Solving Sickle Cell

Investigators at UCLA are at the forefront of research to cure this painful, debilitating and often-deadly blood disorder.
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“...our unhoused neighbors are still our neighbors. They need to be treated with dignity and respect. In some ways, I wish our program didn’t have to exist. I feel that health care is a human right, and we should be able to deliver efficient, effective, equitable care to everybody. But this is the reality in which we live.”
— Brian P. Zunner-Keating, RN
“House Calls Without Walls,” p. 40

BREAKTHROUGHS AND NEWS FROM UCLA HEALTH.

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Patients, or the families of patients, quoted and/or photographed or pictured in this publication have given their consent to have their names and/or images used and their stories told.

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Science Wins

In the race to cure sickle cell disease, the same spirit that brought us COVID-19 vaccines will power us across the finish line.

The disease causes a litany of miseries: excruciating pain crises, organ damage, bone loss, stroke, blindness, lung disorders, anemia. It both shortens and circumscribes patients’ lives, undermining their ability to pursue an education, earn a living or raise children. Yet, as you will read in the cover story of this issue of U Magazine (“Solving Sickle Cell,” p.30), scientists are closing in on a cure for this complex disease — enough to ensure that it had a chance of working. Since then, dozens of patients who have received such therapies — including some at UCLA — have found lasting relief after a single treatment. More time and study are needed to monitor for long-term efficacy and potential delayed side effects, but there’s ample reason for optimism.

Such successes help explain why scientists are willing to spend decades pursuing research that has no immediate application and conducting trials that don’t pay out. In part, it’s sheer curiosity — a yen for knowledge. But it’s also a desire to make a difference. Scientists watch their friends, family members, neighbors or loved ones suffer. If they’re clinicians, they witness their patients struggle. They want to help. And that deeply human impulse keeps them at the lab bench or the study site, day after day, year after year.

“It is sometimes said that science has nothing to do with morality,” the biochemist Linus Pauling once observed. “This is wrong. Science is the search for truth, the effort to understand the world; it involves the rejection of bias, of dogma, of revelation, but not the rejection of morality.”

I’d go a step further: Science, at its best, is driven by morality. It aims not only to find the truth, but also to harness it for the betterment of the human condition. That’s why, sooner or later, science always wins.
THE RUSSIAN INVASION OF UKRAINE has displaced more than 12 million people, among them nearly 180,000 newly diagnosed cancer patients in need of treatment and medication. As they have in past international crises, people at UCLA Health stepped up to help.

Since June, two shipments of cancer drugs and supplies gathered by faculty, staff and students of UCLA Health have been shipped to Ukraine for patients desperately in need. The first shipment, coordinated by John A. Glaspy, MD ’79 (RES ’82, FEL ’83), Simms/Mann Family Foundation Chair in Integrative Oncology and professor of medicine at the UCLA Jonsson Comprehensive Cancer Center, and Project HOPE, a global health and humanitarian aid organization, arrived in Kharkov, Ukraine, on June 8.

“Typically, in a situation like this, people might buy [cancer] drugs and donate them, but that isn’t efficient or sustainable,” Dr. Glaspy says. Instead, he went straight to the source—the manufacturers—who spoke with biopharmaceutical CEOs about sending donations to Ukraine.

Both companies, Amgen and McKesson, agreed to the arrangement.

“THE DELIVERY WAS COMPLEX, involving import and export regulations and customs in three nations—the United States, Poland and Ukraine,” says Jason Obten, Project HOPE global logistics director. “It required precision timing to ensure that the cold-chain requirements were maintained throughout the shipping process up to the point of delivery in Kharkov.”

The shipment included 3,000 vials of filgrastim, a drug to help the body make white blood cells after chemotherapy treatment. The donation to the Grigoryev Institute of Medical Radiology and Oncology of The National Academy of Medical Sciences of Ukraine has thus far helped treat more than 50 patients.

“We cannot thank Dr. Glaspy and UCLA Health enough for the tremendous effort to make this donation possible,” Obten says.

A second shipment followed in July, 25 pallets of medical supplies, ranging from surgical masks and face shields to sponges and bandages—more than 13,000 pounds—to the International Medical Corps of Ukraine in Kyiv.

“We had leftover medical supplies from Care Harbor (an annual clinic to provide medical care to underserved populations in Los Angeles), and donating to Ukraine was the best way for us to utilize them,” says Candis Crockett, principal analyst at UCLA Health, who helped manage the donation logistics. “It’s been a difficult time with the global supply chain, so it made sense that sending supplies, rather than money, would have a greater impact.”

Students from Medical Aid Initiative, a student-run organization partnering with UCLA Health to share resources globally, also participated in the effort, donating supplies and time in the warehouse.

“Every time there has been an international crisis, we have turned to the MAI students to help support our humanitarian efforts, and their contribution as they gather and prepare shipments of available medical supplies has been invaluable,” says Fedra Djourabchi, director of strategic marketing at UCLA Health.

One of the greatest aspects of this donation was that people from all areas of the organization joined in, according to Crockett. “From clinical engineers helping with CO2 monitors to the patient-trans- port team, who shuttled students and volunteers from campus to the warehouse to help assemble the pallets, everyone pitched in.”

It’s “our responsibility as a health organization to help not only our own patients, but patients in our global community,” Djourabchi says.

UCLA Health has a long history of such engagement. When a devastating earthquake struck Haiti in 2010, a team of doctors and nurses assembled to help. Some went as part of an organized UCLA effort—Operation Haiti—while others traveled on their own or with other non-governmental organizations. In 1999, when war broke out between ethnic Albanians and ethnic Serbs and the government of Yugoslavia in Kosovo, a 26-member UCLA medical team joined with International Medical Corps to deliver care to Kosovar refugees. And for the past six months, UCLA Health recreational therapist Christie J. Nelson has been working on the Poland-Ukraine border to provide aid to Ukrainian refugees fleeing from the Russian invasion of their country (see Epilogue in this issue, “Letter from Medyka,” page 60).

Dr. Glaspy was motivated to act in response to what he sees as a disturbing trend in geopolitical dynamics, a situation that has him contemplating history and moral values. “What we see happening in Ukraine is not new,” he says. “The bigger picture is that good and evil have been afoot in the world for as long as there’s been people. And in my view, evil has been slowly winning.”

As further evidence, he calls forth a Pulitzer Prize-winning photo taken during the famine in Sudan in the early 1990s of a frail child who has collapsed trying to reach a feeding station just a half-mile away, while a vulture lurks in the background. “We are in a world where every day there’s one of those pictures playing out and there’s a vulture that’s getting closer and closer,” Dr. Glaspy says.

In the end, it comes down to how far each of us is willing to go to try to make a difference. Says Djourabchi, “All the humanitarian efforts we’ve done—we whether in Beirut, Armenia, Haiti and now Ukraine—they all have the mission of healing humankind.”

Jocelyn Apodaca Schlossberg is a senior writer focused on equity, diversity and inclusion for UCLA Health Communications.
Add to that disturbing list an estimated 3 million children who are exposed to gun violence each year. When children are exposed to violence, it leads to increases in stress and anxiety, and decreased physical activity, as a result of feeling unsafe. The effects of gun violence disproportionately impact communities of color. Black, Hispanic and Indigenous youths are more likely to die from firearm homicide than their white counterparts. Exposure to gun violence in these communities contributes to trauma and health inequities, with lifelong implications that exacerbate unacceptable health disparities.

We can’t talk about firearm violence without talking about trauma. Science teaches us that such violence can have life-long negative impacts on physical and mental health and well-being. We owe it to our children to protect them from this trauma.

It is not just the victims of gun violence who experience trauma. Often the precipitator to such violence. A recent study by The Violence Project, a nonprofit and nonpartisan research center focused on violence prevention and intervention, found that 100% of the perpetrators of mass shootings from firearm when we were teens. One of my brother’s best friends was shot in our home by his irate cousin. He was 21, and his wife and my mother were there when it happened. My mother said over and over, “There was so much blood. We couldn’t stop the bleeding.” He died before the ambulance arrived.

There have been other deaths as well. Mine is not a unique story. Far too many Americans have been affected far too many times by gun violence. We need to do more, and we need to do better.

As some of the examples I’ve given demonstrate, unsecured firearms are a threat to public safety. A multisite study found that keeping a gun locked and keeping a gun unloaded have protective effects of 73% and 70%, respectively, with regard to risk of both unintentional injury and suicide for children and teenagers. Funding to educate and train health care providers to identify individuals at high risk for suicide, communicate effectively with patients about firearm safety and/or to support suicide-prevention best practices can have a dramatic impact on reducing youth suicide.

6 7

ON THE MORNING OF MAY 24, 2022, the students of Robb Elementary School, in Uvalde, Texas, started their day like any other. They tied their shoes, put on their backpacks and said goodbye to their parents and caregivers. They went to school expecting to see their friends, to learn and to prepare for the start of summer break in just a few short days. Many of them received awards for being on the honor roll that very morning. It should have been an ordinary day.

It was not. The lives of 19 third- and fourth-grade students — ages 9, 10 and 11 — were taken in a horrific display of violence. On that day, Dr. Roy Guerrero, Uvalde’s only pediatrician, was called to the emergency room to help with the injured children.

During that day, Dr. Roy Guerrero, Uvalde’s only pediatrician, was called to the emergency room to help with the injured children. He went to school with the weight of his professional and personal life. Three boys I grew up with died by suicide with a firearm when we were teens. One of my brother’s best friends was shot in our home by his irate cousin. He was 21, and his wife and my mother were there when it happened. My mother said over and over, “There was so much blood. We couldn’t stop the bleeding.” He died before the ambulance arrived.

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WE CAN DO MORE TO PROTECT CHILDREN FROM GUN VIOLENCE

By Moira A. Szilagyi, MD, PhD

ON THE MORNING OF MAY 24, 2022, the students of Robb Elementary School, in Uvalde, Texas, started their day like any other. They tied their shoes, put on their backpacks and said goodbye to their parents and caregivers. They went to school expecting to see their friends, to learn and to prepare for the start of summer break in just a few short days. Many of them received awards for being on the honor roll that very morning. It should have been an ordinary day.

It was not. The lives of 19 third- and fourth-grade students — ages 9, 10 and 11 — were taken in a horrific display of violence. On that day, Dr. Roy Guerrero, Uvalde’s only pediatrician, was called to the emergency room to help with the injured children. Ultimately, he lost five of his young patients — children he had taken care of for much of their lives. Helping keep children safe is one of the most essential roles of pediatricians like myself and Dr. Guerrero. We have advocated for car seats and safe-sleep practices. To keep children safe from disease, we encourage vaccinations. We remind our patients to wear their bicycle helmets and suggest their parents monitor their children’s social-media use. We do this because protecting children from preventable injury and death is, perhaps, the most fundamental obligation we owe our young people. But there is a limit to what pediatricians can do in the exam room.

Public policy is an essential tool as well. Across the country, states have established laws requiring the use of helmets, car seats and immunizations to attend school. The federal government also sets critical public policy. Just this year, Congress passed an important law prohibiting dangerous infant-sleep products.

We’ve made fantastic progress reducing child injury and death from a variety of causes. But not when it comes to guns. In fact, firearms are now the leading cause of death in children, surpassing car accidents. Pediatricians counsel families about gun safety, but the duty to keep children safe extends beyond pediatricians and educators. It is a duty we share as a society.

I am sorry to say, we have failed our children. Every year in the United States, more than 3,500 children and teens die by firearms, including those by suicide. That is like having a Uvalde-scale tragedy every other day. Roughly another 15,000 children and teens are wounded by firearms every year.

1966 to 2019 had a history of childhood trauma — child abuse or neglect, emotional abuse, bullying or exposure to significant violence. Research also shows that childhood trauma can lead to negative changes to the body’s stress response; the brain of a traumatized individual is wired to scan for danger and has less capacity for emotional and behavioral regulation.

Not only do we need to do more to directly protect children from firearms, we also need to identify affected children and engage them in a trauma-informed way and get them the care they need, as well as ensure they cannot access firearms. However, access to mental-health services and trauma-informed care alone will not solve the epidemic of gun violence. Therefore, we have no choice but to also address the availability of firearms for individuals who are at risk for doing harm to themselves or others. Over the course of three decades as a pediatrician, I have treated five children who were accidentally shot by themselves or another child with a gun that was left unsecured. I once cared for a 2-year-old in the emergency department who died after finding an unlocked, loaded pistol under the couch in his home. I cared for a 14-year-old who died after a bullet pierced his aorta when his best friend accidentally shot him with an unlocked, loaded pistol they were playing with. A teenage girl was shot in the spine by her boyfriend as they pretended to play Russian roulette with a gun they assumed was unloaded; she lost all bodily function below her waist. Two others survived gunshot wounds, but with injuries that will burden them for life. We simply must do more to encourage gun owners, especially those with children, to safely store their firearms.

You might expect that gun violence would touch my professional life as a doctor. But gun violence has also touched my personal life. Three boys I grew up with died by suicide with a firearm when we were teens. One of my brother’s best friends was shot in our home by his irate cousin. He was 21, and his wife and my mother were there when it happened. My mother said over and over, “There was so much blood. We couldn’t stop the bleeding.” He died before the ambulance arrived.

There have been other deaths as well. Mine is not a unique story. Far too many Americans have been affected far too many times by gun violence. We need to do more, and we need to do better.

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In addition to other potential measures, there is a critical need for increased federal investment in gun-violence-prevention research. A recent Centers for Disease Control and Prevention (CDC) report showed that the United States experienced a historic rise in gun deaths in 2020, affecting all age groups and widening existing racial and ethnic disparities in firearm-related deaths across the nation. The dearth of research on how best to prevent firearm-related morbidity and mortality makes the problem difficult to address.

Fedally funded public health research has a proven track record of reducing public health-related deaths in instances ranging from motor-vehicle crashes to smoking. This same approach can be applied to increasing gun safety and reducing firearm-related injuries and deaths. Continuing and expanding CDC and National Institutes of Health research will be critical to that effort.

While we know some of what works, we must never stop learning better strategies to keep our children safe. They are counting on us.

By Moira A. Szilagyi, MD, PhD

Dr. Moira A. Szilagyi is Peter Shapiro Term Chair for the Promotion of Child Developmental and Behavioral Health in the David Geffen School of Medicine at UCLA, chief of the Division of Developmental/Behavioral Pediatrics and president of the American Academy of Pediatrics (AAP). This column is edited from Dr. Szilagyi’s testimony before the U.S. Senate Committee on the Judiciary in June 2022.
In a paper published last year, Ellen Gabel, MD (RES ’15), assistant clinical professor of anesthesiology in the David Geffen School of Medicine at UCLA, and UCLA Anderson School of Management’s Velibor V. Milic and Kumar Rajaram explore how best to evaluate possible algorithms, or machine-learning models, that would seek to identify patients at risk of readmission. Understanding the value of a machine-learning model from a clinical perspective is not straightforward. In machine learning, a commonly used metric is something called the area-under-the-curve (AUC), which addresses the following issue. Suppose we are given a patient who will be readmitted, and a patient who will not be readmitted, but we do not know which is which. What is the chance that the model identifies the higher risk for the patient who goes on to be readmitted than the patient who is not?

If we opted to flip a coin and make a random guess as to which one will be readmitted, we would be right only 50% of the time. If we had a perfect model, we would be right 100% of the time. So, this metric ranges from 50% to 100%. In practice, an AUC of 70% is considered fair, an AUC of 80% is considered good and an AUC of 90% is considered excellent.

But AUC is abstracted from the realities of clinical decision-making. It does not take into account that a provider is using the model to identify patients and is operating under a limited schedule. It does not take into account the cost savings of each readmission that the model correctly anticipates, or the costs of the provider needed to operationalize that model.

Using data on 19,331 surgical admissions to Ronald Reagan UCLA Medical Center during an 847-day period ending in 2018 — and the 969 patients (5% of total) readmitted to the hospital’s emergency department within 30 days of being discharged — the goal is to see whether, and how well, machine-learning models could have identified that subset of patients and thus prevented readmissions.

The authors test four machine-learning models and examine their performance at various levels of availability of care providers (physician or nurse). In addition to improving patient outcomes, an algorithm needs to fit into the workflow of care providers and also be cost effective, the authors note.

To be sure, unlimited patient access to a physician or nurse’s time would reduce readmissions. The models’ job is to stop potential readmissions without wasting those valuable resources on patients who’ll do fine after discharge. Surgeons and specialists aren’t always available every day, so the authors test the four models under three provider schedules:

- Providers see eight patients every Monday.
- Providers see eight patients on Monday and eight on Wednesday.
- Providers see eight patients per day, Monday to Friday.

Two of the models, for instance, are only applied on the date of a patient’s discharge, so that if a patient is discharged on a Tuesday, those models won’t select that patient to see a provider on the first two schedules. Thus, they yield lower figures on the “patients seen” metric.

When provider availability is limited, the use of a more sophisticated machine-learning model that incorporates lab test results improves readmission results significantly. As provider availability increases, the difference between a model that uses lab results and one that eschews labs narrows.

Cost savings roughly track readmissions, though provider time is expensive and it reduces savings. The authors’ results show that models that rigidly call for examination, say, on day of discharge, are less valuable for predicting patient readmission and for cost savings.

This could be because care providers aren’t available on that day, or, conversely, they may see patients who are discharged on that day, even if that patient is not the most in need of their care.

The authors’ simulation model is helpful for hospital administrators and staff as they determine which machine-learning models will be useful for their particular clinical setting and level of staffing and resources.

By Anna Louie Sussman

CONSUMERS ARE FAMILIAR WITH HOW ALGORITHMS WORK. Amazon, using your prior buying habits, suggests similar purchases. YouTube, based on what you’ve already watched, offers related videos. The consumer can take it or leave it, and the company has spent little to make the offer. If the algorithms don’t work for you, not such a big deal.

But what about in a far more critical setting? One with countless variables, such as a hospital? Algorithms certainly hold out the promise to improve medical decision-making and reduce costs but implementing just one — and there is the potential for thousands in a major medical center — is a complex task and requires careful monitoring of its performance and patient outcomes.

A favorite target of performance-improvement methods — manual or digital — at hospitals is readmissions. When patients have to return to the hospital after a surgery or treatment, it suggests a complex task and requires careful monitoring of its performance and patient outcomes.

READMISSIONS?
EATING FOR A HEALTHY PLANET

By Dana Ellis Hunnes, PhD, MPH, RD

MY SUSTAINABILITY JOURNEY BEGAN as a nutrition-science major at Cornell University. It was there that I first learned about the connections between our own personal health and the foods we eat, which led me to become a registered dietitian. Then, in 2008, I was reading the book Whose Water Is It Anyway, detailing the many legal fights that occur in the Western U.S. over the rights to water to grow the foods we all need to survive. This eye-opening read led me to research the effects that climate change has on food security — specifically in Ethiopia, a country that depends on rain for most of its food needs.

While in Ethiopia, I met dozens of individuals who had migrated from their farming villages into the capital city, Addis Ababa, because there hadn’t been enough rain for them to grow their food. They came to Addis to earn a cash income so they could buy enough imported food to feed their families for that harvest year and pay their land-taxes. They all hoped this move would be temporary and they’d be able to return home during the next harvest season, when the rains should return. For most of these families, farming is their livelihood. Without it, they lose their culture and way of life, and they are at extreme risk for malnutrition. To them, climate stability means everything.

From this experience, I realized just how much climate change will affect humanity’s ability to grow enough food for a swelling population. The impacts of an increasingly erratic environment are very apparent in places like Ethiopia, but they also are taking a toll everywhere. In parts of the United States, for example, groundwater is drying up and topsoil is blowing away, potentially leaving us in a situation where our own food security will also be at risk.

And it isn’t just that climate change affects our ability to grow food; it’s also that the foods we grow and eat affect the environment, sometimes in dramatically negative ways.

For example, it takes 10 times as much land to produce one gallon of cow’s milk as it does to produce one gallon of oat milk. Likewise, it is possible to grow 50-to-100 times more calories of plant-based foods, such as wheat, corn or soy, on an acre of land compared with the calories derived from beef raised on that same acre of land. And when you consider the proportion of greenhouse gases that come from animal agriculture — more than that produced by all the cars, planes, trains, and ships in the world — you quickly realize just how much the foods we eat affect the environment.

As I grappled with the difficult realities of the connections between climate and food security in Ethiopia, and globally, I also came to more deeply understand how the foods we eat affect our own health — either contributing to illness or helping to alleviate, or even reverse, chronic diseases such as diabetes, heart disease, stroke and cancer.

By the time I gave birth to my son in early 2014, I already was a plant-based consumer for health reasons. Yet, I couldn’t ignore everything I had learned about the food-environment connections. So, I doubled down on plant-based eating for my health, for sustainability and for environmental reasons. I do it for my son and his generation.

When we eat a whole-foods, plant-based diet, we not only can improve our own health, but we also can help the environment support our children’s future by reducing the greenhouse-gas emissions produced by farming the food we currently consume while also decreasing the amount of land that is needed to grow it. This change alone can significantly mitigate the need for further deforestation — and we seriously need to protect our greenhouse-gas-scrubbing forests. Additionally, a plant-based diet also significantly reduces the amount of water that is needed to produce our food, which is critical because just 3% of water on Earth is freshwater.

Dr. Dana Ellis Hunnes is a senior dietitian at UCLA Health and adjunct assistant professor of community health sciences at the UCLA Fielding School of Public Health. She is the author of Recipe for Survival: What You Can Do to Live a Healthier and More Environmentally Friendly Life (Cambridge University Press, 2020). This essay is adapted from the original version published online at mindbodygreen.com.
MARIO DE LOPEZ

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their adoptive families in distinct young women, each known as Josie, and Maria

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siologists, surgeons, pediatricians, — surgeons, pediatricians, after the operation involved

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International, that helps brought to UCLA under the of southwest Guatemala and

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and Maria Teresa Álvarez, babies — Maria de Jesús

as "The Little Marias." The affectionately become known

operated to separate con - watched as UCLA surgeons

arrival of hundreds of health care work-
ers — surgeons, pediatricians, nurses, radiologists, anesthe-

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gled cat-shaped purse that the youngerster immediately 

wear in a joyful way. Bertoli

definitely put a smile on her face," the girl’s mother says.

The team decks out a second room in green with a baseball theme, including a new mitt for the hospitalized child. Another is turned into a turquoise unicorn wonder-

land, with tassels hanging from the ceiling and a plush unicorn toy on the bed. By the time the decorating is done, the child in the room is

enjoyed on many beautiful people on staff — put two cots together and dropped the divider

between," recalls Jorge Lazareff, MD, then the chief of pediatric neurosurgery and leader of the team that cared for the twins and now emeri-
tus professor of neurosurgery.

"They cushioned with pillows all four sides of the cot so the girls would not bump into each other. Maria Teresa was facing one way and Maria de Jesús was facing the other side, almost 180 degrees. One of the nurses got a mirror and put the mirror in front of Maria Teresa so she could see her sister. And I think that perhaps was the first time they saw each other’s face."

TRENDS IN THE OPENING EDGE U Magazine Fall 2022

TWENTY YEARS AGO

this past August, the world watched as UCLA surgeons operated to separate con-

joined twin girls who had affec-
tionately become known

"The Little Marias." The babies — Maria de Jesús and Maria Teresa Álvarez, craniopegus twins fused at

the skull facing opposite directions — were born the previous July in a rural region of southwest Guatemala and brought to UCLA under the auspices of an international nonprofit, Mending Kids International, that helps provide advanced surgical care to children in need across the globe.

The exquisitely complex surgery to separate the girls on August 6, 2002, took more than two months to plan and nearly 24 hours to complete. Their caskets and a span after the operation involved

hundreds of health care work-
ers — surgeons, pediatricians, nurses, radiologists, anesthe-

siologists, interns, residents, technicians and social work-
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definitely put a smile on her face," the girl’s mother says.

Today, Maria de Jesús, known as Josie, and Maria

Teresa, or Teresita, are two, distinct young women, each living her own life with their adoptive families in Los Angeles, where they re-

turned after it became clear that they could not receive the ongoing care they would need in Guatemala. On July 25, they turned 21 years old. Over the years, Josie and Teresa have periodically returning to UCLA to volun-
teer with a project to brighten the lives of young patients. Most recently, Josie was at UCLA Mattel Children’s Hospital for her Once Upon a Room project, a nonprofit she created when she was 12 years old with her best friend, Siena Dancsecs, and adoptive mother, Jenny Hull, to make over the rooms of pediatric patients and decorate them like the colorful bedrooms they might have at home. On this day, they transform the room of one 8-year-old girl from plain hospital white to Hello Kitty hot pink, complete with colorful comforters, banners bearing the girl’s name and a single glittery pink wings. "It makes the kids so happy," Josie says. "I know how the kids feel when it’s just blank, with no decoration."

As she makes her way down the hall, a nurse calls his name and a span after the operation involved hundreds of health care work-
ers — surgeons, pediatricians, nurses, radiologists, anesthe-

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definitely put a smile on her face," the girl’s mother says.

Josie has graduated from high school and is looking toward college, preferably UCLA and a future career as a child-life specialist. Though

she still contends with health and mobility challenges and uses a specialized scooter to get around, she’s outgoing, with an easy, warm smile. "She sees everything through happiness,” she says.

Perhaps that is because The Little Marias were im-

mediately embraced with love and joy when they arrived at UCLA as infants, and that has endured over the years. "The whole nursing team — unknown, anonymous, some of the many beautiful people on staff — put two cots together and dropped the divider in between," recalls Jorge Lazareff, MD, then the chief of pediatric neurosurgery and leader of the team that cared for the twins and now emeri-
tus professor of neurosurgery.

"They cushioned with pillows all four sides of the cot so the girls would not bump into each other. Maria Teresa was facing one way and Maria de Jesús was facing the other side, almost 180 degrees. One of the nurses got a mirror and put the mirror in front of Maria Teresa so she could see her sister. And I think that perhaps was the first time they saw each other’s face."

Teresa has faced more health complications than her sister. A bout with meningitis shortly after the sisters returned to Guatemala following their surgery left her non-verbal and reliant on a wheelchair. "(Maria Teresa) has faced a lot of circumstances you could not see her surviving from, but she’s come a long way," her adopted sister, Vivian Cajas, said at the girls’ quinceañera in 2016. Josie has graduated from high school and is looking toward college, preferably UCLA and a future career as a child-life specialist. Though

she still contends with health and mobility challenges and uses a specialized scooter to get around, she’s outgoing, with an easy, warm smile. "She sees everything through happiness,” she says.

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Kindness continues to be the hallmark of the twins’ experience at UCLA, Hull says. Dr. Lazareff has come to

many of the twins’ birthday celebrations, and Hull is still connected to members of the hospital staff who went out of their way to share kindness and support. She recalls custodial workers who

"came in every day they were at work. They were probably the biggest joy during our time being there because they weren’t who you expect to be the pick-me-up people."

Nancy Tag is one of those angels. He started working at UCLA shortly before The Little Marias arrived. As soon as he saw them, “I knew I had to take care of them,” he says. He brought in foam mats so the girls could safely play on the floor. “From that point on, I was in there every day,” he says. “Those are my Guatemalan twin babies.”

When the twins turned 10 years old, Dr. Lazareff reflected on the cooperation and teamwork it took to care for Las Marititas del Milagro — the little miracle Marias. “The story of Maria Teresa and Maria de Jesús Quijé Álvarez brings me back to the first stanza of Questions From a Worker Who Reads, by Bertolt Brecht,” he wrote in an article for this magazine.

"Who built Thebes of the seven gates?/In the books you will find the names of kings/Did the kings haul up the lumps of rock?” This, Dr. Lazareff wrote, “is the beauty of medicine: It assembles people with different understand-
ings of the realities of life and knits them together in an united effort to do the difficult work of helping to heal a stranger in need.”

Sandy Cohen
Examining Racial Differences in Children’s Chronic Kidney Disease

CHILDREN WITH CHRONIC KIDNEY DISEASE (CKD) are at an increased risk of developing a sometimes-detrimental bone disease that falls under the umbrella term chronic kidney disease-mineral and bone disorder, or CKD-MBD. Intriguingly, the severity of CKD-MBD and the success of treatment appear to be affected by the race and ethnicity of patients, according to studies conducted by a UCLA researcher.

The work by Marciana L. Laster, MD (FEL ’17), assistant professor-in-residence of pediatric nephrology, could inform new treatments for pediatric nephrology, could inform new treatments for children with kidney disease based on their own unique genetic makeup.

CKD-MBD arises because faulty kidneys don’t appropriately balance the levels of various hormones and minerals in the bloodstream and body that are necessary for good bone health. Poorly functioning kidneys lead to the reduced conversion of vitamin D, a hormone necessary for strong bones, into a vitamin D, a hormone necessary for strong bones, into a

This combination of abnormal turnover and mineralization, she says, contributes to high fracture risk, short stature and deformities. “More important is the fact that the bone disease interacts with the blood vessels and heart and causes our children to die from cardiovascular disease at rates much higher than healthy children. Because of this long-term impact, accurately treating this disease is very important,” she says.

Current treatments for CKD-MBD involve what Dr. Laster calls a “one-size-fits-all approach.” Most often, patients are given medications that suppress PTH. “My research into racial differences demonstrates that this blanket approach is not sufficient and could potentially drive disparities in mortality,” Dr. Laster says.

Indeed, Dr. Laster’s studies suggest that Black children may be prone to overtreatment of their bone disease. “My work has largely investigated differences by racial group, but race is a generally flawed social construct — race tends to represent the societal impact on health rather than the biological impact of belonging to any particular group,” she explains. “My current research seeks to find genetic markers that determine how CKD-MBD manifests.”

“Once we understand which variants are important, we can tailor treatment according to a patient’s genetic makeup and their unique biology. The hope is that my findings will alter how we treat our patients.”

— Kathy Svitil

PREVIOUSLY, SCIENTISTS HAD THEORIZED THAT human sex chromosomes arose in the distant past when a pair of autosomes (non-sex chromosomes) underwent a series of specific changes. Mathematical modeling supported this theory. Yet something crucial was missing. “Most prior studies looked at animal species in which the two sex chromosomes were already highly differentiated. Direct evidence of a transition from autosomes to sex chromosomes was lacking,” says Longhua Guo, PhD, a postdoctoral research fellow.

A study by Dr. Guo and other UCLA researchers offers fresh insights into how our evolutionary ancestors came to develop X and Y sex chromosomes. Rather than studying fish or flies, Dr. Guo zeroed in on a particular type of planarian — a flatworm. This planarian has a characteristic that made it a good candidate for study: It is a hermaphrodite, having both male and female sex organs in the same body.

The first step was to map the planarian’s genome — the full set of genetic instructions found inside a cell. “Before, we had an incomplete genome sequence that was in a bazillion pieces. You couldn’t put together entire chromosomes. You couldn’t put together entire chromosomes,” says Leonid Kruglyak, PhD, Distinguished Professor of Human Genetics and Biological Chemistry and Diller – von Fürstenberg Endowed Chair in Human Genetics. “Now, we have a great resource for anyone studying planarians.”

As the researchers investigated the planarians, one pair of autosomes stood out. “These autosomes are not sex-determining at this point,” Dr. Kruglyak says. “Yet, they look like they may be sex-primed. In other words, they are starting to show some features that may mark the early evolution of sex chromosomes.”

Specifically, these autosomes showed suppression of recombination and genetic divergence. In most chromosome pairs, genetic material is exchanged through a process called recombination. In sex chromosomes, however, most of the Y no longer shares material with the X. Likewise, in the key pair of planarian autosomes, a big portion of each has stopped sharing material with its counterpart. These large portions are genetically distinct. Interestingly, they contain many genes that function only in one sex or the other.

Does this mean that the planarians are partway down the path of evolving from hermaphrodites into two separate sexes determined by sex chromosomes? Only time will tell for sure, Dr. Kruglyak says. “We think we have caught evolution in the act.”

— UCLA Health

“Island-Specific Evolution of a Sex-Primed Autosome in a Sexual Planarian” — UCLA Health

“We think we have caught evolution in the act.”
Scarless Surgery to Reduce Adam’s Apple

ALTHOUGH THERE ARE SEVERAL GENDER-AFFIRMING procedures that can be addressed through hormone-replacement therapy, the Adam’s apple is one of a few anatomical features that can only be treated with surgery. The traditional tracheal shave procedure involves making an incision in the neck and then using stitches to close it up. Now, doctors at the UCLA Gender Health Program have developed a technique to reduce an Adam’s apple bump without leaving a scar on the patient’s neck.

The advance could be an important and welcome one for transgender men and non-binary people, for whom a neck scar can be a telltale sign of their surgery — often exposing them to discrimination, hate and violence.

After reviewing outcomes for 77 people who underwent the surgery at UCLA Health facilities, the search physicians concluded that the procedure is an effective way to optimize care for people receiving gender-affirming surgery. Specifically, they found that the procedure — which can be performed in 90 minutes — is effective at removing the Adam’s apple, that it can be performed using only the equipment already available in most surgical suites in addition to a few other inexpensive tools, and that it could be readily adopted by plastic surgeons and head and neck specialists.

The procedure is called “scarless” tracheal shave, thanks to the lack of a scar on the patient’s neck, although it does, in actuality, create a small, hidden scar on the inside of the patient’s lip. “The location through which a surgeon inserts cartilage-trimming forceps and a polishing tool to shave down the extra cartilage that forms the Adam’s apple,” says Abie Mendelsohn, MD ’06 (RES ’11, FEL ’11), associate professor of head and neck surgery. “It represents a massive shift in the ability to provide optimal gender-affirming care for patients.”

The study found that there were no voice changes or damage to the vocal cords among the patients, but further research is needed to corroborate those results, and to understand what effects the UCLA-developed technique might have on patients’ quality of life and mental health.

Dr. Mendelsohn says many transgender people fear going about the activities of daily life due to the threat of being “clocked,” or identified as a trans person by others, against their wishes. “When we live in fear, that’s really no life at all,” he says. “With this original approach, we have the opportunity to surgically treat fear, and that’s an incredibly rewarding aspect of the work we do.”

“Our memories are a huge part of who we are. The ability to link related experiences teaches us how to stay safe and operate successfully in the world.”

— Evelyn Tokuyama

The UCLA team focused on a gene that encodes a receptor for CCR5 molecules — the same receptor that HIV hitches a ride on to infect brain cells and cause memory loss in patients with AIDS. As people age, the amount of CCR5 expressed in the brain rises, and, as Silva’s lab has demonstrated in earlier research, increased CCR5 gene expression reduces memory recall.

The findings suggest a new method for strengthening human memory in middle age and a possible early intervention for dementia. “Our memories are a huge part of who we are,” says Alcino J. Silva, PhD, Distinguished Professor of Neurobiology and Psychiatry. “The ability to link related experiences teaches us how to stay safe and operate successfully in the world.”

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How the Brain Links Memories

OUR BRAINS RARELY RECORD SINGLE MESSAGES. Instead, they store memories in groups so that the recollection of one significant memory triggers the recall of others that are connected chronologically. As we age, however, our brains gradually lose this ability to link related memories. Now, UCLA researchers have discovered a key molecular mechanism behind this memory linking. They’ve also identified a way to restore this brain function genetically in aging mice — and an FDA-approved drug that achieves the same thing.

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Which begs the question: Why does the brain need a gene that interferes with its ability to link memories?

“Life would be impossible if we remembered everything,” Dr. Silva says. “Once we fully understand how memory declines, we’ll possess the potential to slow down the process.”

— Elaine Schmidt

“Scarless Surgery to Reduce Adam’s Apple”

“Photos of one patient before (top row) and after (bottom row) surgery to reduce the size of the Adam’s apple without a visible scar.”

“Severable Gender-Affirming”

“Facial Plastic Surgery & Aesthetic Medicine, June 14, 2022

“Development and Deployment of a Novel Approach to Reduce the Size of the Adam’s Apple”

“Other inexpensive tools, other inexpensive tools, other inexpensive tools, other inexpensive tools, other inexpensive tools, other inexpensive tools, other inexpensive tools.”

“COURTESY OF UCLA GENDER HEALTH PROGRAM

“Dr. Silva and his colleagues discovered a key mechanism underlying mice’s ability to link memories of their experiences in two different cages. They found that boosting CCR5 gene expression in the brains of mice interfered with memory linking. The animals forgot the connection between the two cages. But when the scientists deleted the CCR5 gene in the animals, the mice were able to link memories that normal mice could not.

Dr. Silva had previously studied the drug maraviroc, which the U.S. Food and Drug Administration approved in 2007 for treatment of HIV infection. His lab found that maraviroc also suppressed CCR5 in the brains of mice. “When we gave maraviroc to older mice, the drug duplicated the effect of genetically deleting CCR5 from their DNA,” says Dr. Silva, who also is a member of the UCLA Brain Research Institute. “The older animals were able to link memories again.”

The finding suggests that beyond reversing the cognitive deficits caused by HIV infection, maraviroc can also be used to help restore middle-aged memory loss. “Our next step will be to organize a clinical trial to test maraviroc’s influence on early memory loss with the goal of early intervention,” Dr. Silva says. “Once we fully understand how memory declines, we’ll possess the potential to slow down the process.”

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— Elaine Schmidt
Off-the-Shelf Immune Cells to Combat COVID-19

WHILE VACCINATIONS ARE CRITICAL FOR CONTROLLING COVID-19, a percentage of vaccinated individuals can become infected with the novel coronavirus, especially as it evolves. The situation is compounded by the continual emergence of new variants and subvariants with the ability to evade even a vaccinated primed immune response. What’s needed are treatments for combatting SARS-CoV-2 infection after the virus takes hold in the body.

To that end, a team of UCLA researchers has genetically engineered a normally uncommon type of immune-system cell — one that can safely and effectively destroy SARS-CoV-2, the virus that causes COVID-19 — so the cell is produced in very high numbers. From a single cord-blood donor, more than 1,000 therapeutic doses of HSC-iNKT cells can be generated.

In cell cultures and in animal models, these new HSC-iNKT cells “selectively killed cells infected with SARS-CoV-2, and they also eliminated inflammatory immune cells that are associated with the immunopathology of severe COVID-19,” says molecular biologist and immunologist Yanruide (Charlie) Li, PhD, a postdoc in Dr. Yang’s lab. The engineered cells, Dr. Yang says, “have unique properties that make them promising for off-the-shelf therapy, meaning they can be given to any patient, regardless of their genetic makeup.”

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COURTESY OF DR. LILI YANG AND DR. YANRUIDE LI

Quick-Screening Tool Facilitates Faster Dementia Diagnosis

FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS, taking early action to manage the challenges of the condition can lead to an improved quality of life. Yet, many people with dementia are not diagnosed until the later stages, says Timothy S. Chang, MD (RES ’18, FEL ’20), PhD, assistant professor of neurology. “The reasons for that may include the stigma attached to Alzheimer’s disease or people thinking cognitive issues are a part of normal aging. Another reason is that primary care providers (PCPs) do not have enough time to ask about cognitive health,” he says.

To address the latter issue, Dr. Chang and his team developed a brief questionnaire designed to help PCPs screen for dementia in less than five minutes.

Dementia is characterized by impaired memory, language and thinking skills. About one-in-nine Americans age 65 and older lives with dementia due to Alzheimer’s disease, the most common form. Latino and Black Americans are at particular risk. They are one-and-a-half to two times more likely than white Americans to develop dementia, yet many are not diagnosed until later in the disease. By that time, functional decline and caregiver burden may already be taking a heavy toll.

One aim of the new screening tool is to improve the detection of dementia in these underserved groups, with a version created specifically for Latino patients, translated into Spanish and reviewed to accurately assess cognitive health with cultural competence.

The tool consists of three questions about changes in memory/thinking, language or personality within the last five to 10 years. Each comes with examples of common changes to prompt accurate responses. For instance, examples of memory/thinking changes include trouble recalling recent events and repeating oneself often.

The screening is designed to be done annually in patients age 60 and older. There are two forms of the questionnaire: The patient completes one and the other is designed to be completed by someone who knows the patient well, such as a family member.

“Many patients with early cognitive symptoms will not say or believe they have any issues.”

COURTESY OF DR. TIAN DI CHANG ET AL.

Developments in Off-the-Shelf Hematopoietic Stem Cell Engineering Invariant Natural Killer T Cells to Combat Therapeutic Intervention - Hematopoietic Stem Cells and Mitigate Disease Progression

THE CUTTING EDGE U Magazine Fall 2022

“For people with dementia and their caregivers, taking early action to manage the challenges of the condition can lead to an improved quality of life. Yet, many people with dementia are not diagnosed until the later stages,” says Dr. Chang.

Having input from an informant who knows the patient well can be very helpful,” Dr. Chang says. But because an informant is not always available, the PCP can also conduct a very short psychological test called the Mini-Cog. This test is already well-established in clinical use.

“A yes” answer to a question (or a positive Mini-Cog score) cannot in itself diagnose dementia. But it does prompt the clinician that more assessment is needed. The PCP can then do further workup or refer the patient to a specialist.

“Timely diagnosis of dementia is important for several reasons,” says Dr. Chang. “There are medications that can delay some symptoms progression. There are also numerous drugs in clinical trials.”

In addition, Dr. Chang says, we know that controlling conditions such as heart disease and high blood pressure can help delay the progression of certain types of dementia. “That may give patients another motivation to stay on top of their health,” he says.

- UCLA Health
An Electrical Pulse Can Jump-Start Breathing following Opioid Use

OPIOID USE CAN LEAD TO DEATH by suppressing respiratory activity. These problems can occur from street-use of the drugs, but also as post-operative complications from anesthesia because opioids desensitize the brain stem to rises in carbon dioxide. Current treatments, such as manual lung inflation and medication, can work in the short term to combat breathing problems following opioid use, but getting patients to breathe independently remains a challenge.

Now, UCLA research points to a novel intervention for respiratory depression associated with opioid use that could offer an alternative to pharmacological treatments, which can cause withdrawal symptoms, heart problems and negatively affect the central nervous system. The therapy, called epidural electrical stimulation (EES), administers electrical pulses to the back of the neck, helping patients regain respiratory control following high-dose opioid use. EES administered at the cervical spinal cord activates a network of neurons in the brain stem that stimulates and coordinates respiratory muscles and improves the rate and depth of breathing.

The UCLA researchers targeted sensory-motor circuits in the cervical spinal cord of 18 patients with degenerative spine diseases who were anesthetized for surgical treatment. They delivered 30 Hz to EES to the cervical spinal cord continuously for no longer than 90 seconds. “We can compare the human body to a car; our goal is to jump-start the body so it can run by itself without periodic pushes.”

Future trials in humans with larger cohorts will be conducted to determine if EES can alleviate or reduce the need for ventilator support in acute pathological conditions such as opioid-induced respiratory depression, stroke, and traumatic brain, brain stem or spinal cord injury. “We hope to use EES to provide novel approaches to restore breathing as we are now using defibrillation devices for restoring cardiac activities,” Dr. Lu says.

— Elaine Schmidt

Understanding and Preventing Blindness in Premature Babies

ONE-IN-TEN VERY PREMATURE INFANTS — those born at less than 30 weeks gestation — are affected by retinopathy of prematurity (ROP), the leading cause of childhood blindness. During fetal development, the blood vessels of the retina grow steadily out from the center of the eye toward its periphery, only reaching those edges when the fetus is close to full-term gestation. If the baby is born early, this process is disrupted, which raises the risk for retinal detachment and consequent blindness. “The infection and inflammation experienced by many premature infants can affect normal blood-vessel growth. So, too, can the relatively high oxygen levels that are commonly administered after delivery,” says Alison Chu, MD, assistant professor of pediatrics and neonatology.

Immediately following delivery, the amount of oxygen available to the newly born premature infant may suddenly decrease to levels that are potentially toxic. This condition, known as hyperoxia, may lead to the narrow- ing of retinal blood vessels, or vascular attenuation. It is then often followed by local hypoxia, or low oxygen levels, which encourages the growth of new blood vessels but at an aberrant pace and pattern that may actually lead to retinal detachment.

In recent years, Dr. Chu and her colleagues have been taking a detailed look at the mechanisms behind these processes in both humans and animal models. The work could lead to the development of both preventive and therapeutic strategies to reduce risk of ROP development, and to improve long-term neurovision outcomes for premature babies.

Studies by Dr. Chu and others have shown several key genes that help drive retinopathy, including hypoxia-inducible factor one alpha (Hif1a) and vascular endothelial growth factor (VEGF). “My group is particularly interested in studying a protein called epithelial membrane protein 2 (EMPs), which may regulate these vascular-growth factors,” she says.

The EMP2 gene is involved in regulating angiogenesis — the growth of new blood vessels. This normally vital role becomes problematic in ROP; however, where excessive blood vessel formation can lead to retinal detachment. In a recent paper, Dr. Chu and her colleagues showed that mice that were genetically engineered to not express the EMP2 gene (so-called “EMP2 knock-outs”) were protected against oxygen-induced retinopathy.

“We are interested in understanding how this could be translated to therapy in human babies,” she says. “Moreover, we are interested in understanding how retinopathy of prematurity may result in long-term adverse visual outcomes, by studying the vascular and neuronal changes both during active disease and in the long-term.”

To do so, Dr. Chu’s laboratory has teamed up with Tsung Hsiai, MD, PhD, professor of bioengineering at the Samueli School of Engineering at UCLA. They are tracking the progression of oxygen-induced retinopathy in mice using advanced imaging techniques that offer deep and three-dimensional insight into disease progression in animal models. “As a field, we are understanding more and more how early-life exposures affect later adult outcomes,” Dr. Chu says, “and I think it’s important to consider not only the short-term, but the long-term effects of the treatments we use in neonatology.”

— Kathy Svitil

“Epithelial Membrane Protein 2 (EMP2) Promotes Epithelial-Mesenchymal Transition in Murine Oxygen-Induced Retinopathy”

Understanding and Preventing Blindness in Premature Babies

“One-in-ten very premature infants — those born at less than 30 weeks gestation — are affected by retinopathy of prematurity (ROP), the leading cause of childhood blindness. During fetal development, the blood vessels of the retina grow steadily out from the center of the eye toward its periphery, only reaching those edges when the fetus is close to full-term gestation. If the baby is born early, this process is disrupted, which raises the risk for retinal detachment and consequent blindness.”

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— Kathy Svitil
Gene on Y Chromosome may Explain Men’s Lower Risk for Pulmonary Hypertension

A UCLA STUDY HAS IDENTIFIED A GENE ON THE Y CHROMOSOME that protects against pulmonary hypertension, a rare and potentially fatal disease that occurs four times more often in women than men. A chronic disease characterized by high blood pressure affecting the lungs arteries and heart, pulmonary hypertension appears most often in young women. It has no definitive cure, and many patients eventually require a lung transplant. Typically, men have one X and one Y chromosome on the 23rd pair while women have two X chromosomes. Previous research from the group doing the current study found that women have higher rates of pulmonary hypertension because they lack the Y chromosome’s protective features. But the gene responsible for that protection had not been identified. In the new study, researchers aimed to further understand how the Y chromosome confers protection against the disease.

To conduct the experiment, which was done in mice, researchers silenced each gene in the Y chromosome, one by one, to tease out which is linked to the development of pulmonary hypertension. After observing each gene’s function, the researchers found that the gene Uty stops an inflammatory pathway in the lungs in male mice and thereby halts development of the disease. The researchers also induced pulmonary hypertension in female rats and then treated them with AMG-487, a drug that blocks inflammation and was developed as a treatment for psoriasis. After dosing the rats twice a day for two weeks, the researchers found that AMG-487 was effective in treating pulmonary hypertension by blocking the inflammation that leads to the disease.

“Microchip System Examines Migraine-Sleep Relationship”

CORTICAL SPREADING DEPRESSION, OR CSD, is a wave of brain activity responsible for migraine aura — a warning symptom such as visual disturbance or flashes of light that often occur before or with the crushing headache. “CSD has been commonly used as a model of migraine in mice or rats because it is something that seems to be predictive,” says Andrew C. Charles, MD ’86 (RES ’90, FEL ’92), director of the UCLA Goldberg Migraine Program. “Not only can it tell us about the mechanisms of migraine, but it also seems to be predictive of therapies, meaning things that suppress it are generally helpful as preventive treatments, whereas things that trigger it may be things that trigger migraines.”

Dr. Charles notes there is a complex bi-directional relationship between migraine and sleep, but the basic mechanisms are poorly understood. “On one hand, being male is the single biggest factor in avoiding the development of pulmonary hypertension. The researchers realize that inflammation is not just associated, but can also be causal in this disease, and it could be a very promising or exciting new avenue for therapy.”

Dr. Charles and other UCLA researchers have been studying the phenomenon of CSD for some time; however, in order to trigger and record it, typically the mouse had to be under anesthesia — an artificial situation that changes the interpretation of the results. To address that issue, two of Dr. Charles’s colleagues, — Dmitri Yousef Yengej, PhD, and Guido Faas, PhD — developed a minimal invasive microchip system that monitors and records brain activity and behavior in freely behaving mice.

“‘If you sleep too little or too much, that’s commonly identified as a migraine trigger,’” says Dr. Charles, “so this study will help researchers realize that inflammation is not just associated, but can also be causal in this disease, and it could be a very promising or exciting new avenue for therapy.” Dr. Cunningham says. — Kelsie Sandoval

“Different Characteristics of Cortical Spreading Depression in the Sleep and Awake State,” Headache, April 25, 2022

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CORTICAL SPREADING DEPRESSION, OR CSD, is a wave of brain activity responsible for migraine aura — a warning symptom such as visual disturbance or flashes of light that often occur before or with the crushing headache. “CSD has been commonly used as a model of migraine in mice or rats because it is something that seems to be predictive,” says Andrew C. Charles, who also is a member of the UCLA Brain Research Institute. “For those with frequent migraine, it becomes a vicious cycle where the migraine causes sleep disruption, which then turns around and further exacerbates the migraine.”

“Dr. Charles and other UCLA researchers have been studying the phenomenon of CSD for some time; however, in order to trigger and record it, typically the mouse had to be under anesthesia — an artificial situation that changes the interpretation of the results. To address that issue, two of Dr. Charles’s colleagues, — Dmitri Yousef Yengej, PhD, and Guido Faas, PhD — developed a minimal invasive microchip system that monitors and records brain activity and behavior in freely behaving mice.

“‘If you sleep too little or too much, that’s commonly identified as a migraine trigger,’” says Dr. Charles, “so this study will help researchers realize that inflammation is not just associated, but can also be causal in this disease, and it could be a very promising or exciting new avenue for therapy.”

Dr. Charles notes there is a complex bi-directional relationship between migraine and sleep, but the basic mechanisms are poorly understood. “On one hand, being male is the single biggest factor in avoiding the development of pulmonary hypertension. The researchers realize that inflammation is not just associated, but can also be causal in this disease, and it could be a very promising or exciting new avenue for therapy.” Dr. Cunningham says. — Kelsie Sandoval

“Different Characteristics of Cortical Spreading Depression in the Sleep and Awake State,” Headache, April 25, 2022
Carol Mangione, MD, has a new title to add to her already crowded business card: chair of the U.S. Preventive Services Task Force (USPSTF). Created in 1984, the USPSTF is an independent, volunteer panel of national experts in prevention and evidence-based medicine that makes evidence-based recommendations on clinical services such as preventive screenings, counseling and use of medications aimed at preventing illness. Dr. Mangione, whose other titles include Distinguished Professor of Medicine in the David Geffen School of Medicine and Distinguished Professor of Public Health in the UCLA Fielding School of Public Health, as well as director of the UCLA Resource Center for Minority Aging Research, has been a member of the preventive services panel since 2016 and was vice chair from 2020 to 2022. She spoke with Enrique Rivero, senior media relations officer for UCLA Health, about her new role, lessons learned from the COVID-19 pandemic and dealing with the glut of misinformation that is choking the national dialogue about scientific and medical issues.
Let’s jump right in with the hard stuff. How do we break through the noise of disinformation to disseminate and create acceptance for evidence-based scientific and health-related information?

Dr. Carol Mangione: This is a huge problem right now. With the proliferation of social media and the Internet, it’s hard for people to sort through all the uncurated information that is out there. Transparency is essential, and the task force has a long history with regard to putting some of these methods on our website for anyone to read. If we are addressing a new topic, we post our research plans on the website for public comment, read and give consideration to every comment we receive, and then we post the final research plan and our draft recommendations before we publish them. Part of why the task force is so trusted is because we have always employed rigorous, transparent, evidence-based methods to develop our recommendations. To grade a recommendation, the key metric we use is net benefit for the patient. We always balance benefit against harm. No service comes without both sides, so we have to have moderate-to-high net benefit to be able to give an A-grade or B-grade recommendation. When we find that there is no net benefit or there is potential harm from a given service, we will give that recommendation a D-grade, and we use an I-grade when there is insufficient evidence for or against the use of a preventive service.

“I think what we really have learned is that access to care and services is fragile.”

What lessons have we learned over the course of the pandemic?

Dr. Mangione: I think what we really have learned is that access to care and services is fragile. When the pandemic happened and all of a sudden there were a lot of new rules and policies to try to reduce transmission of COVID-19, combined with people’s fears about contracting the virus, people who fund medical research in this country is very important. Partnering with organizations that advocate for access to care and reducing the number of those who are in need is also very important. Representatives from these groups come to our meetings and observe our processes, and when we make recommendations, all out for public comment, they will make comments and pick up on things that we might have missed or need to emphasize. And we’ve been very focused on making sure there is a broad racial and gender and geographic representation on the task force.

What about the disproportionate underuse of services among people who have the highest prevalence of medical conditions and the worst health outcomes? The USPSTF is the group that is going to address health in this country, we’re going to have to address this. COVID-19 was a terrible thing, and it has killed more than a million Americans. But if we look at the actual data overall, what we see is that the lowest access to care was the highest among Latino people. It was also very high among Black people. This is unacceptable. The virus isn’t selective. It is not choosing which populations to strike hardest. Something else in our society is driving this. If we had fair and equal access to resources, I don’t think we would see a differential in who dies from breast cancer or who dies from prostate cancer, or who dies from cervical cancer or who dies from prostate cancer, so it isn’t all just about screening. Even if we fix the prevention problem completely, we still have to have the systems in place to deliver evidence-based treatments to the people who are diagnosed with serious conditions.

What is your greatest hope?

Dr. Mangione: My greatest hope is that we get the right services to the right people at the right time. But it is important to understand that the task force never makes decisions about whether or not services should be given, but rather, we make recommendations on what services are needed, and that includes about health benefit balanced against harms and coming up with evidence-based recommendations that, I would say, are completely insurance-coverage and cost agnostic. When the Affordable Care Act passed, the legislation said that for people with private or commercial insurance, all Grade A and Grade B recommendations have to be covered with no cost sharing; that’s a huge step in the right direction. But the task force has no regulatory or decision-making power that influences who ends up insured in this country and who has access to services.

The task force’s recommendations have not been without controversy.

Dr. Mangione: That is true. Since our last breast-cancer screening recommendation came out in 2016, there’s been a long-running controversy about the value of screening annually versus every two years. There is a lot of evidence to say whether to start screening at age 40, age 45 or at age 50. Some professional organizations have recommedations for those over 70 to move the age for greater frequency of screening. In 2016, the task force looked very carefully at the evidence and the marginal benefit of screening every two years versus every year in average-risk women and concluded that the benefit of annual versus biennial was so small that we ended up recommending screening every two years. Some groups felt strongly that that was a big problem and push for screening that is more frequent for high-risk groups like Black women. The task force takes this concern very seriously and will continue to carefully examine the evidence that supports specific screening intervals. If we were to see evidence that shows that the benefit of starting a preventive service at a younger age or using it more frequently outweighs the harms in one group versus another, then these findings would support the development of groups-specific recommendations. But, unfortunately, this evidence from well-designed studies is often times very hard to come by.

What role can the task force play in increasing access to care?

Dr. Mangione: I think the biggest role we can play is to point out the problem to the people who pay for research and pay for health care in our country. Our reports to Congress often focus on disparities in access to care and outcomes. Our recommendations fall into three categories: screening tests, preventive medications for conditions like high cholesterol and short behavioral interventions that can either be delivered outside of the health care system, such as brief interventions to reduce unhealthy alcohol use. We feel strongly that for the health of the nation, people should have access to these screenings and treatments, and our role can be to communicate this to the public and to make it clear in our recommendations where there are challenges for implementation. We also have a section in our recommendations called “clinical considerations” — often that is where we will talk about access issues — and a section on research gaps, which often focuses on issues with health care delivery. With our national platform, the task force is in a position to talk to legislators, to talk to people who fund research, to people who fund clinical care, and to point out to them these big problems that need to be addressed if we are to improve the health of all Americans.
As head of the Laboratory for Image Guided Immunotherapy, Olulwatayo “Tayo” Ikotun, PhD, assistant professor of molecular and medical pharmacology and a member of the Crump Institute for Molecular Imaging, uses nuclear imaging to better understand how the immune system responds to the onset of disease and therapeutic interventions. She hopes that the knowledge gleaned from her studies will lead to where I started doing actual science.

WHAT WAS YOUR FIRST EXPERIMENT?
I was a late bloomer. My first real experiments were in general chemistry labs, mixing an acid and a base together and measuring the pH, making soap, doing titrations, that sort of thing. It was pretty rudimentary, but I always enjoyed seeing the color changes — cooper going from blue to green, for example. I thought that was cool. I like colors.

WHAT HAS BEEN THE GREATEST CHALLENGE IN YOUR WORK?
Assay development. I think that’s the bane of most people working in laboratory science. It can take a lot of time, and it can be very frustrating because it’s test, change a variable, repeat, change another variable, repeat. It’s the hardest step, and it is possible while you’re trying to get it right to lose faith in the project. But once you have it, then it’s smooth sailing. Just having the patience to do all of the right steps in the right order and not be sloppy and not jumping ahead, but sitting and doing that meticulous, often-tedious repetition, can be a challenge.

WHERE DOES YOUR INSPIRATION COME FROM?
From my parents. They sacrificed a lot for us; their children are at the same level as me, or just a few years ahead, and when we get together, we talk about where the field is and what do we think about this or that and why something maybe isn’t working. Having a safe space to explore what you’re thinking, no matter how kooky, and seeing if you can convince people who are comfortable telling you that your idea is dumb because of this, or is great because of that, is really inspiring.

WHAT DO YOU CONSIDER TO BE YOUR FINEST ACHIEVEMENT?
I’m still waiting on that. I feel like I’m still a baby scientist, just starting to figure out my place in the scientific world.

WHAT IS YOUR GREATEST VIRTUE?
I think that I am empathetic. I try to understand where people are at. I think that empathy also carries over into vigilance; we have to keep the patients and their families who are looking to us to help them at the forefront of our minds when we are at the bench.

WHAT IS YOUR GREATEST FAULT?
I’m a direct person. I try to recognize that can be off-putting, and that maybe that can make students feel like I’m not on their side. But that is not the case at all; I am 100% committed to their learning and success. I feel clarity and directness are important for science and their training.

WHAT IS YOUR MOTTO?
“The only failure is failure to learn.” Also, one that I live by is, “If you’re not learning, then you better be dying.” That one came from my PhD advisor.

WHOM DO YOU MOST ADMIRE?
My mom. Life has thrown her so many curves, and she just gets on with it. She put that into raising us and taught us to pull ourselves up and keep it moving. Professionally, my PhD advisor at Syracuse University, Robert Doyle. He was tough on us so that we would be good scientists, but he’s always been there for us and still makes himself available — a mentor for life. Ann-Marie Chacko, a colleague at Duke-NUS Medical School in Singapore, also is someone who always inspires me. She’s like a shot of Red Bull for me.

IF NOT A SCIENTIST, WHAT WOULD YOU BE?
Maybe I would have gone into acting or stand-up comedy. I was really into performance arts when I was younger — member of the drama club, acting in school plays, being in an acting troupe. My brother thinks I should try stand-up comedy. I was really into that sort of thing. It was pretty fun, like a shot of Red Bull for me.

WHAT IS YOUR MOST TREASURED POSSESSION?
My dog, Milo. He is a real emotional support for me. Rough day at work? He’s right there to be a bud. Long nights in the lab? He’s up for that, too. He’s a Bernese mountain dog-poodle mix and is the sweetest dog ever.

TO WHICH SUPERHERO DO YOU MOST RELATE?
My favorite is Rogue, from the X-Men. She’s always the pinch hitter, and even though she’s not the leader, she is the strongest. I think I relate to that because in life, I’m generally the pinch hitter, the one my friends call in an emergency and things like that.

WHAT KEEPES YOU UP AT NIGHT?
Worrying that I won’t contribute anything insightful to the field, that I won’t be the mentor that my students need — not the one they want, but the one they need — and that we won’t get funding.

WHAT IS THE BEST MOMENT OF YOUR DAY?
When I see a student get it. It’s like seeing a scientist being born and is the most rewarding thing.

HOW DO YOU HOPE TO CHANGE THE WORLD?
I’d like to help deliver something that actually gets implemented in the clinical setting to benefit patients. And also, I really want to have inspired the next generation of scientists in some way, whether it’s for them to have someone who believed in them before they believed in themselves, or for them to have someone who will advocate for them and push them toward achieving their scientific dreams. Ultimately, I hope that my students will be better than I am.

WHAT IS YOUR DEFINITION OF HAPPINESS?
Being content with the things around you, having the grace to accept the things you cannot change, being lucky enough to do what you feel you were put on this earth to do and finding people who see that passion and excitement in you and who celebrate it with you and inspire you to be better.

WHAT IS YOUR DEFINITION OF MISERY?
Being extraordinarily ordinary. Not being challenged or working at my fullest potential. Misery would be just existing, getting up and not doing something that really excites me, that makes me feel vibrant or passionate or alive.

WHAT MUSIC DO YOU LISTEN TO WHILE YOU WORK?
When I was spending a lot of time in the lab, it would be ‘90s hip-hop, but now that I spend more time pondering, I enjoy listening to Lo-Fi beats. It’s very Zen. It’s also something in the background that keeps me moving but doesn’t distract me. But when I’m in the lab pipetting, it’s ‘90s hip-hop, R&B and pop.
Solving Sickle Cell

Investigators at UCLA are at the forefront of research to cure this painful, debilitating and often-deadly blood disorder.

By Kenneth Miller
If you’d met Evie Junior three years ago, you never would have guessed that his own blood was gradually killing him. At 27 years old, he was tall and muscular, capable of bench-pressing 300 pounds. He pulled long hours as an emergency medical technician, hoisting patients into an ambulance with ease. For most of his life, however, an insidious ailment had been sapping his strength and sending him into paroxysms of pain.

Junior was struggling with sickle cell disease, an inherited disorder marked by defective hemoglobin — the protein in red blood cells that carries oxygen throughout the body. Cells with sickle hemoglobin are stiff, sticky and crescent-shaped. They often clump together, blocking small blood vessels. These snags cause agonizing episodes known as pain crises, centered on the limbs, back or chest. The reduction of blood flow can damage bones, skin and vital organs. Because sickle cells live for only days, compared to months for normal red blood cells, people with the disorder are prone to anemia, with symptoms including fatigue, dizziness and shortness of breath. They’re also vulnerable to stroke, vision loss, lung troubles and infections.

These miseries arise from a defect in a single gene — a mutation most common in people of African ancestry, though it’s also found among several other ethnic groups. People who inherit the glitch from one parent usually have no symptoms. People with copies from both parents may start out with mild illness, but their suffering typically worsens with age. Among the 100,000 patients with sickle cell disease in the United States, median life expectancy is in the 40s.

Growing up in the Bronx, New York, Junior — who is Black and Puerto Rican — faced challenges beyond the poverty endemic to his tough neighborhood. When he was a toddler, his mother would sometimes find him curled on the floor crying, unable to walk. At 3 years old, he had his spleen removed; at 16, his gallbladder. In high school, he was a fierce competitor on the basketball court and the gridiron, but he was dropped from the football team when a pain crisis made him miss tryouts. Though he was smart and intellectually curious, college was out of the question. “I couldn’t enroll in a class and then go to the hospital for three days,” he explains.

Junior did his best to stay well — eating right, exercising devoutly — and took on physically demanding jobs despite his illness. After graduating high school, he worked as a personal trainer, then moved to Portland, Oregon, where he became an EMT. But the pain crises began striking more frequently, often sending him to the emergency room. He was hospitalized with pericarditis, an inflammation of the thin, sac-like tissue surrounding the heart. He developed patches of dying bone tissue in both legs.

Aside from painkillers, few effective treatments are available for sickle cell disease. Four medications have been approved by the Food and Drug Administration (FDA); although they can ease symptoms for some patients, they can also cause troublesome side effects. A bone-marrow transplant from a sibling can eliminate the disorder, but fewer than 20% of patients have a brother or sister who is an eligible match.

Junior tried two of the medications. The first made him tired and breathless, and the second did nothing whatsoever. The others, at thousands of dollars per month, were financially out of reach. His doctor referred him to a hematologist, who suggested he look into a transplant. Junior’s sister agreed to be tested as a possible donor, but she proved to be incompatible. His only remaining option, the specialist said, was an experimental treatment: stem-cell gene therapy, in which his blood stem cells would be genetically modified to produce non-sickling hemoglobin. But no one could be sure that it would help him, she warned, and there was a chance that it would do him harm.

“I told her I was willing to risk it all,” Junior recalls. “Nothing could be worse than just sitting here and dying slowly.” He asked where the nearest clinical trial was being conducted. That’s how he found himself at UCLA.
By Courtney Perkes

When E. Dale Abel, MD, PhD, chair of the Department of Medicine in the David Geffen School of Medicine at UCLA and executive medical director of the UCLA Health Department of Medicine, looks at the incidence of sickle cell disease and how patients are treated, he sees a portrait of unequal care that is “spotty at best, and very fragmented.”

“We live in a city that has significant health care disparities, and this is exemplified by sickle cell disease, which primarily affects people of color,” he says.

To address this problem, UCLA Health launched a new center in September with the goal of improving quality of care and increasing life expectancies for patients with sickle cell disease. In addition to primary and preventive care, and early management for complications, the center provides access to specialty care that often is lacking for patients with the disease, which can affect multiple systems in the body.

“There’s hardly an organ system that’s not affected by the sickle process,” says Gary J. Schiller, MD (RES ’87, FEL ’90), a hematologist and director of the Bone Marrow/ Stem Cell Transplant Program. As Dr. Abel notes, access to appropriate health care resources is a significant problem for patients with sickle cell disease, an assertion that is supported by organizations such as the CDC Foundation, an independent nonprofit that works closely with the Centers for Disease Control and Prevention. The foundation reports there are a limited number of physicians who are trained willing to treat adult patients with sickle cell disease. And because most patients with sickle cell disease are covered by Medicaid rather than private insurance, fewer doctors accept their government insurance.

In addition, people with sickle cell disease may be inaccurately perceived as drug seekers, and they often face longer wait times to see a doctor or receive pain medication when visiting an emergency department, according to the foundation.

Disparities are also reflected in shorter life spans. Nationwide, the median life expectancy for a person with sickle cell disease is 42-47 years. In addition, Californians with sickle cell disease have higher rates of emergency department visits and hospitalizations than those in other states. “We don’t do a good job of taking care of patients with sickle cell in California,” Dr. Schiller says. “We don’t really have adult-focused programs.”

Dr. Abel is hopeful that UCLA will be able to improve turn-around the statistics in this community, but it is worth every bit of effort and every penny of investment we are putting into this.”

In 2019, California allocated $15 million in state funds over three years to establish new sickle cell disease centers to provide cost-effective, coordinated care. The effort is overseen by the Networking California for Sickle Cell Care Initiative (NCSCI), which was launched by the Center for Inherited Blood Disorders and the Sickle Cell Disease Foundation.

Dr. Kuo believes that in the coming years, UCLA will be caring for most adults with sickle cell disease in the region. “My goal is not just to increase the life expectancy of patients, but also to increase their quality of life,” Dr. Kuo says. “I hope that by giving sickle cell patients access to high-quality primary care, we will take care of their medical condition and get them on the right path to learning how to manage their condition, so they can then live their lives to the fullest.”

THE TRIAL THAT JUNIOR JOINED IN JULY 2019 IS ONE OF SEVERAL SICKLE CELL STUDIES currently ongoing or planned at the Eli and Edythe Broad Center of Regenerative Medicine and Stem Cell Research at UCLA. It’s also part of a larger group of studies, at academic centers and biotech companies in several countries, whose preliminary findings offer hope that a cure for sickle cell disease is close.

In the past five years or so, dozens of participants in these trials have found lasting reprieves from their pain and other complications from a single infusion of genetically modified stem cells. There have been setbacks, too, and the durability of the positive results remains to be seen. Still, the mood in the field is jubilately upbeat. “It’s too soon to use the ‘c’ word, to say there’s a cure,” says Donald B. Kohn, MD, Distinguished Professor of Microbiology, Immunology & Molecular Genetics, and professor of pediatric hematology-oncology. “But things are looking very promising.”

What makes the recent breakthroughs all the more remarkable is that research on gene therapy for sickle cell began far later than for many other conditions. In part, this reflects the perennial shortage of funding for maladies that mostly affect people of color in low-income parts of the world. But the slow start also stems from the nature of this disease.

“IT WILL PROBABLY TAKE A NUMBER OF YEARS FOR US TO REALLY TURN AROUND THE STATISTICS IN THIS COMMUNITY, BUT IT IS WORTH EVERY BIT OF EFFORT AND EVERY PENNY OF INVESTMENT WE ARE PUTTING INTO THIS.”

“IT’S TOO SOON TO USE THE ‘C’ WORD, TO SAY THERE’S A CURE.”
The patient must take immunosuppressant drugs to prevent rejection, raising the risk of infections and malignancies. The transplanted marrow can attack the patient’s tissues, a reaction known as graft-versus-host disease. Or the patient’s refurbished immune system can malfunction, failing to guard against microbial intruders.

Gene therapy strives to avoid these downsides by using cells harvested from the patient’s own body. These are genetically modified to combat a specific disease, then returned to the patient in a so-called “autologous” transplant. The process was first completed successfully in 1990, in a 4-year-old girl with a form of immunodeficiency known as ADA-SCID. An NIH team made the breakthrough, using a tool that Dr. Kohn had worked on during his fellowship: a retroviral vector.

A vector is the technical term for a carrier that delivers new genetic information into target cells. Viruses are well-suited for this purpose, because they reproduce by reprogramming a cell’s DNA. And retroviruses, which carry their genetic material in the form of RNA, have an added advantage: Unlike some of their viral kin, they can integrate their genes into a host’s chromosomal DNA, ensuring that the changes are preserved as cells reproduce.

The mutation that causes ADA-SCID occurs in the ADA gene, which enables the body to produce an enzyme crucial to the growth of T- and B-lymphocytes — white blood cells that function as the foot soldiers of the immune system. Without this enzyme, stem cells that give rise to the lymphocytes die before they mature. To fix the problem, the researchers made a vector based on a mouse leukemia retrovirus. After removing the virus’s disease-causing RNA, they used genetic engineering to load it with a corrected version of the ADA gene.

Next, the NIH team collected T-lymphocytes from the girl, who was taking medication that enabled them to grow to maturity. After culturing large numbers in the lab, the team infected the cells with the modified retrovirus. Finally, the researchers infused the infected T-cells — now carrying the corrected gene — back into the patient.

The girl’s immunodeficiency improved markedly, and she was able to enroll in school and live a normal life. But her lymphocyte counts fluctuated, and she needed continuing treatments to remain healthy. Among the lessons that researchers learned from this experiment was that gene therapy for blood disorders had to be aimed at stem cells to have maximum effect. This is because blood stem cells can self-renew and produce all kinds of blood and immune cells, which means that genetically corrected blood stem cells should be able to persist and produce healthy cells throughout a patient’s life.

While the NIH researchers were delivering the first gene therapy for ADA-SCID, Dr. Kohn and his lab at Children’s Hospital branched out to other diseases — mainly HIV and blood cancers — while developing new methods for culturing stem cells and creating viral vectors. Like many other gene-therapy researchers, he was eager to try such approaches on sickle cell disease, as well. But there were two major obstacles: First, judging by the results of bone-marrow transplants, controlling sickle cell symptoms would require correcting 20-to-50% of a patient’s blood stem cells, versus just 5% in SCID. “We needed to get better at transferring genes into the stem cells,” Dr. Kohn explains. The second hurdle to tackling sickle cell disease was that the mutation that caused it was dauntingly complex. Unlike the defect in the ADA gene, which prevented cells from producing a necessary enzyme, the sickle cell mutation instructed cells to make an abnormal protein.

“We had to find some way to counter it,” says Dr. Kohn. “The technology wasn’t there yet.”

**BY THE EARLY 2000s, GENE-THERAPY TECHNIQUES FOR BLOOD DISORDERS HAD MADE BIG STRIDES.** After a handful of patients developed leukemia in clinical trials using retroviruses, many researchers switched to lentiviruses (a group of slower-acting retroviruses, such as HIV), which are less likely to integrate with the genome in locations that can cause cancer. Scientists had learned that treating patients with chemotherapeutics before giving autologous transplants created space for the corrected cells, though the dose could be lower than with conventional, or allogeneic, transplants.

Meanwhile, other researchers had gained crucial insights into sickle cell disease — particularly, the role of fetal hemoglobin in the disorder’s progression. It had long been known that the structure of hemoglobin changes with age. In human fetuses, the four-part protein that consists of two alpha units and two gamma units; a few months after birth, production of gamma mostly stops, and blood cells begin producing beta instead. The sickle cell mutation affects only the beta unit. In 1994, a study showed that patients whose hemoglobin was more than 8.6% gamma had milder symptoms and survived longer than those with lower levels.

Soon afterward, teams at UC Berkeley and the University of Alabama found a way to model the persistence of gamma-globin in genetically engineered mice, and to switch production on and off. The stage was set for scientists to begin investigating how fetal hemoglobin modified disease symptoms, and whether similar effects could be obtained through gene therapy. A few researchers at other institutions began doing just that.

What emboldened Dr. Kohn to attack the sickle cell conundrum was the advent of the California Institute for Regenerative Medicine (CIRM). Created in 2004 by a state ballot initiative, the institute authorized $3 billion in funding for stem-cell research, with the goal of accelerating treatment for patients with unmet medical needs. Dr. Kohn was among the first scientists to be awarded a grant to study sickle cell disease, and CIRM has supported his research on the topic since 2008. The following year, he joined the faculty at UCLA.

Dr. Kohn began his work on sickle cell with preclinical studies, adapting some of the methods he and others had developed for disorders such as ADA-SCID and leukemia and testing them in cell cultures. In 2013, a Massachusetts company called Bluebird Bio launched the first human trial of a gene therapy for the disease, beating him to the punch. But the early success of that trial, in which nearly all patients experienced relief from their symptoms, was encouraging news. At this stage of the game, there was plenty of room for exploration and innovation.

Like Bluebird Bio, Dr. Kohn launched a clinical trial that used a lentiviral vector to deliver a different gene meant to inhibit sickling. His research has expanded outward from there. Dr. Kohn also has developed, in collaboration with researchers at UC Berkeley and UC San Francisco, an approach employing the gene-editing tool known as CRISPRCas-9 to correct the sickling mutation in the hemoglobin gene. Yet another method combines two different anti-sickling genes developed by Dr. Kohn and pediatric hematologist-oncologist David A. Williams, MD, of Boston Children’s Hospital. In addition, Dr. Kohn is principal investigator on a grant submitted to CIRM to develop a more affordable gene therapy for sickle cell disease, based on a small vector dubbed Mini-G. Designed by a project scientist in his lab, Roger Hollis, PhD,
and Richard Morgan, MD '21, PhD '21, who was then a fourth-year medical student in the UCLA-Caltech Medical Scientist Training Program, the vector can be produced in larger quantities, and get into stem cells more efficiently, reducing costs.

Theodore Moore, MD (RES '92, FEL '95), chief of pediatric hematology-oncology and director of the Bone Marrow Transplant Program at UCLA, is another UCLA researcher at the forefront of investigation into a cure for sickle cell disease. He and hematology-oncology fellow Shanna White, MD, are engaged in a clinical trial testing a gene therapy designed by Dr. Williams to prevent sickling by jamming a molecular “switch” that normally turns off fetal hemoglobin production in the first months of life. All these diverse methods are intended as better alternatives to bone-marrow transplants for patients with sickle cell disease who don’t have a viable donor, or who are too high-risk to be candidates for that grueling procedure. Researchers also envision them as eventual options even for those who could have a transplant from a donor, but prefer to avoid the dangers of rejection and the need to take immunosuppressants. “The quality of life is so much better with gene therapy,” Dr. Moore says. “We have a saying: ‘The best transplant is one you never have to do.’”

DR. KOHN STARTED HIS CLINICAL TRIAL OF THE LENTIVIRAL VECTOR in December 2014, partnering with Gary J. Schiller, MD (RES ’87, FEL ’90), professor of medicine and director of the Bone Marrow/Stem Cell Transplant Program at the David Geffen School of Medicine at UCLA. “It’s a natural fit,” Dr. Schiller says. “I’ve been harping on the idea of gene therapy for more than 30 years on the faculty. I’ve seen how patients suffer with sickle cell disease. I think it’s safe to say that chapter of my life is over,” he says.

The idea was to start with a small clinical trial testing the therapy’s safety and efficacy on a total of six young adults with severe disease. Their first patient treated was not a success. Collecting enough of her stem cells proved unexpectedly difficult. After the cells were exposed to the vector and returned to her bone marrow, it turned out that few contained the corrected gene. Her symptoms failed to improve, and, sadly, she died of sickle cell complications in 2017.

The team spent a year retouching. “We learned where we were on the map,” Dr. Kohn said in an article published in the Los Angeles Times about the trial. “We were in the middle of the ocean. Now we’re on dry land.”

Instead of harvesting bone marrow surgically, they decided to use medication that drives stem cells into the bloodstream. They’d also give the next patient blood transfusions before starting chemo, to improve the stem cells’ health and reduce inflammation in the bone marrow. And they would switch to a smaller vector, manufactured by a lab in Italy, that could be inserted more easily into target cells.

Meanwhile, Dr. Kohn scored a significant victory over the disease that launched his career: In a trial of his gene therapy for ADA-SCID, developed in collaboration with Claire Booth, MD, at Great Ormond Street Hospital in London, immune function was restored in 48 out of 50 pediatric patients. Patient number two in the UCLA sickle cell trial was Evie Junior. He enrolled in July 2019, after relocating to Los Angeles with his girlfriend — an audiologist he’d met on the job in Portland. As with the study’s previous participant, things moved slowly. Junior met with Dr. Kohn and Dr. Schiller, who explained the purpose and protocol of the study, outlined the risks, and sent him home with an informed-consent form to consider participation in the research. “He was kind of the ideal patient,” Dr. Schiller recalls. “Very knowledgeable, very strong. We could tell he was going to adhere to the program so that we could analyze what would happen.”

Once Junior signed the papers, he underwent a month of tests: lung function, heart function, kidney function. He had an MRI to check his iron levels. He underwent a bone-marrow biopsy to make sure his bone marrow was healthy enough to yield a good number of stem cells.

Then came two months of transfusions, followed by three stem-cell-collection sessions. Junior’s stem cells were cultured, treated with the vector and frozen for storage. Between procedures, he worked for a private ambulance company.

Then, in early 2020, COVID-19 hit. For several months, the preparation process shut down. “I was feeling a little defeated at that point,” Junior recalls. “It was July, they called and said, ‘Either we do this now or we’re gonna have to wait until the pandemic is over. Your choice.’ I was like, ‘I want to do this now.’”

Shortly thereafter, he checked into Ronald Reagan UCLA Medical Center, where a central venous line was placed in his chest and he spent four days receiving chemotherapy. The experience was grueling, with mouth sores, nausea and exhaustion that persisted over the next weeks. But the staff worked hard to keep him as comfortable as possible. “I felt like I had a team there supporting me,” he says.

When that was over, it was time for the transplant. His thawed bag of genetically corrected cells was hung on an IV pole and infused through his port. As the bag drained into his body, nurses gathered around and sang “Happy Birthday.”

Today, Junior is living in Seattle. It took him a few months to recover from the chemo, but he eventually felt strong enough to return to work. Fed up with the stress of ambulance riding, he trained as an electrician, and now makes his living upgrading residential systems and installing solar panels.

He hasn’t yet regained his athletic vigor, though he hopes to bring himself gradually back up to speed. Nonetheless, two years following treatment, he’s grateful for what he’s been able to leave behind: his pain crises. “I think it’s safe to say that chapter of my life is over,” he says. Which means, he adds, that new chapters can begin. “My partner and I have been talking about kids. When I was dealing with sickle cell, that was a topic I didn’t feel comfortable discussing.”

As for Dr. Kohn, he’s continuing the current trial and getting ready to start new ones.

“I consider it an honor to do this work,” he says. “To see this degree of benefit is amazing every time.”
On a Saturday afternoon this past spring at a neighborhood park in Santa Monica, a park “ambassador” approached Kendal M. Wilkie, RN, and told her about a man who appeared to be asleep on the cement floor of the restroom. He'd been there for nearly an hour, the ambassador said.

Wilkie and UCLA Health emergency department physician Natasha Wheaton, MD, who were in the park with a team of UCLA health care workers to deliver medical services to people experiencing homelessness, followed him to the restroom, where they found the man unconscious in a tiny, dimly lit cubicle. His inert body was blocking the door and had to be pushed aside to get it open.

The man, perhaps in his 50s and dressed in jeans and a polo shirt, wasn't sleeping; he had overdosed and was barely breathing. His skin was greyish, and he was cyanotic, his lips turning blue. What appeared to be drug paraphernalia was on the ground next to him.

“It was obvious,” Wilkie says. “He was very much in need of urgent assistance.”

Wilkie and her colleagues were at the park that day as part of the recently launched UCLA Health Homeless Healthcare Collaborative. They were getting ready to move on to their next stop when the ambassador approached. While Dr. Wheaton stayed with the man and began maneuvers to stimulate his breathing, Wilkie ran back to their van to retrieve a dose of Narcan to reverse the effects of the overdose. A passerby in the park saw what was happening and called 9-1-1.

“He woke up a little bit when we gave him the Narcan. Luckily, the paramedics got there straightaway,” Wilkie says. “They pulled him out of the bathroom and gave him another dose or two of Narcan, and he came fully around.”

Wilkie believes that if the UCLA team had not been there, the ending to the man’s story would have been tragically different. “Without intervention, he would have died,” she says.
AS THE COVID-19 PANDEMIC REVEALED THE DEPTH OF HEALTH CARE DISPARITIES throughout the country, UCLA Health joined with community-health and social-service organizations to establish the UCLA Health Homeless Healthcare Collaborative. It started in January with a fleet of specially equipped vans to provide primary- and urgent-care services to street, shelter and interim-housing sites throughout the city. Services include preventive care, screenings, vaccinations, wound care, assessment and monitoring of chronic diseases, behavioral-health screenings, prescriptions, lab services and specialty-care referrals and coordination.

“We hope that by creating this durable structure to expand access to comprehensive, high-quality health care and social services we can play a significant role in improving the lives of so many people who too-often fall between the cracks,” says Johnese Spisso, MPA, president of UCLA Health and CEO of the UCLA Hospital System. “At UCLA Health, we see firsthand the detrimental health consequences that can be brought on by homelessness. Providing quality care not only improves the overall health of people experiencing homelessness, it also improves their chances of receiving housing and employment opportunities.”

For the UCLA health care workers like Wilkie and Dr. Wheaton staffing the vans, the work can resonate with deeper meaning.

“We are seeing an under-resourced population that desperately needs care and attention and who have been overlooked in the past,” Wilkie says. “It brings up a lot of emotions, really. So many of these people have had bad experiences in the past with the health care system, and they are frightened and distrustful. Whatever we can do to make that a better, more positive experience for them is so important. We don’t judge anyone. We come to where they live to care for them no matter what their need is.”

California has the largest number of people experiencing homelessness in the country, an estimated 160,000. There are more than 66,000 unhoused people in Los Angeles County, with more than 41,200 in the Greater Los Angeles area. While data is yet to be released for the 2022 Greater Los Angeles homeless count, it is believed that the COVID-19 pandemic has caused an increase in the number of people experiencing homelessness due to unforeseen economic hardship.

“Our unhoused neighbors are still our neighbors,” says Brian P. Zunner-Keating, RN, director of the UCLA Health Homeless Healthcare Collaborative. “They need to be treated with dignity and respect. In some ways, I wish our program didn’t have to exist. I feel that health care is a human right, and we should be able to deliver efficient, effective, equitable care to everybody. But this is the reality in which we live.”

“WE HOPE THAT BY CREATING THIS DURABLE STRUCTURE ... WE CAN PLAY A SIGNIFICANT ROLE IN IMPROVING THE LIVES OF SO MANY PEOPLE WHO TOO-OFTEN FALL BETWEEN THE CRACKS.”
In their lives are so difficult." The tunnel when the things happening
"Sometimes the biggest part of our job
They learned that this patient wasn’t
and scheduled an eye exam for the man.
barrier to care," Nuñez says. "The case
the man had no local identification or
Wilkie says. "It instilled hope in him," Nuñez says.
he could not stand up to walk out of his
shelter is crucial to understanding their
getting facility for people awaiting more
recalls one patient at a transitional-hous-

to confirm his identity because he lacked
a skin infection. He told us he had not visited a doctor in years. It was a struggle, he
decided to ask why he didn’t want to go to the hospital.
"I don’t want to lose my bed,” he said.
Equipped with this new understanding, we discussed the patient’s needs with the shelter staff, and they agreed to hold his bed and store his belongings until he was stable enough to return.
It was from experiences like this that I learned an essential lesson in medicine. The most important thing we can do as physicians is listen and to seek to understand our patients. Only then, can we truly advocate for them. As physicians, we can urge our patients to seek treatment and follow our medical advice. But, as in the case of my first patient, it is meaningless unless we listen to them and understand the circumstances in their lives, which may be preventing them from being the best course for their health.
As a young medical student, I was ready to accept and respect — as we were taught to do — our patients’ wishes and their autonomy. But something about this nagged at me, and I decided to ask why he didn’t want to go to the hospital.
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The Most Important Lesson

By Charley Jang, MD ’22

COMING FROM A FIRST-GENERATION IMMIGRANT FAMILY, I watched my parents struggle to navigate their way through a foreign and complex health care system. They strained to obtain affordable and adequate health care, and often refused to seek medical attention, even when it was clearly necessary, for fear of the financial burden. Seeing my parents forgo needed medical care and watching as their chronic illnesses worsened as a consequence, made a commitment to reduce health care disparities for others.

The UCLA Student Run Homeless Clinics (SRHC) became the avenue for me to fulfill that commitment.
Staffed entirely by medical students, under the supervision of Mary M. Marfisee, MD (RES ’05, FEL ’06, ’08), of the UCLA Department of Family medicine, and community physicians, the SRHC provides basic medical care at various sites around Los Angeles to more than 1,600 patients experiencing homelessness each year. For many medical students, these are the first patients we see in our medical training.
I saw my first patient at a shelter in downtown Los Angeles. He approached us with worsening typical chest pain. We were concerned his symptoms suggested acute coronary syndrome and called for an ambulance to take him to the emergency room. But when the ambulance arrived, the patient refused to go. He told us, “I don’t need to go to hospital” and “I don’t want to go.”

Toward the end of my second year of medical school, I became administrative chief of the SRHC. Throughout my time with the program, I witnessed the compassion and empathy of my classmates, faculty and shelter staff. We became not only doctors-in-training, but also communicators, fundraisers and advocates.
At a clinic in Santa Monica, we met a man who sought our care after he was assaulted and robbed. We learned that he had been a store manager and was doing well until he lost his job. A difficult divorce followed, and he fell into depression. Unable to keep up with his mortgage payments, he eventually became homeless. He lost trust in the health care system for being home, and for his history of substance abuse. He felt his medical concerns were not taken seriously, and he eventually stopped trying to access health care services. He lost trust in the system because he had felt invisible and dehumanized.
Again, our students sat with him and listened as he described his struggles and negative experiences. Over time, the student became more open to us, and we were able to get him into a primary care clinic that would manage his multiple chronic conditions.
This is the foundation upon which we hope to build our future careers as a physician and healer. The SRHC has repeatedly taught me the importance of compassion, empathy and humanism in medicine. These are the lessons upon which they will continue to draw and pay forward as they mentor other students and colleagues and care for patients.

Dr. Charley Jang is a first-year resident in internal medicine at NYU Langone Health in New York City.
Brittany Jasker and Nancy Vega (left) nurse Kendal M. Wilkie prepare to visit an encampment. Brittany Jasker and Nancy Vega visit an encampment.

Dr. Marfisee promises to come back. "As we got closer, we saw that the distance, it looked like she had measles," says Medell K. Briggs-Malonson. "We cannot do this alone," Dr. Briggs-Malonson says. "We pride ourselves on building strong partnerships." She acknowledges that UCLA Health is not one of the collaborative's specialty-care services that has been done by these and other organizations for decades, "Dr. Briggs-Malonson says. "We are not here to compete — we are joining them in this important work fighting the health care and social ills that plague those who are experiencing homelessness, filling in the gaps in primary and specialty care that others may not be able to provide and doing our best to connect our patients to housing resources."

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"EVERYONE SHOULD HAVE ACCESS TO HIGH-QUALITY HEALTH CARE, BUT THE PLAYING FIELD IS NOT EVEN."
The woman lived for years on a sidewalk in South Los Angeles, and she had no intention of leaving. Her corner was a typical nondescript L.A. intersection, bustling with traffic and surrounded by a check-cashing business, a doughnut shop, a nail salon and a 7-Eleven. But the woman in her head demanded she stay. Loud and unrelenting, they encouraged her to bark and make shoes at the gas station. They convinced her she was a government spy. The people in her head had power over her. They could control her every thought and action. She was their slave, and they were her masters.

While homelessness fundamentally is a problem of scarcity and unaffordability of housing, many unsheltered individuals also have severe mental illness — a formidable complicating factor that, among other things, may lead them to resist the mental health treatment that could begin to reverse their downward spiral. Says Elizabeth A. Bromley, MD (FEL ‘04, ’06), associate professor in residence of psychiatry and biobehavioral sciences in the UCLA Semel Institute for Neuroscience and Human Behavior and also a member of UCLA Health’s Homeless Healthcare Collaborative team, “They believe their delusions — that they are being watched over as if they were a government spy, that they are being controlled by the NSA, and that they have no control over their lives because the people in their heads have power over them. They are their own worst enemies.”

The woman allowed Santini to draw her blood and see her allergies and, at her request, her new medical records. She and her UCLA Health Homeless Healthcare Collaborative team members helped her settle into a Section 8 voucher and used to get everyone the treatment they needed and increased her trust. Team members helped her feel safe talking to a street provider, and she eventually agreed to take medication for her schizophrenia. The voices got quieter. The woman followed a Section 8 voucher and used to secure housing. Today, she’s learning skills such as cooking, cleaning and grocery shopping, and HOME team members help drive her to medical appointments.

Sitting in the lobby of the apartment building where she now lives, wearing a long-sleeved shirt and a disposable facemask, Everett sits for the morning. Wearing a white T-shirt, gray pants and a disposable facemask, Everett sits for the morning. Wearing a white T-shirt, gray pants and a disposable facemask, Everett sits for the morning.

Everett is 62 years old and recently homeless. He spent a month on the street and the past several weeks in a downtown shelter. While Santini believed that immediate medical care was necessary, the woman didn’t want it and refused any treatment. It would take time and patience to gain her trust. Trust, Santini learned, is at the heart of street medicine.

In more than three decades of nursing practice, Santini had never seen anything like it. “It immediately put me into ER-mode,” she says. “She needed to go to a hospital.”

While Santini believed that immediate medical care was necessary, the woman didn’t want it and refused any treatment. It would take time and patience to gain her trust. Trust, Santini learned, is at the heart of street medicine.

She and her UCLA Health Homeless Healthcare Collaborative team came back the following week, and this time the woman allowed Santini to draw blood and wash her hair. They gave her food, clothing and new bedding, but she refused to accept any help. She was determined to stay where she was. She wanted to be left alone. She wanted to be left alone.

“From a distance, it looked like she had measles. As we got closer, we saw ... there were body ice-head-to-toe.”

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No Longer Alone

By Dan Gordon

The UCLA Health Homeless Healthcare Collaborative team has been working with the woman living on the street for months. She has, in fact, come down from the numbers that his doctor provided over the phone. “Keep up whatever you’re doing,” she tells him, smiling beneath her mask.

Everett responds that he’s been minding what he eats and exercises when he can. He adds that he often gets breakfast at Denny’s with his girlfriend and daughter, who are staying in a neighboring shelter. “I usually get the pancakes with the sugar-free syrup or a vegetarian omelet,” he says.

Dr. Wheaton asks Everett if he’d like to have his blood pressure checked and if he has any medications. “We see or pains that he has to talk about with her. Everett is living with insulin-dependent diabetes. In addition to having had a stroke, he tells Dr. Wheaton that he also has a heart condition. For the past two months, he has been off his medications because they have been locked up in storage due to fear of contamination.

Nurse Vega checks Everett’s blood pressure and draws blood for a metabolic panel and an A1C test to measure and monitor his blood-sugar levels. He grimaces when Vega pricks his finger. She then walks the sample back to the van to be analyzed.

In the meantime, Dr. Wheaton contacts Everett’s primary-care physician to get a list of his medications. The physi-
TO CRITICS WHO MIGHT SAY THAT STREET MEDICINE IS NOTHING MORE THAN A BAND-AID, Faysal Saab, MD (RES ’16), has a response. “Sometimes if you don’t put a Band-Aid on a problem, it gets worse,” says Dr. Saab, associate director for UCLA Health’s internal medicine Global Health Pathway. “Sometimes a Band-Aid can be very effective in terms of stabilizing a patient. Maybe street medicine can’t help everybody, but for some people, it can make all the difference.”

Dr. Saab adds that “we recognize lack of access to affordable housing is the most significant underlying problem leading to homelessness, but while local officials are working on solutions to that issue, we need to step in and address the existing health problems of this population so they do not get worse in the interim. As health care providers, it is incumbent on us to do our best to reach out to those in need in our community so that people do not suffer more than they already have.”

The combination of medical and social services can have a powerful impact on the street. “When you pair social services with a nurse or a doctor — someone asking about their pain, their health problems, while sitting on the sidewalk with them and cutting their toenails so they can walk again — that looks and feels very different for a human being,” Dr. Saab says. “It feels like someone is caring for you and wanting to help you.”

It all comes back to trust. “If they know you’re going to come every week, then they trust you,” nurse Santini says. “They see that you care. I was cutting someone’s toenails and I started to rub their feet and … the look in their eyes.” For a moment, Santini can’t speak and she wipes away tears. “Listening is huge,” she continues. “Just allowing them to tell their story or talk about whatever they want to talk about. It’s a different type of nursing, right? You don’t have to be treating a wound or taking someone’s blood pressure — you just listen. That means so much to them.”

Jocelyn Apodaca Schlossberg is a senior writer focused on equity, diversity and inclusion for UCLA Health Communications.

For more information about the UCLA Health Homeless Healthcare Collaborative, go to: tinyurl.com/UCLA-Homeless-Health-Care

“Our unhoused neighbors are still our neighbors. They need to be treated with dignity and respect,” says collaborative director Brian P. Zunner-Keating.
Every morning, Deanna Attai, MD, strolls through her organic garden full of spaghetti squash, strawberries and sunflowers, taking stock of what needs water or trimming. This daily ritual of tending to her garden’s herbs, flowers, vegetables, and fruit has been a welcome distraction from the stressful nature of her job as a breast-cancer surgeon. Dr. Attai feels an urge to get back to her own experience as a patient. “It’s really hard to wrap a surgical brain around the same things,” she says. “You can set up everything right, but a severe drought or flood, or an infestation, will stunt the plants.”

Dr. Attai’s interest in gardening originated with the onset of an autoimmune disease in 2007. Feeling fatigued and experiencing joint pain, Dr. Attai sought out doctors to diagnose and treat her unexplained symptoms. After seeing five rheumatologists over six to eight frustrating months of worsening pain, she finally was diagnosed. “A breast-cancer surgeon, Dr. Attai felt an urge to get back to basics and start a garden. In part, because eating a healthy diet eases the symptoms of autoimmune disease, but at the same time, “nature was calling,” she says.

It took Dr. Attai several years to decide on site and plan her garden and uprooting in the sunny valley where she lives. She first had to remove a pine tree in her backyard, and then, bit by bit, take out areas of grass. Once the space was cleared, she started to plant for a few hours on the weekends. Now, the 40-by-15-foot garden is brimming with galactic scabiosa (also known as “pincushion”) flowers, cucumbers, green beans and more, occasionally providing Dr. Attai with an entire meal, like kabocha squash soup. And it also makes for a lively environment for lizards to find shelter and for bees to feast on pollen.

Working with such unpredictable conditions of nature, Dr. Attai has learned that influenced her outlook on a breast-cancer diagnosis: “The more time I spend in the garden, the more I realize that you can’t force things,” she says. “You can set up everything right, but a severe drought or flood, or an infestation, will stunt the plants.”

In the same way, Dr. Attai’s patients and her engagement on social media have inspired her to share her story. “My garden has helped me a lot,” she says. “I am much calmer and more at peace with my life.”

Given the fulfillment she gets from tending her flowers and vegetables, Dr. Attai encourages medical students and residents to find an outlet outside of their work. Before her illness, Dr. Attai said she lived and breathed surgery, with little time to unwind. She began growing in 2016 and now 24/7 work lifestyle played a role in her developing an autoimmune disease. Discovering the meditative process of gardening, she feels, saved her life. “If I hadn’t been pulled out of myself, I don’t think I’d be alive right now,” she says.

Her Healing Garden
By Kelsie Sandoval

AWARDS & HONORS
Dr. E. Dale Abel, Williams B. Adams Distinguished Professor of Medicine and chair and executive medical director of the Department of Medicine, was elected to the National Academy of Sciences.

Dr. Mopela A. Adeyemo, clinical instructor of nutrition, was named a Future Scientist from the Endocrine Society.

Dr. Elizabeth S. Barnert (FEL ‘14), associate professor of medicine, joined the National Commission on Correctional Health Care’s board of representatives as the Society for Adolescent Medicine liaison.

Dr. Timothy F. Cloughesy (RES ‘91, FEL ‘92), director of the UCLA Neuro-Oncology Program, was elected to the Association of American Physicians.

Dr. Judith S. Currier, chief of the Division of Infectious Diseases, was elected to the Association of American Physicians.

Dr. Daniel Geschwind (RES ‘95, FEL ‘97), Gordon and Virginia MacDonald Distinguished Professor in Human Genetics and director of the UCLA Institute for Precision Health, received the 2022 Cotzias Lecture and Award from the American Academy of Neurology.

Dr. D. Jose Hines (RES ‘97), Robert and Katy Day Professor of General Surgery and interim chair of the Department of Surgery, received the 2022 Sherman M. Mullikin Faculty Award, the highest honor from the David Geffen School of Medicine at UCLA.

Dr. Varghese John, professor of neurology and director of the Drug Discovery Lab at UCLA, received a bestowed prize from the Oakl Fischer Prize for Alzheimer’s disease research.

Dr. Carol M. Mangione, chief of general internal medicine, was elected to the Association of American Physicians.

Dr. Gatien Moriceau, assistant adjunct professor of medicine and a member of the UCLA Jonsson Comprehensive Cancer Center, received the Young Investigator Award from the Melanoma Research Alliance.

Dr. Thomas Rando, director of the Cell and Tissue Biology Program, was promoted to professor of cellular and molecular medicine and to chief of the Division of Infectious Diseases.

The Department of Medicine and chair and executive medical director of the Department of Medicine, was elected to the National Academy of Sciences.

Dr. Christina Puig Saus, assistant adjunct professor of medicine and hematology/oncology, a senior fellow at the Parker Institute for Cancer Immunotherapy and a member of the UCLA Jonsson Comprehensive Cancer Center, received the Young Investigator Award from the Melanoma Research Alliance.

Dr. Kalyanam Shivkumar (FEL ‘06), professor of radiological sciences, was named future scientist from the American Association of Medical Physicians.

Dr. Aparna Sridhar (FEL ‘13), associate professor of statistics and genomics, received the Martin-Peterson Scholars Award from the American College of Obstetricians and Gynecologists.

Dr. Rena M. Sturm (FEL ‘20), assistant professor of urology, received the 2022 Research Award of Distinction from the Urology Care Foundation.

At the West LA VA, where he built the endocrine division, ran the inpatient endocrine service and developed an endocrinology fellowship program. He published more than 50 research papers, chapters and reviews. He received multiple honors and awards and was founding editor-in-chief of the journal Thyroid and past editor-in-chief of Clinical Thyrology.

Dr. Norman S. Namerow (MD ‘58, FEL ‘62), professor emeritus of neurology, died on June 23, 2022. He was 95 years old. Dr. Namerow graduated among the first medical school classes at UCLA, completing his residency at UCLA and went on to dedicate much of his professional life to UCLA neurology and the field of neurorehabilitation. With a graduate degree in physics at UCLA, he applied his interest in that field to the study of physical medicine and how this influenced neurologic disease, particularly recovery. He received the Outstanding Physician of the Year Award from the California Governor’s Committee for People with Disabilities, the inaugural inpatient rehabilitation center at Daniel Freeman Memorial Hospital, where Dr. Namerow served as medical director for more than 10 years, was named the Norman S. Namerow M.D. Rehabilitation Center in his honor.

In Memoriam
Dr. Jerome M. Hershman, Distinguished Professor of Medicine Emeritus and past chair of medicine at the West Los Angeles VA Medical Center, died on July 18, 2022. He was 89 years old. Dr. Hershman came to UCLA in 1973 as chair of endocrinology

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HONORING 25 YEARS ADVANCING PANCREATIC-CANCER RESEARCH

SOME OF THE MOST POWERFUL CHANGES IN MEDICINE have come about following a tragedy. In 1997, Ronald S. Hirshberg died from pancreatic cancer at the age of 54. That year, his wife, Agi Hirshberg, dedicated herself to advancing pancreatic-cancer research by establishing the Hirshberg Foundation for Pancreatic Cancer Research in memory of her late husband. As the first beneficiary of the Foundation for Pancreatic Cancer Research by establishing the Hirshberg Center for Pancreatic Diseases. "The Hirshberg Foundation’s generosity has helped elevate the UCLA Hirshberg Center to one of the nation’s premier, comprehensive programs for pancreatic cancer and diseases," said Dr. D. Joe Hines (RES ’97), director of the UCLA Agi Hirshberg Center for Pancreatic Diseases, interim chair of the Department of Surgery and Robert and Kelly Day Chair in General Surgery. "From the very beginning, Agi and her family and team at the foundation vowed to raise sorely needed funds for research to broaden treatment options and give hope to pancreatic-cancer patients. She continues to advocate for change and her dedication inspires physicians, researchers, patients and their families."

Twenty-five years ago, the Hirshberg Foundation was the only organization of its kind focused solely on finding a cure for this devastating disease. Since then, the partnership between UCLA and the Hirshberg Foundation has driven advances in the understanding and treatment of pancreatic cancer for the benefit of thousands of patients and their families. Through a wide range of activities, including fundraising, education, advocacy and patient support, this remarkable collaboration has opened the door to countless discoveries and shaped the future of pancreatic cancer treatment.

In 2022, the American Cancer Society reported an increase in the five-year survival rate for pancreatic cancer to 11%, up from 6% just 10 years ago. This tremendous progress speaks to the vision and determination of the Hirshberg Foundation to provide funding for high-impact investigations, and of the UCLA faculty who pursue innovative avenues of research.

The Hirshberg Foundation Seed Grant Program is one such area that has benefited from the foundation’s funding. Directed by Dr. Vay Liang W. Go, Distinguished Professor of Medicine in the UCLA Vatche and Tamar Manoukian Division of Digestive Diseases and co-director of the UCLA Agi Hirshberg Center for Pancreatic Diseases, the program fosters leading-edge research on a global level by providing strategic investments in research that enable investigators to gather preliminary data that can then be used to apply for larger grants. "Seed funding supports highly innovative research projects that are not usually funded by government agencies," said Dr. Go. "Agi understands this and is a valued partner in our work. Philanthropic support of this kind for early research is indispensable to investigations that have the potential to make a profound impact on this disease and create a roadmap toward better treatments and, one day, a cure."

Since 2005, 104 seed grants have been awarded to 40 medical-research institutions in the United States and internationally, resulting in myriad discoveries and approximately $180 million in National Institutes of Health funding. UCLA is a partner in administering these grants and about 30 UCLA research projects have benefited from this support through the years.

The foundation also has invested in the UCLA Pancreatic Tissue Bank, a vital resource for pancreatic disease researchers at UCLA and the wider scientific community; an annual symposium that brings together patients and families with leading researchers; and psychosocial support to those impacted by cancer and their families at no cost to patients at the Simms/Mann-UCLA Center for Integrative Oncology. The Hirshberg Foundation’s 25th Annual LA Cancer Challenge 5K walk/run, which to date has raised more than $9.6 million mostly directed to UCLA for pancreatic cancer research, was held at UCLA in October.

"SINCE ESTABLISHING THE FOUNDATION 25 YEARS AGO, WE HAVE BEEN UNWAVERING IN OUR MISSION TO BE RELENTLESS IN FINDING NEW WAYS TO ADDRESS AND HEAL Pancreatic Cancer. OUR PARTNERSHIP WITH UCLA HAS AMPLIFIED OUR ABILITY TO MOVE THE NEEDLE IN RESEARCH AND WAYS TO HELP Pancreatic Cancer Patients."

"Since establishing the foundation 25 years ago, we have been unwavering in our mission to be relentless in finding new ways to address and heal pancreatic cancer," said Hirshberg. "Our partnership with UCLA has amplified our ability to move the needle in research and ways to help pancreatic cancer patients."

The special collaboration between UCLA and the Hirshberg Foundation for Pancreatic Cancer Research has laid the groundwork for a model in which the needs of people with pancreatic cancer are met in one location with the most advanced treatment options available. In addition to accelerating the pace of medical discovery, the foundation also has raised awareness of the disease and supports patients and their families at all stages of treatment and survivorship by disseminating information and providing resources. Construction of a new, state-of-the-art home for the UCLA Hirshberg Center in the Vatche and Tamar Manoukian Medical Building is in progress.

"My husband, Ron, always thought a problem was an invitation: ‘No’ meant ‘maybe’ and ‘maybe’ meant ‘yes.’ It is with this strong determination that he battled cancer, and it is still the way the foundation will continue Ron’s fight to win the battle against pancreatic cancer," said Hirshberg. "I know the crucial role philanthropy plays in fueling pioneering thinking and research and I am so proud of what the foundation’s partnership with UCLA has accomplished. With our shared purpose, I am certain this is only the beginning of what we can do together."
Taste for a Cure Raises Money for Cancer Research

"Interestingly, we were supposed to receive this award in March of 2020, but, sadly, it was put on hold two times. So, in the great tradition of TV exes exaggerating their figures, I’d like to say how honored we are to win this award three years running. Or in streaming metrics: 1 trillion minutes."

The evening also featured a musical performance by Grammy Award-winning artist Robin Thicke. Attendees enjoyed tastings from Far Niente Winery, ElNifio Winery, California vintners, as well as those from Italy and France. Guests were treated to a lavish array of dishes from Hinoki and the Bird, Lumière Brasserie and the Fairmont Century Plaza Hotel.

Event co-chairs, who dedicated their time to ensure the success of Taste for a Cure, included Joe Cohen, head of television at Creative Artists Agency; E. Brian Dobbins, talent manager, producer with Artists First; Jon Holman, president of The Holman Group; Jake Hancock, producer, director, writer and filmmaker; Larry Maguire, vice chairman, president emeritus and founding partner of Far Niente Winery; Tendo Nagenda, president of Netflix Originals; Gary Newman, executive partner in Attention Capital; Larry Maguire, writer and filmmaker; Larry Maguire, writer and filmmaker; Larry Maguire, writer and filmmaker; Larry Maguire, writer and filmmaker.
ADVANCING PEDIATRIC SOCIAL WORK

The UCLA Health Department of Care Coordination and Clinical Social Work has received an anonymous $600,000 contribution to benefit pediatric social work and the greatest needs of UCLA Mattel Children’s Hospital. This funding will provide families with financial assistance for a range of challenges experienced by the hospital’s most vulnerable patients, including those who are underserved. This patient group and their families who need to be close to the hospital for extended care can receive help with housing and living expenses — including food, parking and transportation vouchers, as well as funds for prescription copays and durable medical goods.

For more information, contact Lisa Haggard-Dugan at 310-221-6096

CONTINUED FUNDING FOR OLOFSON SCHOLARSHIP

Scott Olofson and his wife, Zuzana, through the Tom W. Olofson Family Foundation, have renewed their commitment to funding the Tom W. Olofson Scholarship in the UCLA Center for Prehospital Care. The scholarship provides full and partial scholarships to all three annual UCLA Paramedic Program classes, with up to six scholarships per year. The full scholarship covers tuition and required materials; the partial scholarship of $3,000 assists with tuition. As of 2019, 20 people have received the Tom W. Olofson Scholarship, with the next two recipients scheduled to receive the award in September 2022. Scott Olofson graduated from the UCLA Paramedic Program in 1996, and his experience as a paramedic has stayed with him throughout his career. The scholarship is dedicated to Scott’s father, Tom Olofson, who was a successful business executive, investor and philanthropist. Scott continues his father’s legacy by making it possible, through the scholarship, for paramedic students to pursue their dream in emergency medical services. Scott keeps in touch with scholarship recipients as they go through the program, graduate and reach professional and personal benchmarks.

For more information, contact Niah Green at 310-225-4814

IMPROVING THE LIVES OF LYMPHOMA PATIENTS

Karen Rosenfelt made a gift to the UCLA Jonsson Cancer Center Foundation to establish the Rosenfelt Family Endowed Chair in Lymphoma in the David Geffen School of Medicine at UCLA. This endowed chair will support a faculty member in the Division of Hematology/Oncology with expertise in lymphoma. An international search is underway to identify the inaugural chair holder, who will advance the Rosenfelt family’s mission to improve the lives of patients cured of lymphoma.

For more information, contact Margaret Shuey at 310-880-0734

BRIDGING FUNDING GAPS IN MACULOPATHY RESEARCH

Wendy and Ken Ruby’s gift to the Eli and Edythe Broad Center of Regenerative Medicine and Stem Cell Research at UCLA will support maculopathy research and help bridge the financial gap that often exists between promising preclinical studies and clinical application. UCLA scientists are pursuing innovative strategies to unlock the potential of stem cells for the treatment of blinding eye diseases, including age-related macular degeneration and Stargardt disease. Philanthropy from the Rubys helps advance maculopathy research at the center, providing the foundation to successfully initiate a Phase I clinical trial in the next two years.

For more information, contact Sabrina Ayala at 310-205-3815

SUPPORT FOR PROSTATE-CANCER RESEARCH

The Solich Fund has given $450,000 to the UCLA Department of Urology to benefit the prostate-cancer research of Dr. Robert Reiter, chief of the Division of Urologic Oncology, director of the Prostate Cancer Program and holder of the Bing Professorship of Urologic Oncology. Dr. Reiter is involved in all aspects of urologic oncology, with an emphasis on prostate cancer. This funding will help advance Dr. Reiter’s translational investigations and prostate cancer treatment.

For more information, contact Molly Mauzey at 310-258-4955

DONORS HONOR UCLA HEALTH NURSES

With support from numerous philanthropic partners, UCLA Health celebrated Nurses Month 2022 in May. Donor contributions made it possible to provide meaningful recognition programs for the health system’s more than 6,000 nurses and care partners. This year’s celebration included gift cards for all nurses, complimentary breakfast, cookies and sweet treats, a pizza party and flowers on all of the units. Nurses also received recognition through nursing-award programs that included the DAISY Award for Extraordinary Nurses and UCLA Health nursing awards honoring nursing excellence throughout the health system. The month served as an opportunity to thank UCLA nurses who worked tirelessly through the pandemic and demonstrated grit, commitment and care.

Funding to support Nurses Month this year included several repeat donors, such as the Phantassos Foundation, as well as UCLA Health System Board member Norman Schultz, who said he is “proud to continue support of UCLA Health nurses during Nurses Month by recognizing their dedication and patient-focused approach.”

For more information, contact Leah Green at 424-325-8184

GIFT ESTABLISHES ENDOWED CHAIR IN WOMEN’S LUNG HEALTH

Dr. Allan J. Swartz and Roslyn Holt Swartz have made a $2 million commitment to establish the Dr. Allan J. Swartz and Roslyn Holt Swartz Women’s Lung Health Endowed Chair in the UCLA Division of Pulmonary, Critical Care and Sleep Medicine. The endowed chair will support a faculty member with expertise in women’s health who will propel studies on sex differences in lung disease, the first chair of its kind in North America. Roslyn Swartz, a longtime member of the UCLA community, is a UCLA alumna and a member of the Iris Cantor-UCLA Women’s Health Center Executive Advisory Board. She is passionate about helping advance research in this area and raising awareness about women’s lung health issues. “Allan and I know the importance of supporting lung research,” said Swartz. “Allan, who served at a number of major hospital systems in Southern California, is a survivor of lung cancer, and we are grateful to UCLA surgeons Drs. Frederick (Fritz) C. Elbior, (MD ‘95, RES ‘02), and Jane Yanagawa, (FEL ‘09), who successfully treated him.”

For more information, contact Gemma Badini at 310-206-9235
I WAS ON A SABBATICAL IN LONDON WHEN RUSSIA INVADED UKRAINES in February. Four days later, I was a volunteer behind the wheel of a van in a convoy of seven vehicles driving 20 hours to deliver relief supplies for refugees on the Poland-Ukraine border. I’ve been here ever since. As my companions and I covered the nearly 1,900 kilometers to our destination, we wondered what we might encounter when we arrived. Would we see people who had been shot or injured by bombs? Children with burned or crushed limbs? We had no idea what to expect.

It was scary, but at the same time, I felt grateful to be doing something to try to help. We arrived in the very early morning and unloaded our supplies at a warehouse. Someone then took us to the border crossing to see what was happening there. It was at least -10 degrees Celsius out, and people came up to our van window asking if they could sit inside to warm up. They were waiting for transportation to somewhere else — maybe in Poland, maybe in Germany or some other country — but nothing was moving, and they were freezing. And already there were human traffickers there, taking advantage of the situation and making victims out of victims.

“Yes, get in. Please come in,” we said to the ones who wanted to get warm. I felt desperate to help.

We drove back to London, escorting a Ukrainian woman, Mariana, and her daughter. They had fled their city, which was under siege, and had to leave their grandmother behind. It was horrible for them; they were traumatized and in shock. I knew there was more that I could do. A few days after we returned, I got on a plane and flew back to Poland, where I set up a women’s and children’s center — little more than a small, trash-strewn tent that I commandeered from men working at the refugee center who wanted to turn it into a tea booth — at the border crossing near the village of Medyka.

In those early months, it was bitterly cold, and the line of refugees waiting to cross into Poland could stretch for two kilometers or more. It took days to get through. The route was littered with garbage. There were no bathrooms. Nearly everyone in that line was a woman or child. They carried what few possessions they could manage and slept outside in the wind and rain. And once they did cross, mothers often came to us with babies who were wet and chilled to the bone, nearly hypothermic. We brought them into the warm tent and gave them new, dry clothes, and provided the women with feminine-hygiene supplies.

It is mostly men working in the refugee center, but it’s important for the women and children to see the smiling face of a female, someone who understands their needs and problems. I say to them, as best I can, in Ukrainian, “laskavo prosimo,” “welcome,” and try to make them feel comfortable. They are exhausted, and shy. I don’t allow men into my women’s tent.

The women are so grateful. So many hugs. For me, it feels close to a spiritual experience. These women, my sisters, and children crossed the border fleeing in terror from bombs and gunfire and death in their towns and cities. Most left the adult and near-adult males in their families behind, many of them to engage, and perhaps die, in the fight against the Russians. Tears filled the eyes of many — tears of fear and tears of uncertainty for what lay ahead. I continue to be impressed by their resilience.

Sometimes the older women, the grandmothers, come and sit and talk with me. They’ve seen so much in their lives. The grandmas melt my heart. Though I’ve picked up some Ukrainian, I use a digital translator to communicate with them. They’ll talk about things that are jovial and sweet, but then switch to the bitter truths of their new reality. “My beautiful city, it is destroyed,” they will say. “My town is now rubble.” It is so difficult hearing their stories. I try to imagine what it would be like if it were my town or my city — if it were Westwood that had been bombed and destroyed. I can’t.

The days are very long, sometimes 18 hours or more, but the support I have received from my colleagues at UCLA, as well as family and friends, has been very gratifying. They send money to buy diapers and other supplies, and they offer encouragement.

One day a girl, maybe 10 or 11 years old, who was with her father, an American volunteer, handed me an envelope and said, “My class did a play about the Holocaust as a fundraiser, and I want you to take this money for your project.” There was about $600. This is sacred money, I thought, a pure act of giving. I used it to buy sandals and summer clothes for the children. Over the months, the scope of my work has expanded. I’m no longer tethered to the border and have now crossed into Ukraine numerous times to deliver supplies to hospitals as far away as Lviv, a battered city about 90 kilometers east where basement windows are blocked over with sandbags, turning them into makeshift bomb shelters.

My head reels from many of the things I’ve seen. Being here is so different from anything I’ve done before, and the experience has changed me. Things that once seemed important don’t anymore, and other things that were unimportant in the past now have new meaning. I love what I am doing here. I want to help and make some kind of contribution, and I will stay for as long as it takes.

Christie J. Nelson is a recreational therapist at UCLA Resnick Neuropsychiatric Hospital.
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