A November ballot initiative that jeopardizes health care in our communities

In the Nov. 6 election, Palo Alto and Livermore residents will be asked to vote on an extremely misleading ballot initiative — called Measure F in Palo Alto, and Measure U in Livermore — that purports to control health care costs in our communities. In reality, it would have the opposite effect.

While we at Stanford Health Care are always focused on reducing the costs of the high-quality care we provide, the ballot initiative will not help us accomplish this goal.

We strongly oppose this misguided initiative and hope you will join us in voting no on Measure F in Palo Alto and Measure U in Livermore, and in educating friends and family who are Palo Alto and Livermore residents. To be clear, the initiative does nothing to address health care costs or limit prices charged to patients who have insurance coverage. Nothing in the initiative improves quality of care.

SEE COMMUNITY MATTERS ON PAGE 3

What it means, and how Stanford Medicine continues to improve

Quality of care takes into account a variety of measures, including rates of surgical complications or postoperative infections, using electronic systems for medication orders, patient mortality rates, the care and service patients receive in the hospital, and the average length of stay.

As an academic medical center with highly trained physicians in a broad range of specialties, Stanford Medicine treats some of the sickest patients in the country. Many patients come from other hospitals in the region because of the expertise and care that are available only at Stanford. Caring for the sickest patients means they also are most vulnerable to hospital-acquired infections.

Both hospitals have earned reputations for providing the highest levels of care to the most acute patient populations in the nation, and Donnelly and Frush say they are working with their teams to build new quality initiatives on the hospitals’ strong foundations.

“Over the past 15 years, we’ve learned a lot about the science of safety and quality,” said Frush, who joined Stanford Health Care from Duke University this summer. “Stanford — as a center for science, with so many amazing faculty and staff — has helped define that science. And one of the key things we’ve learned is that we can always get better.”

Donnelly, who came to Packard Children’s from Texas Children’s Hospital last November, oversees three areas for the children’s hospital: quality and safety, performance improvement, and patient experience. Donnelly said
STANFORD MEDICINE NEWS

“We’ve invented solutions that have allowed us to do things that we could never do before. We’ve invented methods that work better for kids. We’ve introduced MRI equipment that's tailor-made for children’s needs.”

Mary Leonard, MD, professor and chair of pediatrics, on the new main building for Lucile Packard Children’s Hospital Stanford. Aug. 11

How Stanford research is making MRI scans safer for children

An interview with radiologist Shreyas Vasawala

When it comes to medical imaging, pediatric radiologist and biomedical engineer Shreyas Vasawala knows that kids aren’t the same as adults.

Vasawala, MD, PhD, professor of radiology at the Stanford School of Medicine, has spent the last 10 years studying how to improve magnetic resonance imaging scans for his smallest, wiggliest patients. Now, he’s putting his MRI innovations to work in the Cynthia Fry Gunn and John A. Gunn Imaging Center at the new Lucile Packard Children’s Hospital Stanford, which opened in December.

Vasawala talked with Stanford Medicine News about the needs that spurred his inventions and how the new hospital’s state-of-the-art technology will improve his team’s ability to care for children who need medical scans.

MRI scans are noninvasive and painless, don’t use radiation, and give clear images of soft tissue such as muscles and tendons, but children who could benefit from MRIs don’t always get them. Why not?

Magnetic resonance technology is challenging to develop and use. Most of the MRI equipment on the market was designed to meet the needs of adult patients, who receive about 90 percent of MRI exams.

In an MRI scanner, the body is exposed to a very strong magnetic field. The protons in the body’s water molecules align themselves with the magnetic field. Then, as they return to their usual state, they give off radio-frequency signals detected by the scanner, which translates the signals into a picture.

To produce a clear picture, a traditional MRI scan requires that patients hold very still, sometimes for up to an hour. That’s difficult for young children. Children are also smaller, breathe faster and have higher heart rates — all factors that make the imaging challenges harder from a physics perspective. Kids may be given anesthesia to help them hold still, but that carries its own risks.

As part of your research at Stanford, you’ve been designing MRI equipment especially for children. What improvements have you introduced?

We’ve invented solutions that have allowed us to eliminate the need for anesthesia in many cases.

We’ve been collaborating with engineers from UC-Berkeley to create new designs and production methods for highly flexible and lightweight MRI signal-receiving coils tailored to children’s bodies. Standard coils are larger than what children need, making them unnecessarily heavy and uncomfortable.

Larger-than-necessary coils also pick up extra noise or interference, reducing the image quality. Child-size receiver coils increase image clarity and lower scan times.

The smaller coils greatly enhance the performance of a novel hybrid imaging technology called PET-MR, which we are now offering to patients in our new imaging center at Packard Children’s Hospital. The coils are being developed commercially as well.

You’ve also improved the computing software that processes MRI data. How?

We’ve created new image-reconstruction algorithms that work better for kids. We deployed motion-correction strategies that produce sharp images even when a child is moving slightly — this helps address the challenge of kids’ faster heart rates and breathing rates. Simultaneously, to reduce scan times, we implemented novel, high-dimensional imaging and compressed sensing coupled with artificial intelligence. These techniques allow the computer to reconstruct a full MR image from much less raw data. Scans that once took an hour are now complete in five to 10 minutes. This has had a particularly large impact for our cardiac, oncologic and musculoskeletal exams.

What most excites you about the new imaging center at Packard Children’s?

For the first time, we have an MRI scanner located inside our neurosurgery operating suite. It allows our neurosurgeons to confirm the success of a surgical procedure, such as a tumor resection, before surgery is complete. This saves time by eliminating a separate post-surgical MRI and the risk of needing an immediate repeat surgery. Patients will be spared a second round of anesthesia, hospital stays will be shortened, and families will know if the surgical aims have been achieved as soon as their children are out of the operating room.

By the end of 2019, we will have a next-generation MRI scanner with much stronger magnetic field gradients that can be altered at high speed. This enables faster imaging and better image contrasts. Also, this new MRI scanner will come with a noninvasive technology used to kill certain types of tumors with sound waves. Known as MR-guided high-intensity focused ultrasound, it lets us pinpoint abnormal areas in the body, such as some types of tumors, and heat them to destroy abnormality without cutting into surrounding healthy tissue.

The Boston Globe

“It’s not sterile expanses of white walls. We’re trying in every way we can to not have it feel like a hospital.”

Mary Leonard, MD, professor and chair of pediatrics, on the new main building for Lucile Packard Children’s Hospital Stanford. Aug. 11

abc NEWS

“These glasses are perfect for something like this, they’re able to provide real-time feedback.”

Dennis Wall, PhD, associate professor of pediatrics, on his research that found an app connected to Google Glass could help children with autism better understand facial expressions. Aug. 2

"There’s been all this awareness on opioids but very little focus on benzodiazepines and yet people are dying from them.”

Anna Lembke, MD, associate professor of psychiatry and behavioral sciences, on the rising use of benzodiazepines. July 27

npr

“We’ve made big advances in emergency care by having some basic standardized approaches to emergencies. That’s what we’re bringing to maternity care now.”

Elliott Main, MD, clinical professor of obstetrics and gynecology, on California’s efforts to reduce the number of women who die in childbirth. July 29
In the Nov. 6 election, Palo Alto and Livermore residents will be asked to vote on a ballot initiative — Measure F in Palo Alto and Measure U in Livermore — sponsored by the local union Service Employees International Union-United Healthcare Workers West (SEIU-UHW) that purports to control health care costs in their communities. We at Stanford Health Care are always focused on reducing the costs of the high-quality care we provide, the ballot initiative won’t help us accomplish this goal. Here are some facts you should know about this misguided initiative:

Why is SEIU-UHW promoting this ballot initiative?
The objective of this initiative is to pressure SHC into allowing the union direct access to non-unionized employees so that the union can expand its membership. The union has used this tactic at other health systems across California, and it is turning up the heat on Stanford Health Care in the hope that we give in to its demands.

SEIU-UHW says the measure will control health care costs. If this is a top priority at Stanford Health Care, why would we not support it?
The fact is, nothing in the initiative would limit what patients are charged. Rather, it would mostly benefit for-profit, out-of-state insurance companies by requiring local providers and hospitals — including Stanford Health Care — to pay rebates to insurers without any requirement that the rebates be passed on to patients. Simply put, SEIU-UHW’s motive is not the cost of care at Stanford Health Care, or the interests of patients, community residents and employees.

What are the consequences if this ballot initiative passes?
This misguided initiative poses far-reaching, negative consequences for a broad range of local health care providers: the Palo Alto and Livermore city governments; and, ultimately, the patients and people we care about and serve.

First, it would reduce community access to quality health care. The care providers affected by this initiative — including large providers as well as local dentists, optometrists and other small specialty practices — will be forced to cut back services, reduce staff or relocate to communities not affected by this measure.

For SHC specifically, this would mean a budget cut of up to 25 percent — making it difficult, if not impossible, to continue our current offering of patient care services and programs. It would also force SHC to reconsider how to use the new hospital building opening next year and eliminate our ability to retrofit current facilities. Patients would lose access to all but a small subset of specialty services, and SHC would be forced to look at reductions in staff, salaries and benefits. In addition, it would threaten our world-class status as an academic center that supports research and education.

Second, it would place a tremendous burden on local governments. The cities of Palo Alto and Livermore would be required to implement and enforce this confusing and ill-advised initiative, costing taxpayers’ money and potentially putting other public services at risk. Hospitals are already highly regulated by federal and state governments. Adding another layer of unnecessary bureaucracy will drain taxpayer dollars.

What can I do to help?
If you are eligible to vote in Palo Alto or Livermore, please vote no on Measure F in Palo Alto and Measure U in Livermore in the Nov. 6 election. In addition, please educate your friends and family on the potential impact of these initiatives if they are passed — every voice matters. You can learn more about the negative impact of these initiatives and how you can help at www.protectpaloalto.org and www.protectlivermore.org.

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Large windows with sweeping views. In-room sleeping areas for families. Bathrooms that meet the specific needs of hospital patients. The private rooms in the recently opened Lucile Packard Children’s Hospital Stanford expansion and the new Stanford Hospital have been designed to improve patient safety, promote healing, and enhance the patient and family experience.

“Most new hospitals are being built with single rooms because of the desire to provide privacy for patients and families, to ensure uninterrupted sleep, to provide a site for consultations with the patient and to foster a supportive ‘home away from home’ feeling,” said Norm Rizk, MD, chief medical officer for Stanford Health Care. “Providing single rooms reinforces Stanford’s desire to be a leader in innovative patient care and to meet our patients’ needs for a reassuring environment.”

George Tingwald, MD, AIA, director of medical planning for Stanford Health Care, said the hospital industry has moved toward making all patient rooms private. One reason is that viruses and bacteria pass more easily between patients sharing the same room despite consistent and thorough hand-washing and cleaning practices. “It is well-studied that private hospital rooms reduce hospital-acquired infection rates,” he said.

Fewer falls
Single-patient rooms also help reduce the incidence of falls. In adult hospitals, where a high percentage of patients are over the age of 65, negotiating the bathroom door is a primary source of falls. The new Stanford Hospital has larger bathrooms with sliding doors that will be left open at night.

At the new main building for Packard Children’s Hospital, which opened in December, the private-room design has already shown positive results. “We have seen a reduction in infections and an improved patient experience,” said Kelly Johnson, PhD, RN, vice president of patient care services and chief nursing officer at Packard.

One of the cornerstones of the private room design is that family members can stay in the hospital room at night. Every patient room in both hospitals, including those in the intensive care unit, has ample space for the care team, the patient and the family. The family space in the patient rooms at Packard Children’s Hospital features a sofa that converts into a bed, a safe for valuables and a second television.

“The Packard Children’s patient rooms are designed to be healing, comfortable spaces for the whole family,” said Johnson. “It’s not just a place for essential medical equipment and visits from doctors and nurses. It’s the place where patients and families spend most of their time, many of whom travel long distances for extended stays at the hospital.”

Having a family member room with a patient can help improve patient care, said Tingwald. Family members know the patient best, so they can quickly spot changes in a patient’s health or mental status. They also absorb important knowledge about caring for the patient, which helps improve care at home.

“We are encouraging patients’ families to spend the maximum amount of time possible with their family member, which means staying overnight and being with the patient at all times,” said Tingwald.

Improved efficiency
Private rooms provide a more efficient use of space. With shared rooms, nurses must spend a portion of each shift trying to create compatible roommate situations and reduce the risk of infection. As a result, about 20 percent of beds in shared rooms go unoccupied. With all private rooms, Stanford will be able to operate at nearly 100 percent capacity.

“We want to offer care to as many patients as possible who need our services,” said Ann Weinacker, MD, associate chief medical officer for patient care services at Stanford Health Care. “When we are unable to use beds, that decreases our patients’ access to our care.”

Faster healing
In designing the new hospitals, Stanford and Packard used evidence-based principles to improve safety and promote healing. For example, research has shown that patients who have a view of a garden or a tree outside their window, rather than a view of a brick wall, require less pain medication and are discharged sooner. Natural light also lets patients keep track of day and night, a factor in normalizing sleep-wake cycles.

“The power of design in the new Stanford Hospital is stunning,” said Tingwald, who is doubly trained as a physician and an architect. “These rooms have the largest views to nature that I have ever seen in a hospital.”

Private rooms are also quieter, another factor in achieving better sleep. “Allowing people to have the rest they want, allowing people to have the privacy they want, really improves their well-being,” said Weinacker. “And we all know that emotional well-being contributes greatly to physical well-being.”

When the new Stanford Hospital opens in 2019, every patient room will be private, including those in the intensive care unit. Once construction of the new Stanford Hospital concludes, work will begin on converting the existing hospital’s double rooms into private rooms. At Packard Children’s Hospital, all patient rooms in the new main building are private.

“The goal of offering private rooms has been part of the plan for many years,” said Tingwald. “We are well on our way.”

**Private rooms for all patients at Stanford’s new adult and children’s hospitals**

The patient rooms will promote healing and enhance care
Students find family at Stanford

Homar Murillo was 4 years old when he first suffered from heart failure. Doctors near his home in Hayward implanted a pacemaker when he was 5, which he had for nine years. He also suffered from severe asthma, recurrent pneumonia and — because his pacemaker limited his activity — obesity, which led to blood circulation problems and extreme numbness in his legs.

Today Murillo, 17, is a senior at Leadership Public High School — and he’s healthy. Inspired by the medical teams who helped him recover, he’s determined to become a trauma surgeon.

Murillo’s school counselor encouraged him to apply to the Stanford Medical Youth Science Program, a free, five-week residential summer program for low-income high schoolers from Northern California who aspire to careers in the medical and health sciences. Murillo attended the 2018 session — the program’s 30th — bringing its alumni roster to more than 700.

“I expected study, study, study, and no one talking to each other,” Murillo said. “But you walk into these doors and it’s like you have a whole new family. I’ve never gotten so close to people as I have in this program.”

Nurturing connections

The program combines science education, clinical internships, human anatomy lectures and labs, research projects on health disparities, and group activities that facilitate bonding and personal development. Strong connections that form among the 10 Stanford undergraduate counselors and 24 high school participants create a sense of belonging and kinship, according to several participants in the program. At least half of the teens in the program are away from home for the first time.

“We have identity workshops; ‘todos time,’ when everyone responds to a question; and storytelling,” said Luis Arreola, 18, a rising sophomore at Stanford and 2018 program counselor. Arreola, from El Sobrante, is an alumnus of the 2015 program. “All these activities push the participants out of their comfort zone. They become closer, more authentic. It’s almost as if you knew these people your entire life.”

The close, community experience is especially important for students with big goals complicated by challenging backgrounds. “This is a program for students who are low-income, who often experience high levels of adversity. And for counselors, it’s not just a summer job,” said Alivia Shorter, executive director of the program. Shorter was a counselor in the program in 2008, following her sophomore year at Stanford. “It’s a transformative experience for counselors, too, many of whom come from a similar background and felt that a mentor really changed their lives. Now they want to do that for someone else.”

Among students who fail to complete high school in California, the vast majority — 80 percent — are low-income, according to a 2018 report from Johns Hopkins University. Close to 100 percent of participants in the Stanford Medical Youth Science Program graduate from high school, and just over 80 percent graduate from a four-year college. “We’ve been tracking alumni since day one,” said Shorter, who is also the director of diversity and outreach for Stanford Pre-Collegiate Studies, a set of programs for teens of which the Stanford Medical Youth Science Program is now a part.

Changing their communities

The criteria for acceptance into the program are selective but aren’t focused solely on academic achievement. “We’re looking for students who are ready to dive in deep,” Shorter said. “And we know that might not mean the highest GPA. We’re really asking them, ‘What do you see in your community that you want to change, and how are you already taking those steps?’ How are you already getting involved in this world outside of just your coursework?” We’re looking at their academic potential from a bigger picture above their test scores.

The program was conceived by two Stanford pre-med students, Michael McCullough and Mark Lawrence, who in 1987 approached Marilyn Winkleby, MPH, PhD, now a professor emerita of medicine at the Stanford Prevention Research Center, seeking faculty sponsorship and financial support. Winkleby, who came from a low-income background, embraced the idea and secured funding. In 2011, the program was recognized with the U.S. Presidential Award for Excellence in Science, Mathematics and Engineering Mentoring.

An immediate benefit of the program is what the students bring back to their communities, Shorter said. “We can touch only 24 lives each summer,” she said. “But the students take home so much. They’re changing their communities the day they go home. It doesn’t just happen years from now when they become doctors. We don’t have to wait for them to be leaders. They are leaders right this very second.”

Winkleby still attends the first day of every summer session and stays involved with many former students for years after they finish the program, supporting alumni as they navigate the academic and professional worlds.

“Given my background, I had to learn to walk in the world of Stanford. And that was challenging. We’re empowering these students to know that you can walk in both worlds,” Winkleby said. “We’re empowering them to know that they’re smart, they belong in college and we need them in health careers.”

The program’s online application portal opens in mid-December each year, with applications due by Feb. 15. Admission information for the program is available online at smysp.stanford.edu.
his teams in all of these areas work to achieve quality care and high value for patients. “Ensuring the reliability of our processes is the foundation of providing high-quality care,” Donnelly said. “Through the performance improvement group, processes are continuously being evaluated and improved. And the patient experience team ensures that families are heard and that we use their feedback to continue to improve the health care experience.”

The renewed push for quality improvement

Frush and Donnelly say that safety and quality in health care are priorities that took on renewed importance in 2010 with the inception of the Affordable Care Act, which included measures for quality improvement. In March 2011, the Agency for Healthcare Research and Quality created a national strategy to guide quality improvement efforts at the local, state and national levels.

“Having an emphasis on quality and safety and a dedicated chief quality officer position is much more common now than it was 15 years ago,” said Frush, who is also a clinical professor of emergency medicine at the Stanford School of Medicine.

“Packard Children’s has always prioritized safety,” said Donnelly, who is also a professor of pediatric radiology at Stanford. “Our emphasis is on decreasing variation in the ways teams work to improve their respective areas.”

A good example is Packard Children’s progressively decreasing rates of infections from central lines, which are catheters placed in large veins. Because of the move toward more standardized processes, the hospital has seen a 30 percent reduction in central line infections thus far in 2018. “While we won’t be satisfied until preventable harm is eliminated, we are encouraged by the progress,” Donnelly said.

Reducing central line infections has also been an area of focus at Stanford Health Care. In the past, central line catheters were sometimes inserted in the operating rooms. Now the insertions are done in the ICU, which has better infection-control mechanisms. Additionally, because infections are likelier the longer a catheter stays in the body, protocol at Stanford encourages care teams to remove the catheters as soon as possible.

In all, Stanford Health Care has more than 120 safety and quality initiatives in place. One of those initiatives focuses on pressure ulcers that develop on the skin or other tissues. Many intensive care patients are fed through nasal tubes. A nurse in one of the hospital’s ICUs developed a novel way to secure the feeding tube so it doesn’t press against the nose, thereby avoiding damage to the tissue.

In addition, Stanford Hospital has started using robots that disinfect rooms with pulsed xenon ultraviolet light to clean spots that are difficult and time-consuming to reach with traditional techniques. This technology has allowed cleaning staff to disinfect rooms quickly and efficiently.

Patients with complex needs

Donnelly also points to Packard Children’s history of excellence in providing quality care in its renowned specialty centers like those for transplant and complex cardiac care.

“These programs are among the largest in the country in volume and have the best clinical outcomes,” he said. “This has led to Packard Children’s being known for providing the highest quality care to the most complex pediatric medical population in the country.”

When asked what it takes to maintain a culture of safety, Donnelly said it involves “consistency and creating an environment where people feel comfortable speaking up. Historically, that has been a challenge with the hierarchical culture in the medical environment. But I think we are making great progress toward amending that.”

Frush agreed. “Ultimately, the goal for us is zero health-care-acquired infections,” she said. “If we all work together — physicians, nurses, residents in our training programs, researchers, safety and quality experts, environmental care staff, etc. — we can eliminate preventable infections. Nobody in health care will be satisfied until the preventable infection rate is zero. It takes a whole lot of effort, it takes new science and new technology, but it can be done.”
Google Glass helps kids with autism understand faces

Stanford-developed app makes a game of recognizing facial expressions

Alex took part in a pilot study in which a smartphone app paired with Google Glass was shown to help children with autism understand emotions conveyed in facial expressions.

Last year, a few weeks after he began participating in a Stanford pilot study of a novel autism treatment, a boy named Alex did something that really surprised his mother.

“He was engaging with my eyes, flickering his eyes at me,” said Donji Cullenbine, whose son is now 9. It was a big change for Alex, who had always felt anxious about looking at people’s faces and had struggled to understand what others might be thinking.

The pilot study demonstrated that Google Glass technology could help kids with autism recognize facial expressions. Stanford researchers devised an app that pairs with Google Glass to act as an emotion-recognition tutor for children with autism. After one to three months of regular use, parents reported that children in the study made more eye contact and related better to others.

“Across the country, we have too few autism practitioners,” said the study’s senior author, Dennis Wall, PhD, associate professor of pediatrics and of biomedical data science. Early autism therapy has been shown to be particularly effective, but many children aren’t treated quickly enough to get the maximum benefit, he said.

“The only way to break through the problem is to create reliable, home-based treatment systems. It’s a really important unmet need.”

Learning game

Autism is a developmental disorder that affects 1 in 59 children in the United States, with a higher prevalence in boys. It is characterized by social and communication deficits and repetitive behaviors.

Before her family participated in the study, Cullenbine tried using gentle encouragement to boost Alex’s social interactions. “I would smile and say things like, ‘You looked at me three times today!’ But it didn’t really move the bar,” she said. Using Google Glass transformed how Alex felt about looking at faces, Cullenbine said. “It was a game environment in which he wanted to win — he wanted to guess right — and he got an instant reward when he did.”

‘Superpower Glass’

The researchers named the new therapy “Superpower Glass” to make it appealing to children. The therapy is based on applied behavior analysis, a well-studied autism treatment in which a clinician teaches emotion recognition using structured exercises such as flash cards depicting faces with different emotions. Although traditional applied behavior analysis helps children with autism, it has limitations: It must be delivered one on one by trained therapists, flash cards can’t always capture the full range of human emotion, and children may struggle to transfer what they learn to their daily lives.

The Google Glass device, which is linked with a smartphone through a local wireless network, consists of a glasses-like frame equipped with a camera to record the wearer’s field of view, as well as a small screen and a speaker to give the wearer visual and audio information. During the “Superpower Glass” therapy, as the child interacts with others, the app identifies and names their emotions through the Google Glass speaker or screen.

The app recognizes eight facial expressions and can be used in three modes: free play, in which the device names the expression of anyone in the wearer’s field of view, and two game modes that provide fun, rewarding ways for children to practice naming the facial expressions.

The study included 14 families, each of whom had a child between ages 3 and 17 with a clinically confirmed autism diagnosis.

At the end of the study, the children’s scores on a social-skills questionnaire indicated less-severe autism symptoms. Six participants had experienced changes in their scores large enough to move down one step in the severity of their autism classification, and 12 of the participating families reported that their kids made more eye contact.

Marked improvement

Parents’ comments in interviews with the researchers helped illustrate the improvements, Wall said. “Parents said things like ‘A switch has been flipped; my child is looking at me.’ Or ‘Suddenly the teacher is telling me that my child is engaging in the classroom.’ It was really heart-warming and super-encouraging for us to hear.”

A few weeks into the trial, Alex began to realize that people’s faces hold clues to their feelings. “He told me, ‘Mommy, I can read minds!’” Cullenbine said. “My heart sang. I’d like other parents to have the same experience.”

Wall’s research team is now completing a larger, randomized trial of the therapy. They also plan to test it in children who have just been diagnosed with autism and are on a waiting list for treatment. The project’s website, autismsglass.stanford.edu, has more information about ongoing clinical trials for those interested in participating in the research.
Rachel Hale knew her adolescence was unusual. The headaches, the nausea, the dehydration, the blood draws leaving scars on her arm — this wasn’t what most other kids her age were going through.

By the time she was 24, Hale was on her fourth diagnosis and had been on headache medication for years. Her condition prevented her from participating in sports and social events — sometimes she couldn’t even go out to eat with friends. She had bounced from physician to physician and hospital to hospital, without much relief.

Then, in November 2017, when Hale was at Stanford Hospital, she met Linda Nguyen, MD, a clinical associate professor of gastroenterology and hepatology at the Stanford School of Medicine who was assessing Hale’s gastrointestinal issues.

Nguyen had recently heard from Ian Carroll, MD, a headache and orofacial pain specialist at Stanford. Carroll had shared information with her about cerebrospinal fluid leaks: He said the leaks were characterized by chronic, intractable nausea in addition to ringing in the ears, vomiting and headaches.

When Nguyen contacted Carroll about Hale, he immediately took an interest in her case. He ran scans and imaging, and diagnosed a CSF leak. “I don’t think I’ll ever forget doing the first diagnostic test where he just had me lie flat,” recalled Hale. “It was the first time my headache has ever gone away, and it was a huge ‘Aha!’ moment for me.”

A patch made from blood

A CSF leak occurs when the meninges — a covering that protects the brain and spinal cord and holds the cerebral fluid in place — forms a tear, allowing the fluid to escape. CSF leaks can occur spontaneously, but people with Marfan and Ehlers-Danlos syndromes, both connective tissue disorders, are at the highest risk.

To treat the CSF leak, Carroll performed an epidural blood patch. In the procedure, the patient’s own blood is injected into the meninges, creating a seal over the tear in the covering.

After her first blood patch, Hale improved substantially, and Carroll was confident they were on the right path.

“We want multiple dimensions across her life to improve so she can return to function and do the things a young woman wants to do instead of seeing doctors all the time,” said Carroll, who is also an assistant professor of anesthesiology, perioperative and pain medicine at the School of Medicine.

Carroll believes that CSF leaks may be more common than anyone thought, and often misdiagnosed. He speaks from personal experience: His daughter had a CSF leak that had gone undiagnosed. That’s when he began to think about the interplay of different syndromes and symptoms, and how important it was for a major academic medical center like Stanford Health Care to collaborate across departments.

Orthostatic headache, or headache that is worse when upright, is a key feature of a CSF leak, but is also a common feature in patients with postural orthostatic tachycardia syndrome, or POTS.

Targeting patients at risk

“Patients shouldn’t have to wander from doctor to doctor until they randomly interact with one who happens to know that some people are at greater risk of developing a leak. After the personal experience I had with my daughter, I started reaching out to the Stanford Headache Clinic as well as the POTS and Marfan clinics. Now we’re all reading about these leaks and it has created a great dialogue,” said Carroll.

Hale laughed when Carroll insisted she watch three videos and read a paper about her procedure before he would even talk to her. But in the end, his advice was right: “He involved me a lot and kept me updated, which I really, really appreciated,” she said.

Hale’s headaches aren’t as common as they once were, and the sensory overload feelings are subsiding. She will continue to receive the blood patch procedures to keep her symptoms under control.

“This blood-patching thing, from a nerdy, scientific perspective, I think is so fascinating,” she said. “I love it.”