been treated with the B&W and burdock leaves. Because U-M's helicopter was not available, Kristopher was flown to an ABA-verified burn center in Iowa City, where he stayed two days before being taken by ambulance to Ann Arbor.

Soon after arrival at U-M, Kristopher received skin grafting to his trunk and back, the areas most badly burned. Kevin and

Stacey were then allowed to treat their son's hands and face with B&W. "You can barely see that he was even burned on his face and hands," Stacey says. Reflecting on her son's 6-week hospital stay, she adds, "We really appreciate that we were even able to get into U-M and do some of Kristopher's care ourselves. That was just a really wonderful feeling that they trusted us to do that."

The meetings have also begun to lay the groundwork for a clinical trial to assess the safety and efficacy of the B&W and the burdock leaf regimen. Wang serves as the principal investigator with Amy Skyles, a U-M adjunct clinical assistant professor of pharmacy and clinical pharmacist for UMHS Research Pharmacy, serving as one of two co-investigators. Though most in the Plain community want to avoid skin grafting altogether, Skyles, who believes the meetings have helped establish expectations for care, is more measured in her hopes: "Efficacy" could mean the regimen turns out to be a good debrider, minimizing use of painful standard methods and reducing the area that needs grafting.

But hurdles remain, including determining how to standardize the ointment and leaves in order to achieve FDA approval of the study. Herbal supplements are difficult to test: Their chemical makeup varies depending on when and where harvesting occurs. Ideally, Skyles would like to buy standardized sources before compounding the B&W ointment in the pharmacy. The burdock leaves are trickier. Wang and Skyles acknowledge that the leaves work as an occlusive dressing, but the Plain community believes the leaves also contain an active component that seeps into wounds and provides pain relief. They want the leaves simmered or scalded in order to preserve the active component. These heating methods, however, do not kill all bacteria, and so may pose a risk to the patient.

If FDA approval is secured, the university will conduct an open-label pilot study to establish safety under certain parameters, including thickness of burn and the percentage of body surface area burned. U-M will partner with two community hospitals in the Thumb to recruit and treat Plain community patients. If the results are promising, further studies will follow.

These efforts may seem like baby steps, but people on both sides are committed to the project. Keim, who first developed the B&W and the burdock treatment, appreciates UMHS' efforts to care for his community. Though he would like the burdock leaves to be approved, he is prepared to first see how the ointment alone fares in a clinical trial. For his part, Wang believes in the burn unit's efforts to foster a stronger relationship with Plain community patients, one in which mutual understanding, acceptance and trust will lead them to a common ground.

"They're a very separate community," he says. "And then, every once in a while, they need our help. And how we deliver that help, I think, tells everything about us as a society of caretakers." [M]

SPIRITUAL CARE AT THE U-M

UMHS works with patients from a variety of faiths to provide spiritually-tailored medical care. For example, Lena Napolitano, M.D., the Joyce and Don Massey Family Foundation Professor, professor of surgery and division chief of Acute Care Surgery, has published a protocol for treating Jehovah's Witnesses with critical life-threatening anemia, and her research into the area is ongoing. Jehovah's Witnesses are prohibited by their faith from receiving blood or blood products as part of their medical care. At UMHS, these patients may receive a bovine hemoglobin-based oxygen carrier, in addition to high-dose erythropoietin and intravenous iron therapies.

"Spiritual care is essential in helping support patients and families as they grapple with difficulties related to health and well-being," writes Reverend Lindsay Bona, supervisor of the Spiritual Care Department at UMHS. Bona cites a study in the *Journal of Pastoral Care* indicating that for many patients and families, religion is the most important factor enabling them to cope with serious illness.

In addition to working with Jehovah's Witnesses, UMHS has worked with a variety of other religious groups, recognizing that requests for spiritually-tailored care can vary, even among members of the same group.

When possible, for instance, health care teams will wait for a Catholic patient to receive sacraments before undergoing surgery or making the transition to comfort care. Similarly, with Muslim patients, care teams try to conduct rounds and do exams outside of obligatory prayer time, which occurs five times daily at designated intervals. Some members of an evangelical Christian group, Word of Faith, believe healing occurs only in the presence of positive prayer and speech. Spiritual Care chaplains work with these patients and their families to better understand how they define "positive," and to seek a middle ground, such as discussing potentially negative news outside of the patient's room.