

# S T A N F O R D M E D I C I N E

Issue 1 / 2021

special report

## CLOSING THE GAP:

Addressing racial inequity  
in medicine

### Meaningful action

Countering systemic racism through  
research and outreach

### Starting right

Reversing childbirth inequities

### Not a biological construct

Rethinking race in medical care

### A voice for the incarcerated

A conversation with Shaka Senghor

### Diversity champion Eric Sibley

Doctor, mentor, researcher  
extraordinaire

plus

### Formidable opponents

Outsmarting cells that resist  
cancer treatments

### Barbecue with dad

A son witnesses how a well-loved meal awak-  
ens memory





S T A N F O R D  
M E D I C I N E

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# MEET CARMEN, YOUR NEW TRAINER

**SHE'S A VIRTUAL COACH WITH A WINNING TRACK RECORD  
AND BILINGUAL ADVANTAGE**

Regina Sosa's coach was unusual but effective. Over the course of a year, coach Carmen spurred the 70-year-old San Jose resident to increase her daily steps from an average of 2,500 to 10,000. The unusual part? Carmen is a computer program.

"I've really enjoyed it and feel like I've gotten a lot out of it. Every day during the program, I just tried to get more and more steps because I knew that I was going to go in and report my progress to Carmen," Sosa said.

Carmen, who speaks Spanish and English, seems to be a boon for sedentary people seeking to adopt healthier habits, according to a study led by Stanford Medicine professor Abby King, PhD, with lab manager Maria Ines Camp-ero playing a critical role in its execution. The study's 245 participants were between the ages of 50 and 87 and were primarily Latino. The team published the results in the November 2020 *JAMA Internal Medicine*.

"Adults who are around 50 and up tend to struggle with maintaining adequate physical activity," said King, professor of epidemiology and population health and of medicine. "But this is an age when people can really benefit from even small amounts of regular physical activity. It's important for lowering the risk of a number of diseases and health conditions, such as Type 2 diabetes and obesity, as well as helping to maintain cognitive function and well-being."

Low-income Latino adults are at particular risk for inactivity, said King. It was one reason her team configured Carmen to offer her services in Spanish as well as English. And while King's previous research shows physical activity advisers can help adults in midlife or older kick their physical activity habits into higher gear, training coaches can be expensive and time consuming. That's where King thinks Carmen could help.

King and her team collaborated with 10 community centers in California's Santa Clara and San Mateo counties, with half of the centers coaching through Carmen and half through human advisers. In all sessions, advisers asked about the participants' progress toward meeting the nationally recommended goal of walking 150 minutes or more each week.

With Carmen, participants start their sessions by scanning an ID so the program can "remember" previous conversations and data to inform the new interaction. Carmen greets participants by name, asks how they're doing and inquires about their progress. Like a human coach, she's personable with her advisees, asking them, for example, about their weekends. During the holidays, Carmen even revealed her New Year's resolution: to be less glitchy.

If participants meet their walking goals, Carmen encourages them: "Keep it up! Would you like to set higher goals next week?" If they fall short, Carmen asks what stood in the way. Participants respond by selecting answers on a touch screen.

People who were coached by Carmen increased their walking by an average of 154 minutes per week, the study showed. Participants coached by a human increased their walking by an average of 132 minutes per week.

King said the study is the second she knows of to demonstrate that a digital coach can be as effective as a human at helping people increase activity levels, and the first to demonstrate this in a non-English-speaking population.

"While we don't have a way at present to offer Carmen to the general public, we are interested in exploring collaborations with companies and organizations that would help us make virtual advisers like Carmen a widely available, low-cost option," said King. She hopes to expand Carmen's reach internationally, particularly to Latin America. — HANAE ARMITAGE



# STANFORD MEDICINE

## SPECIAL REPORT

### Closing the gap Addressing racial inequality in medicine



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**The promise of precision health is exhilarating. Through the latest advances in genomics, physicians can develop therapies for a patient based on the person's genetic code. Cutting-edge regenerative medicine can help tissues and organs repair themselves.**

Despite these and many other 21st-century wonders, the best predictor of a person's health is still a 58-year-old postal service innovation: the ZIP code. For example, life expectancy across Los Angeles County ranges by as much as 15 years. Plotted on a map, shorter life expectancy closely tracks with lower income, less home ownership, more pollution — and race. Where you live is likely to say more about your health outcomes than your doctor or genes.

Unemployment, poor housing, food deserts, lack of health care, underdeveloped or unsafe parks, crime and violence, and high levels of stress all take a heavy toll on a person's physical and mental health. The medical field has a sterile name for these factors: the social determinants of health.

But when all of these factors consistently and disproportionately affect Black and Latinx communities in city after city, we can also properly identify them as the products of systemic racism. Whether it was the redlining that prevented a Latina businesswoman from getting a loan, or the zoning variance that allowed a polluting factory to open in a Black neighborhood, the institutional, political and cultural processes penalize not just one generation of minority Americans but also future generations.

The insidious effects of racism have become abundantly clear during the pandemic. Anti-Asian hate crimes have soared nearly 150% amidst rising xenophobic rhetoric. And nationally, Black, Latinx and American Indian people are about four times as likely to be hospitalized with COVID-19 as white people, and nearly three times as likely to die of it, according to the Centers for Disease Control and Prevention.

We also must acknowledge the reality of racism within the health care system. In 2003, the Institute of Medicine published the report *Unequal Treatment*, which revealed that racial and ethnic minorities receive lower quality care even after controlling for factors such as insurance status and income. Nearly 20 years later, we continue to see reports of differential treatment for patients of color at hospitals around the country.

Recognizing that quality health care is a basic human right, Stanford Medicine envisions a better future. I believe our precision health campaign can leverage the power of modern medicine to identify the roots of these inequities, lessen their impact and ultimately dismantle them.

Stanford Medicine clinicians and researchers have conducted foundational and innovative work to better understand the interplay of factors facing individual communities and entire populations. We must go further. Academic medical centers like Stanford must make social determinants — and systemic racism — a research priority. And we must enhance our efforts to recruit, train and support a more diverse workforce for careers in health care and biomedical education. We see time and again that diversity pays dividends in clinics and classrooms.

Stanford Medicine is committed to eradicating racism. We know we don't have all the answers, so when we created our Commission on Justice and Equity in November, we recruited leaders, advocates and experts from around the country to help us develop plans to achieve these goals at Stanford, even as we look for ways to lead nationally.

I recognize that the job before us is formidable, but I am undaunted. It will demand a sustained and determined effort, one that employs the energy and creativity of thousands of individuals. I believe we are up to the task. We cannot let racism forever define this nation.

Sincerely,  
Lloyd Minor, MD  
Carl and Elizabeth Naumann Dean of the School of Medicine  
Professor of Otolaryngology – Head & Neck Surgery

GLENN MATSUMURA



# upfront

A QUICK LOOK AT THE LATEST DEVELOPMENTS FROM STANFORD MEDICINE

## Coaxing cartilage growth

STANFORD MEDICINE RESEARCHERS HAVE FOUND A WAY, in mice and human tissue, to regenerate the protective substance that covers the ends of bones at the joints and keeps movement pain-free.

Loss of this slippery and shock-absorbing tissue layer, called articular cartilage, causes joint pain and arthritis, which afflicts more than 55 million Americans.

The method, described in a paper published Aug. 17 in *Nature Medicine*, starts with surgery to cause slight injury to the joint tissue and then uses chemical signals to steer the growth of skeletal stem cells as the injuries heal.

The work builds on previous stem cell research in the Stanford labs of assistant professor of surgery Charles K.F. Chan, PhD, and professor of surgery Michael Longaker, MD, co-senior authors of the paper.

"Cartilage has practically zero regenerative potential in adulthood, so once it's injured or gone, what we can do for



patients has been very limited," Chan said. "It's extremely gratifying to find a way to help the body regrow this important tissue."

Next, researchers plan to conduct experiments in larger animals before starting human clinical trials.

"One idea is to follow a 'Jiffy Lube' model of cartilage replenishment," Longaker said. "You don't wait for damage to accumulate — you go in periodically and use this technique to boost your articular cartilage before you have a problem."

### Twilight surgery

WHEN MODESTO RESIDENT James Ewing needed minimally invasive surgery in 2019 for debilitating back pain, Stanford orthopaedic surgeon Todd Alamin, MD, said he could have it under conscious sedation — a twilight sleep used during colonoscopies — instead of the usual approach, general anesthesia.

Alamin is among few U.S. surgeons using twilight sleep for surgery to widen the spinal canal. Patients who have the surgery under conscious sedation have fewer anesthesia side effects and recover faster, he said. It's also more precise: Conscious patients react — they might move or speak — if his surgical tools compress a nerve, warning him to steer clear.

Ewing doesn't remember the procedure, but he felt better immediately. Now, he said, "I can stand up straight. I can sleep at night."

Scientists at Stanford's clinical virology lab have tested more than 500,000 samples for COVID-19 since March 4, 2020, just after the pandemic began. Read more at <http://stanmd/samples>

## Double agent

A TREATMENT THAT COULD HELP IMMUNE CELLS destroy cancer cells might also reduce the inflammation that causes atherosclerosis, the buildup of plaque in arteries, research shows.

Stanford School of Medicine researchers first suspected the treatment's dual benefit in 2016, building on research from the lab of stem cell biologist Irving Weissman, MD. Weissman's lab discovered that antibodies called anti-CD47 can conceal molecules on cancer cell surfaces that keep immune cells from killing them.

Masking those molecules helps these immune cells — macrophages — devour the cancer cells.

In research published Jan. 28 in the *New England Journal of Medicine*, Stanford vascular medicine physician Nicholas Leeper, MD, and his colleagues studied whether anti-CD47 antibodies, which are in clinical trials for many types of cancer, could also treat atherosclerosis.

The researchers tracked nine trial participants with a blood cancer called non-Hodgkin's lymphoma who also had atherosclerosis. After nine weeks, eight of them had lower levels of arterial inflammation, suggesting that anti-CD47 antibodies could help macrophages scavenge the cells responsible for plaque.

Though more research is needed, Leeper, the study's senior author, said, "The concept of this is truly independent from everything else we can currently offer to patients with cardiovascular disease."

# Schizophrenia secret solved

WHEN NERVE CELLS AREN'T BUSY EXCHANGING INFORMATION, THEY'RE SUPPOSED TO KEEP QUIET. If they're just popping off at random, like children in a noisy classroom, any signals they're transmitting are obscured. But in cases of schizophrenia with the most common genetic risk factor, it seems that nerve cells won't shut up.

Sergiu Pasca, MD, associate professor of psychiatry and behavioral sciences, and his colleagues think they know why.

In a study published Sept. 28 in *Nature Medicine*, the investigators found an aberration in nerve cells from patients with the genetic condition known as 22q11DS, in which a particular section of chromosome 22 is deleted. These nerve cells, generated in a dish from the patients' skin cells, fired spontaneously four times as often as equivalent cells generated from healthy people.

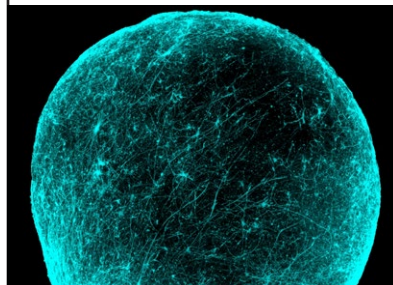
The reason, the researchers learned, was that the voltage difference across nerve cells' outer membranes when they were at rest — which is responsible for keeping these cells from firing randomly — was substantially lower in nerve cells with the deletion than in those without it.

Of the roughly 60 different genes inhabiting the stretch of DNA that's deficient in 22q11DS carriers, Pasca and his teammates identified one whose loss appears largely responsible. That shows drug developers where to aim their attention.

Pasca envisions defining psychiatric diseases in terms of their molecular underpinnings — what he calls molecular psychiatry.

"Probing the underlying biological mechanisms driving psychiatric disorders is hard because we don't ordinarily have access to functional brain tissue from living patients," he said. But a new technology invented in his lab allows for the production of copious living brain tissue, circumventing that difficulty.

"We've been working from behavior down," he said. "Here, we're working from molecules up."



One-way fear signals  
**STRONG SIGNALS FROM THE BRAIN'S FEAR CENTERS** make it harder for anxious and stressed children to regulate their emotions, according to new Stanford research.

The research, published April 21 in *Biological Psychiatry*, explored how anxiety and chronic stress change emotion-regulation circuits in 10- and 11-year-olds. Brain scans examined signals between one of the two amygdalae — fear centers on the brain's right and left sides — and the dorsolateral prefrontal cortex, a region involved in decision-making and regulating emotion.

Anxious and stressed kids had stronger signals from the fear center to the dorsolateral prefrontal cortex, but no such effects in the reverse direction. They were also less able to modify their emotional reactions during the study.

"This study shows that the communication between our emotional centers and our thinking centers becomes less fluid when there is significant stress," said senior author Vinod Menon, PhD, professor of psychiatry and behavioral sciences.

# COVID FOCUS

## A QUICK LOOK AT PANDEMIC-RELATED NEWS

### **Tracking COVID mutations**

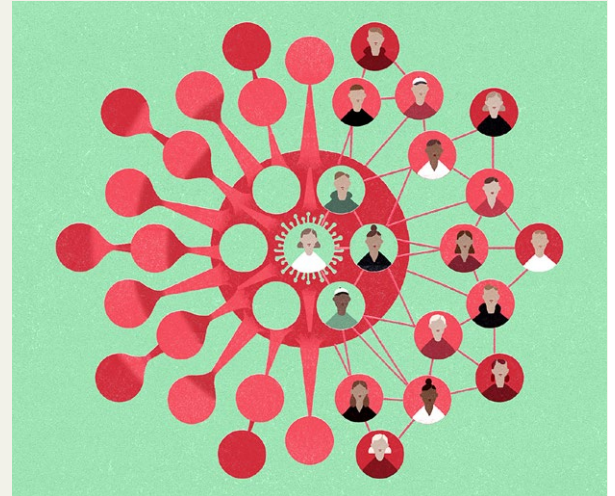
USING THE EXPERTISE THAT MADE THEM a leader in developing COVID-19 diagnostic tests, Stanford Medicine researchers are now tracking the spread of new mutations, or variants.

Testing at Stanford's Clinical Virology Laboratory, led by the lab's medical director, Benjamin Pinsky, MD, PhD, enables large-scale screening of diagnostic samples to track strains of the virus throughout California.

"In most cases it is too early to say whether or how these variants will influence the course of the pandemic, but it is important to monitor their evolution and spread," said Pinsky, associate professor of pathology and of infectious diseases at Stanford's School of Medicine.

Stanford uses a technology called reverse transcription polymerase chain reaction, or RT-PCR, to identify viral genetic material in samples collected from nasal passages. It helps researchers discern whether someone is infected and pinpoint whether they're carrying the original coronavirus strain or a new variant.

Tracking variants and quickly identifying mutations is critical to understanding whether they will spread more easily, cause more-severe disease or render vaccines less effective. — *Read more at [stan.md/samples](https://stanfordmedicine.stanford.edu/samples)*



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pandemic:  
[stan.md/  
covidvoices](https://stanfordmedicine.stanford.edu/covidvoices)

### **A son's fight to save his father**

MONTH AFTER MONTH, AS HIS FATHER, JOHN, suffered the devastation that COVID-19 can inflict, 24-year-old Patrick kept watch. By May, John was on life support and needed a lung transplant to survive, but his doctors in Washington said he was too weak for surgery, said Patrick, whose family didn't want their last name used.

Patrick didn't give up, though, and called transplant centers around the country. Many said no, but Stanford Health Care left a door open. If John could regain some strength, the hospital would fly him to Palo Alto to see if its doctors could help. So Patrick pushed for more physical therapy and kept encouraging his dad.

In August, John was able to board an air ambulance for Stanford. "That was a glorious day," Patrick said. John's kidneys had failed, but lungs and a kidney soon became available. Overnight on Sept. 10-11, John underwent successful lung and kidney transplants, making him among the first COVID-19 patients to undergo a multiple-organ transplant. — *Read more at [stan.md/son](https://stanfordmedicine.stanford.edu/son)*

### **A pandemic residency**

GABRIELA SPENCER, MD, WAS A NIGHT RESIDENT when Stanford Hospital received one of its first COVID-19-positive results for a patient. The challenges of keeping health care workers, staff and patients safe were instantly clear, spurring Spencer to help design and distribute training materials for safety protocols and proper personal protective equipment use for other residents. As the pandemic continued and hospital visitors were restricted, residents became crucial intermediaries between patients and families.

"It sometimes took a few hours just to make calls to the families, keeping them up to date in a very distressing situation," said Spencer. "I'm from Puerto Rico, and a lot of my patients were Spanish speaking. It's really important for me to be able to have these sometimes charged and difficult conversations with their family members in their native language." — *Read more at [stan.md/spencer](https://stanfordmedicine.stanford.edu/spencer)*

GRACIA LAM



COUNTERING  
THE IMPACT OF RACISM  
ON HEALTH

# RIGHTING DECADES OF WRONG

In 1932, 600 Black men signed up for a study that's come to be known as one of the most pernicious, deceitful experiments in American history. The Tuskegee Study of Untreated Syphilis in the Negro Male masqueraded as an investigation into treatments for “bad blood,” a catchall term used in the 1930s for various illnesses. In reality, it was a U.S. Public Health Service study meant to observe how untreated syphilis affected humans.

Lured by free medical care and meals in exchange for participating, hundreds of Black men who had syphilis enrolled. During the 40 years the study ran, more than 100 participants died of the disease or syphilis-related complications at the hands of the U.S. government. Few men received treatment for the disease, despite the discovery in the early 1940s that penicillin effectively treats syphilis. The experiment shut down after the Associated Press exposed the study in 1972.

An enduring mistrust of the medical establishment among Black people — especially Black men — followed, said Italo Brown, MD, a Black clinical assistant professor of emergency medicine, physician and health disparity researcher. Medical mistrust, said Brown, contributes to health disparities. “Medical mistrust exists because of structural racism; inequities in health outcomes exist because of structural racism,” he said. “There’s a common thread, and if we work to address that one underlying factor — structural racism — we’ll see a significant shift towards better, more equitable health for all.”

BY HANAE ARMITAGE

ILLUSTRATIONS BY EDEL RODRIGUEZ





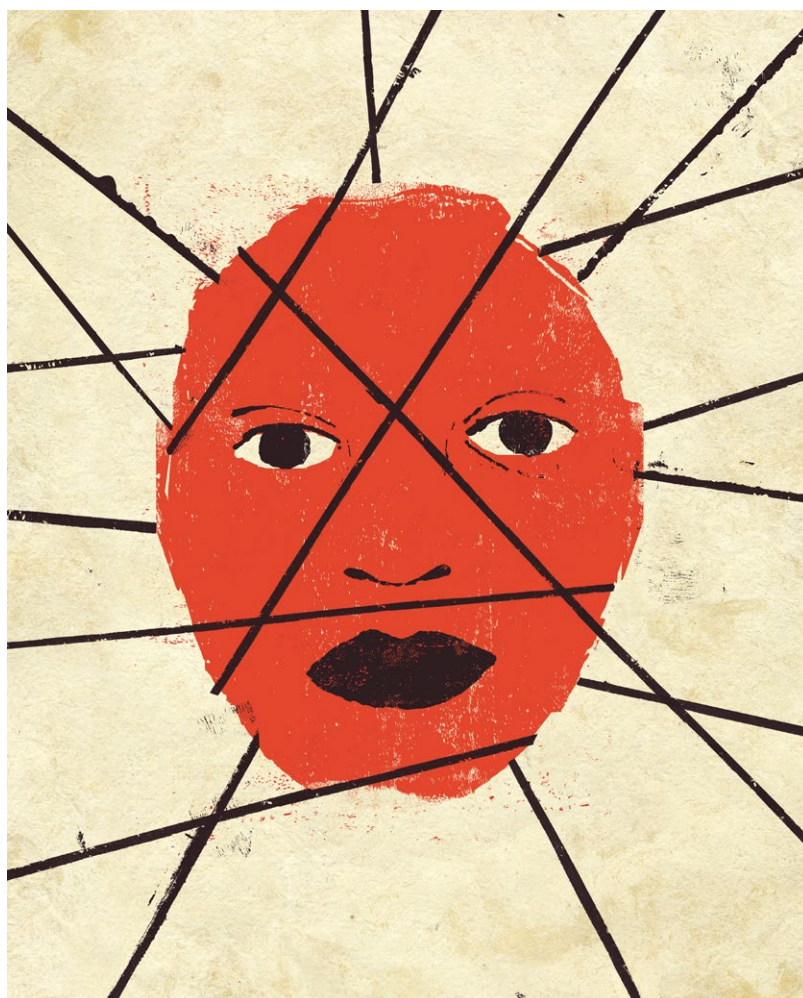
Health and health care inequity in the United States remain entangled with race. African Americans have the highest mortality rate for all cancers when compared with any other racial or ethnic group. Indigenous American and Alaska Native adolescents are 30% more likely to be obese than white adolescents. When compared with white women, Latinas are 40% more likely to have cervical cancer and 20% more likely to die from it. The COVID-19 pandemic has disproportionately affected Blacks and Latinos who, during the first six months of the pandemic, made up 58% of all patients hospitalized for COVID-19 and 53% of those who died from it, according to research from Fatima Rodriguez, MD, assistant professor of medicine.

These are just a few examples of hundreds of documented disparities in what many believe is a legacy of systemic racism that has historically rejected the importance of diversity and equitable access to health care and other critical resources for racial and ethnic minorities. Health disparities can be caused or exacerbated by poor living conditions, a lack of access to health care and low-paying jobs, among other factors.

“Racial inequity is a public health crisis that’s never been solved,” said Lloyd Minor, MD, dean of the School of Medicine. “Academic research plays a critical role in not only shedding light on why these challenges exist but also in devising new solutions that will help dissolve these long-standing disparities and pave the way to health equity.”

The field of health disparities research started to take shape in the 1980s, said Monica Webb Hooper, PhD, the deputy director of the National Institute on Minority Health and Health Disparities. To gauge progress in the field, Webb Hooper looked to the National Institutes of Health’s PubMed database. Between 1980 and 1990, she found just a few published studies on racial health disparities. In the past decade, more than 10,000 mentioning these key words have been published, but there’s still plenty of work to do, she said. “There’s certainly been progress in reducing disparities, but because of the complexity of the issues, it’s not happening at the pace that many of us would like to see,” said Webb Hooper.

The terms we use to refer to people of Latin American descent are evolving. This issue of *Stanford Medicine* uses Latino and Hispanic as well as a newer term, *Latinx*, which is intended to be explicitly gender-neutral.



To that end, Stanford researchers and clinicians are re-designing health care strategies and implementing new approaches to reach marginalized communities. Below is a small sample of their work.

## HEALTH CHECK AND A HAIRCUT

Barbershops serve as sites to help deliver health checks in Black communities.

**WHY IT MATTERS:** *Black men in the United States are less likely to trust doctors and seek medical treatment.*

Barbers in predominantly Black communities are being trained to better serve clients — and it has nothing to do with the ‘do. In two projects with Stanford leaders — the Cut Hypertension Program and TRAP Medicine — physicians teach barbers in cities throughout the United States about health and wellness so they can share what they learn with clients, mostly Black men and boys.

Health disparity researcher Italo Brown conducted a survey of 2,500 Black American men in late 2019 and early 2020 confirming his hypothesis that they were more comfortable

having conversations about health, racism, violence and police brutality in barbershops than at doctor's offices.

"Our big idea is to leverage cultural capital to deliver health information and promote wellness directly to predominantly Black neighborhoods that have been chronically disadvantaged," said Brown, who is chief impact officer for TRAP Medicine (for Trust, Research, Access and Prevention) and served as an early adviser to the program's founder, Jahmil Lacey, during its 2014 launch in Oakland, California.

Barbershop-based health support in Black communities is a strategy that has gained popularity over the past decade. TRAP Medicine's focus is training barbers to dispel stigmas about mental illness and teach about topics including the importance of prostate checks, practicing safe sex, and healthy eating and exercise habits. In some shops, TRAP Medicine arranges for local medical or nursing organizations to conduct free blood pressure or blood glucose checks.

The Cut Hypertension Program, led by Kenji Taylor, MD, instructor of medicine, has a similar mission, with a twist: Taylor founded the program 10 years ago, when he was a medical student at the University of Pennsylvania, to curb the disproportionate cardiovascular disease burden Black people carry. The Centers for Disease Control and Prevention reports that Black people between 18 and 49 are twice as likely to die from heart disease as their white counterparts.

The program certifies barbers as health coaches and trains them to measure blood pressure and talk with clients about their medical problems and cardiovascular health. Barbers refer clients with high blood pressure to local clinics. "This is a partnership between the community, health care professionals and academics," said Taylor. "It's built on trust, communication and data. That's what makes this work."

The Cut Hypertension Program recently implemented a model — developed by researchers at the Cedars-Sinai health organization in Los Angeles — in which a program pharmacist works virtually to treat hypertension in clients receiving health coaching at some Bay Area barbershops.

Both programs are working with barbershops locally and nationally: Cut Hypertension has partnered with barbers in Atlanta, Philadelphia and in the Bay Area cities of Oakland, San Francisco and Vallejo; and TRAP Medicine has partnered with barbers in Atlanta, Los Angeles, New York and Oakland.

In response to the COVID-19 pandemic, the programs have shifted their focus to COVID-19 education. Members of both organizations are compiling resources that spell out how barbers can protect themselves and their clients from

## DESEGREGATING HOSPITALS

HOW MEDICARE'S ARCHITECT FORCED HOSPITALS TO ADMIT BLACK PEOPLE

The landmark Civil Rights Act of 1964 outlawed segregation and discrimination on the basis of race, religion, gender or national origin. Another milestone of the civil rights movement came the following year: the establishment of Medicare — and the end to hospitals nationwide turning away patients because of the color of their skin.

Medicare was the crown jewel of President Lyndon B. Johnson's Great Society, a set of programs aimed at ending poverty and racial injustice. Johnson's assistant secretary of health, Philip Lee, MD, championed the cause by insisting that hospitals receiving the new Medicare funding for their elderly patients follow the Civil Rights Act by ending discrimination against their patients on the basis of race.

His role as the architect of Medicare — and in telling some 7,000 hospitals, "No Black patients, no Medicare funding" — would become his greatest legacy. Lee, a graduate of the Stanford University School of Medicine, died in October at the age of 96.

In a 2015 article in the *Journal of the American Society on Aging*, Lee wrote that in 1965 a cardiologist at Georgia Baptist Hospital told him that if he put a Black patient in with a white one, his white patient "would die of a heart attack."

Lee responded to him and other hospital administrators who balked at admitting Black patients: "Well, it's the law; there's going to be no Medicare money if the hospital doesn't desegregate." By February of 1967, Lee wrote, 95% of hospitals were receiving Black patients.

"For Phil, it was a powerful tool to address the racial and economic injustices that plagued America at the time," said his nephew, Peter Lee, executive director of Covered California, the state's health-care marketplace under the Affordable Care Act. In the early 1960s, Philip Lee had lobbied in support of a precursor to Medicare — in opposition to the American Medical Association. He and LBJ took the political high road in making Medicare and Medicaid funding contingent on desegregation, said Peter Lee. "Money talked — and most hospitals changed their policies almost overnight."

After several senior government roles, Philip Lee returned to California as director of UC San Francisco's Institute for Health Policy Studies and later served as UCSF chancellor. He also taught graduate seminars in health policy at Stanford.

"Dr. Lee was one of the great leaders in American health policy," said Stanford School of Medicine professor Laurence Baker, PhD. "The Medicare program, which he played an instrumental role in implementing, went on to transform access to health care for elderly and disabled Americans, and he had a hand in shaping every piece of our health care delivery system." — BETH DUFF-BROWN



infection — things like social distancing, using personal protective gear and taking heightened hygiene measures. And the programs' leaders are thinking about how barbershops could act as hubs for COVID-19 resources, such as testing or vaccinations in communities of color.

## 'WITH US AND BY US' NOT 'ON US FOR OTHERS'

**In partnership with American Indian tribes, researchers support the infrastructure for a biobank with Indigenous people that is owned and operated by Indigenous scientists and tribal members within the geographic and legal jurisdiction of a tribal nation.**

**WHY IT MATTERS:** *While helping to build a biobank, researchers are recognizing the sovereignty of data and biological samples of Indigenous peoples, respecting the cultural practices and prioritizing precision health by focusing on much-needed public health projects.* Researchers' efforts to collect biological samples from people of varying genetic ancestries often miss the mark on diversity — Indigenous people, for instance, are among the least represented in the United States and, moreover, the Western Hemisphere. Past research that focused on the health of Indigenous Americans has also sown mistrust between some tribes and the scientific community after some researchers said they would use the data to study obesity, but instead used it to study the genetics of the offspring of parents who are close blood relatives.

A newer project, Bio-Repository for American Indian Capacity, Education, Law, Economics and Technology, or BRAICELET, started six years ago in collaboration with a Northern Plains tribe and the Stanford Precision Health for Ethnic and Racial Equity Center as the first biobank to lie within the borders and legal jurisdiction of an American Indian tribe.

"Many of the health inequity and data sovereignty issues that Indigenous people face are playing out for other minority populations, too," said Joe Yracheta, an Indigenous research scientist for the project. "I see American Indians in a crucial leadership role in navigating these complicated social, legal and technological discussions, and our effort to do so is growing every day."

That's why research scientist Jennifer Li-Pook-Than, PhD, takes a different approach to the BRAICELET biobanking project. The focus: data sovereignty, meaning those who provide the data also own that data and decide how and when it is used in research.

The biobank is a four-way partnership between a tribe in South Dakota, two American Indian research organizations, and the Stanford Precision Health for Ethnic and Racial Equity Center. Li-Pook-Than, Stanford's project leader, said that one priority is for tribal members — including research professionals or other scientifically trained individuals — to fully run the biobank. Yracheta sees opportunities to build new infrastructure to support the biobank's growth, which would indirectly boost the tribe's community economy, political leverage and understanding of their health, as well as science and big data.

The project team has collected and stored thousands of samples, which the researchers have used to better understand, diagnose and treat rheumatoid arthritis, an autoimmune disease that is common in American Indians. Research



using biobank data has so far revealed important genetic differences in how rheumatoid arthritis develops and responds in Indigenous people compared with white people, findings that the group hopes to publish soon.

## FOOD AS MEDICINE

Researchers are testing whether better access to healthy foods, including fresh produce and leafy greens, can improve well-being and mitigate chronic disease.

**WHY IT MATTERS:** *People who lack access to healthy foods are at increased risk for a range of chronic diseases.*

A box of produce a week keeps the doctor away — or so goes the saying behind a project led, in part, by Lisa Goldman Rosas, PhD, assistant professor of epidemiology and population health and of medicine. Goldman Rosas, a longtime health researcher and advocate for under-resourced populations, is helping bring healthy foods — carrots, kale, cabbage and other vegetables — to communities where people of color have higher rates of chronic disease and face food insecurity.

“I spent a lot of time working in the Salinas Valley during graduate school with people who were picking the fruits and vegetables that were in local grocery stores, yet they couldn’t afford to buy these foods for themselves,” Goldman Rosas said.

In her latest project, called Food as Medicine, Goldman Rosas has teamed up with community health centers, including ALL IN Alameda County; Community Health Center Network; Open Source Wellness; and Dig Deep Farms, a Bay Area sustainable farm, to provide fresh produce to individuals and families who cannot afford or cannot conveniently purchase such foods.

The project, which is also a study, began in 2018 through a clinic at the Tiburcio Vasquez Health Center, which primarily serves Latinos in San Leandro, California. The project has since launched in Alameda County, hosted through a community health center, which uses state and federal funding to provide care for people who lack adequate insurance.

The idea is to provide a weekly batch of fresh vegetables to patients who are at risk for at least one chronic disease — such as diabetes, high blood pressure, heart disease or depression — and monitor their health over 16 weeks. The researchers use data from electronic medical records to monitor health measures — such as blood pressure, cholesterol and glucose levels — to assess the impact of eating more dark, leafy greens and other vegetables. Participants also attend group counseling to learn about making healthy meals and ways to be more physically active. During

the COVID-19 pandemic, Food as Medicine has switched to delivering a box of produce to patients’ doorsteps and moved counseling online.

After 16 weeks, Dig Deep Farms representatives help families continue to receive healthy produce through food banks by using food stamps and through other means.

Next, the team plans to analyze how a change in diet impacts health, said Goldman Rosas. They’re also expanding the program in Alameda County, where food insecurity has reportedly doubled during the pandemic, she said.

## FINDING THE FULL SPECTRUM

Amid the COVID-19 pandemic, dermatology research is short on data about heavily impacted racial and ethnic minority groups.

**WHY IT MATTERS:** *Skin conditions, including those associated with COVID-19, can manifest differently on skin with varying levels of pigmentation, making it easy to misdiagnose people of color.* Doctors once thought that SARS-CoV-2 attacked only lung tissue, but they now know about a variety of telltale symptoms of COVID-19, including certain rashes and skin lesions — such as painful red or purple areas on toes — called COVID toes.

Yet Eleni Linos, MD, DrPH, professor of dermatology and epidemiology, who leads research focused on applying technology to reduce health disparities, observed an unsettling disconnection between what she saw in her COVID-19 patients and what she encountered in the scientific literature.

“We saw that journal articles describing the conditions were showing dermatological symptoms on almost exclusively light-skinned individuals,” said Linos. “We know people of color are disproportionately affected by this disease, and it didn’t add up.”

She formed a diverse team, including Jenna Lester, MD, a dermatologist at the UC San Francisco, who created the first Skin of Color clinic in San Francisco, and Lucy Zhang, an early Google engineer and one of the creators behind Facebook Messenger. Together, they analyzed skin tones referenced in 36 COVID-related dermatology journal articles published between Dec. 31, 2019, and May 3, 2020.

For their analysis, researchers used a standardized scale known as the Fitzpatrick classification, which categorizes skin tones on a scale of 1 through 6, with 6 being the darkest. The vast majority of the studies on skin-related COVID-19 symptoms included images of skin only in categories 1-4. The analysis also showed that, of the papers that captured

CONTINUES ON PAGE 43



**In July 2019, Erica Chidi called a friend, Stanford obstetrician Erica Cahill, MD,  
to ask for her help with an important project.**

Chidi, a sexual and reproductive health educator, aimed to help other Black women who feared for their health in childbirth. Today, the United States is the riskiest wealthy nation in which to give birth, with Black women facing especially heightened risks of death and devastating complications.

The overall U.S. rate of maternal deaths is more than triple what's seen in other wealthy countries and three times higher among Black than white women. Severe birth complications are rising, affecting more than 1 in every 100 births, with race playing a big role in who is most vulnerable.

"I was pretty frustrated because all I was seeing around the issue was statistical, situational reporting. There weren't any interventions being coupled with the reporting," said Los Angeles-based Chidi, who is the CEO of an online women's health education startup, LOOM, and a former doula, or support person for women in labor. *The New York Times* had recently given her the go-ahead to write a guide for how pregnant Black women could work with their doctors to lower their risk of complications.

"Erica and I talked," said Cahill, clinical assistant professor of obstetrics and gynecology at the Stanford School of Medicine, and Chidi told her, "I have friends and colleagues coming up to me, saying, 'We see all this very terrifying data; what do we do about it?' I have nothing to give them."

Chidi and Cahill aimed to merge their perspectives in *The New York Times* guide. They knew the project would be a difficult needle to thread: Women shouldn't have to ask their doctors to protect them from racism — but many want the tools to try. "We have to start somewhere," said Chidi. "We're in a position right now where we wonder, do we have the conversation and increase the burden on pregnant women, or do we have the conversation and potentially save a life?"

Meanwhile, the U.S. medical profession is waking up to the profound racial inequities around giving birth, with Stanford Medicine researchers and clinicians leading efforts to identify fac-

# childbirth's unequal burden

GOING BEYOND STATISTICS TO END LIFE-THREATENING RACISM IN MATERNAL CARE

BY ERIN DIGITALE

ILLUSTRATION BY MELINDA BECK





tors at work, translate scientific findings into safer medical practice, and foster dialog between health care providers and the women at risk.

## DANGER GIVING BIRTH

**THE UNITED STATES TRAILS EVERY OTHER RICH COUNTRY IN KEEPING BIRTHING WOMEN SAFE, AND RACE IS A KEY FACTOR:** Black and Native American women are about three times more likely than all other groups of women in the country to die from childbirth, facing risks similar to those of birthing women in many developing countries.

But the risks don't end there. All nonwhite mothers — including Asian women and Latinas — are also more likely to experience life-threatening complications of birth. Though not fatal, complicated deliveries cause short- and long-term physical harms — from hemorrhage and seizures to heart problems, kidney failure and emergency hysterectomies — as well as emotional trauma, and lasting effects on women's health and finances.

"Birth equity is where a whole life starts," said Stanford neonatologist Jochen Profit, MD, associate professor of pediatrics, noting that babies born to nonwhite women are more likely to be born so dangerously early that they need intensive care. "Birth is a particularly vulnerable time for families and for babies. Any suboptimal care we deliver can have lifelong ramifications."

Today, several Stanford experts are working hand in hand with maternity care leaders, California health agencies and 40 other organizations to end maternal deaths, reduce severe health complications, and take on racial health disparities that hamper those efforts. At the same time, Profit and other neonatologists are tackling racial inequities for babies hospitalized in neonatal intensive care units [see related story, opposite page].

The collaborations to improve maternal health began in earnest in 2006, when the state provided seed funding for the California Maternal Quality Care Collaborative at Stanford's School of Medicine. Their work centers on sharing maternal health data, and on disseminating information about best practices and resources for improving maternal care.

More than 200 hospitals are members of the collaborative, which has made California a leader in the United States in reversing maternal mortality trends. Since the collaborative's launch, California's maternal mortality rate has dropped to an average of 7 deaths per 100,000 live births, half of its peak in 2006. Other states are following in California's footsteps.

Still, challenges persist across the board. In 2018, for example, 658 women in the United States died during or short-

ly after childbirth. That's 17 deaths for every 100,000 births, 12 more deaths per 100,000 births than seen in the 20 countries in the world with the lowest maternal mortality rates.

Even in California, Black women still face about three times the risk of dying during childbirth than do women in all other racial groups, said Elliott Main, MD, medical director of the collaborative.

"The good news is that the rates went down for all races. The bad news is that we did not narrow the gap," said Main, clinical professor of obstetrics and gynecology.

The bad news also extends to who develops common life-threatening pregnancy and delivery complications that affect more than 1 in every 100 births. Such complications are on the rise: An analysis of 8.2 million California births found that the risk of severe maternal morbidity, the technical name for these complications, consistently nearly tripled across the entire population between 1997 and 2014.

"I don't think anyone has a baby and expects to have an emergency hysterectomy or seizures," said Stanford epidemiologist Stephanie Leonard, PhD, the lead researcher on the study, which was published in the *Annals of Epidemiology* in 2019. While the risk of severe maternal morbidity rose for all pregnant women in California during the time period analyzed, the risk was still higher for those who were nonwhite — regardless of socioeconomic factors — and highest among Black women, affecting 1.63% of their births.

"I don't think the majority of these events were destined to have happened," said Leonard. "Most of them are preventable."

Though it's frustrating, she noted that opportunities now exist for making real change.

## NOT BLAMING MOMS

**THE TRADITIONAL EXPLANATION FOR THE DRAMATIC JUMP IN SEVERE BIRTH COMPLICATIONS** goes like this: Women's health before pregnancy is getting worse. They're having babies later in life and entering pregnancy with higher rates of diabetes, obesity and hypertension.

But Leonard said that narrative is outdated and "is not the driver." In a 2019 study published in *BMC Pregnancy and Childbirth*, her team analyzed how maternal factors — including age, obesity, preexisting conditions and prior cesarean delivery — contributed to severe complications among women giving birth in California between 2007 and 2014.

Severe maternal morbidity rose much faster than the individual-level health markers, they found. Similarly, the pre-pregnancy health and socioeconomic factors of individual

# INFANTS AT RISK

RACE INEQUITIES IN CARE FOLLOW THE MOST VULNERABLE BABIES FOR YEARS

**N**EW MOMS OF COLOR face racial inequality around the time of birth. Unfortunately, so do newborns.

One group of infants is particularly vulnerable — those who need to be hospitalized for long periods in neonatal intensive care units, often after premature birth. More than 10% of infants born in the United States arrive at least three weeks early, putting them at risk for problems with breathing, vision, digestion, hearing and brain development. Prematurity is even more common in Black and Native American populations.

Recent research has uncovered race-based gaps in the care that babies receive in California's NICUs, and in how these infants fare, leading to the unsettling conclusion that racism — whether because of individual bias or unfairness baked into the medical system — is hurting hospitalized newborns.

A 2017 Stanford study of racial inequity in the smallest preterm babies found that California hospitals tended to deliver better care to white infants, and that Black and Latino infants were more likely to receive care in lower-performing hospitals. The study appeared in *Pediatrics*.

"People used to think that all the disparities for neonates were because of poverty and social determinants of health, and that there would be no difference in how we take care of these babies. I think we've kind of blown the lid off that comfortable space," said the study's senior author, Stanford neonatologist Jochen Profit, MD, associate professor of pediatrics at the School of Medicine. "Now it's time to accept it and see whether we can fix it."

For instance, 89% of white infants, 87% of Latino infants and 85% of Black infants in the study received steroids before birth to help their lungs mature. Ideally, all of these

premature infants would have been given steroids.

To change the trends, Profit and his colleagues at the California Perinatal Quality Care Collaborative, founded in 1997, are providing every neonatal intensive care unit in the state with its own real-time equity data. Hospital leaders can view a dashboard showing how babies in each racial and ethnic group are faring and highlighting areas of medical care with inequalities. The dashboard also shows how each hospital compares with statewide averages.

"It turns out some hospitals do really well and others don't," Profit said. "We're trying to figure out what's driving this."

**One key factor:** Babies in intensive care fare better when their families are at the hospital. But inequality persists here, too. Profit and his colleagues have published studies documenting racially biased treatment of parents, and neonatologist Henry Lee, MD, professor of pediatrics, has research underway, funded by the Stanford Impact Labs, to explore the issue.

"In California, health disparities cross many aspects of our diversity. It's not just race/ethnicity, but that is a large component," said Lee. About half of babies in intensive care in California are Latino, and their parents are more likely than non-Latino parents to have language barriers and to have jobs that don't allow for time off.

"It's important for us to make an extra effort to understand that for many families, life is very, very difficult beyond the acute stresses that we would think everybody would have in the NICU setting," Profit said. "When families are not at their baby's bedside, it's not because they don't want to be."

One final baby care inequity came to light when Stanford scientists examined referrals

to the California Children's Services High Risk Infant Follow-Up program, a statewide partnership with the quality care collaborative. The state requires that each NICU ensure babies at high risk for neurodevelopmental delay or disability receive follow-up care after they go home from the hospital. Clinics across the state provide a range of services for eligible children until they turn 3.

But in birth years 2010-11, only 80% of very-low-birthweight infants in California were referred to the program, Stanford scientists found. Those with Black or Latina mothers were two-thirds less likely to be referred than babies with white moms.

"Obviously that was incredibly concerning, since every one of these children should have been referred to follow-up" said Susan Hintz, MD, professor of pediatrics, who led the research.

**Starting in 2013**, Hintz and colleagues led a program through the collaborative to educate caregivers about eligibility, providing each hospital with data on their referral rates and requiring follow-up referral at NICU discharge. The efforts helped. Referral rates for 2014-16 increased to 94.2% for white babies, 94.6% for Black babies and 95.6% for Latino babies, and they continue to rise.

Still, as in other aspects of maternal and infant care, there is more work to do, said Hintz.

"On an individual level, it is heartbreaking if we are not hearing the story of every family so we can respond to what they need," she said. "Big data for the whole state may show us areas we need to focus on, but it really comes down to, 'What are the stories of individual patients and families that we are not hearing? How are we not serving them?'"

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women can't explain the inequality between racial groups.

"The value of big data is that we could say, 'OK, what if we look at college-educated Black women vs. college-educated white women and adjust for their age and body mass index?'" Main said.

In this comparison, the risk of severe maternal morbidity was still twice as high in Black women. "What's even more shocking is that it was two times higher than in white women who didn't graduate from high school," said Main. That's a shock because higher levels of education have been assumed to reduce pregnancy risk. The findings have been presented at scientific conferences, including the March of Dimes annual conference in 2018.

"Many people in the health system like to blame the patient for bad outcomes," he said. But patient-blaming narratives deliver a triple whammy to healthy pregnancies: They put responsibility for safety on patients instead of the medical system, make it harder for women to bring up their concerns — including potentially serious symptoms — and reduce the likelihood that caregivers will really listen to their patients. "We're trying to get folks beyond that."

Leonard and her colleagues, including Stanford's Suzan Carmichael, PhD, professor of pediatrics, and UC Berkeley collaborator Mahasin Mujahid, PhD, recently tested a theory on birthing disparities that focuses on the health care system rather than individuals. They hypothesized that Black women may be systematically directed to worse hospitals to give birth. This idea was borne out by data from New York City, where race-biased patterns of delivery location explain half of the gap in birth complications between Black and white women. But in California, the Stanford team found, gaps related to birth hospitals accounted for just 8% of the difference.

Figuring out the true drivers of severe birth complications will require data sets that link women's birth outcomes, socioeconomic status and geographic location, Carmichael said, but few U.S. jurisdictions share all that data. California has much richer data than most parts of the country, and the Stanford experts are examining how factors that include neighborhood poverty, segregation and crime weigh into birth inequities.

## CHANGING THE TRENDS

**THE ORIGINAL DEEP DIVE INTO CALIFORNIA'S MATERNAL DEATHS,** THE California Pregnancy-Associated Mortality Review that began in 2006, identified the top three causes of maternal deaths: cardiovascular disease; hemorrhaging; and preeclampsia, which is high blood pressure that can lead to fatal seizures.

The report's authors also analyzed medical records from 427 women who died during the year after giving birth, piecing together where better medical care might have helped.

Some deaths occurred in the delivery room, but half of deaths happened three or more weeks after women went home. Some women who died sought care for worrisome postpartum symptoms but weren't taken seriously, the report found. Forty-one percent of California's maternal deaths were likely preventable, the review concluded, noting that hospitals needed better preparation for obstetric emergencies, which can unfold quickly and require a highly coordinated response.

Since the report was published, the Stanford-based collaborative developed eight toolkits for handling the top causes of maternal death and other dangerous birth complications. The kits provide evidence-based ways for health providers to prepare for each problem, such as equipping all labor and delivery units with a crash cart stocked with blood for transfusion, medications and medical devices to treat hemorrhage.

In a paper published last year in the *American Journal of Obstetrics and Gynecology*, Main and his colleagues showed that 99 California hospitals that used the hemorrhage toolkit significantly reduced the racial equity gap in patients who hemorrhaged. At baseline, during 2011-14, about 20% of white women and 29% of Black women who hemorrhaged had severe medical consequences; after the intervention, in 2015-16, this was true of 18% of white women and 20% of Black women.

But, Main said, reducing inequity in hemorrhage is relatively easy. "Hemorrhage happens acutely in the hospital, and we know what to do about it," he said. "The key is to have a standard approach."

Much more work is needed to address inequity in clinical situations that are less clear cut, Main said.

**'If you propose a solution without taking into account the perspective of the person's lived experience, you can do harm. The problem may have more layers than your original hypothesis.'**

“There are a lot of decisions where bias can creep in,” he said. For instance, his team and others at Stanford are launching research to understand why Black women are more likely to have C-sections and not be treated appropriately for iron deficiency anemia.

Maternal-fetal medicine fellow Iroque Igbinosa, MD, hopes to partner with a community birth organization led by Black researchers to explore the experiences of Black women with anemia during pregnancy.

“If you propose a solution without taking into account the perspective of the person’s lived experience, you can do harm,” said Igbinosa. Accounting for how structural racism affects prenatal health care — including anemia treatment — will also be essential, she said. “The problem may have more layers than your original hypothesis.”

## EMPOWERING PREGNANT WOMEN

CHIDI AND CAHILL HAD SOME EXCITING SUCCESS IN OCTOBER, WHEN THEY PUBLISHED *Protecting your birth: A guide for Black mothers*, in *The New York Times*. The guide gives Black women and their care providers specific steps for addressing the higher risks Black women face, starting with scripts for conversations that acknowledge race and racism “in the room,” and for creating a care plan that anticipates that racism might impact pregnancy.

Chidi and Cahill wanted patients and doctors to feel enthusiastic about the guide, so Cahill spent a lot of time considering how to best reach her obstetrician colleagues.

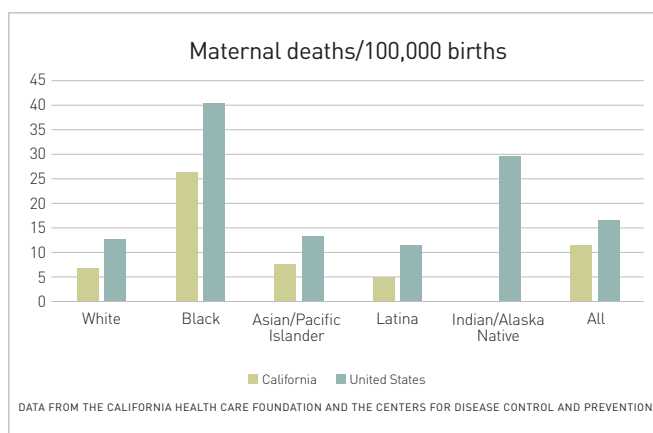
“In talking about racism, people already feel so defensive, and I thought, ‘Let’s figure out a way for this to be received well,’” Cahill said.

The best approach, they decided, was to have patients introduce their concerns to their doctors by talking about data across populations on worse birth outcomes for Black women. “We can frame it as, ‘Racism is in everything; it is here in this data,’ without saying, ‘You’re a racist person,’” Cahill said.

At the same time, few obstetricians are Black, and Black women have dealt with racism throughout their lives, which needs a place in the conversation. “Our lived experience, our felt experience, is not something that can be experienced vicariously or through observation,” said Chidi. “That’s why we need to be involved in developing these tools.”

“When you give people sample language that they can right-size to their experience, it’s modeling that there is a way to try to do this,” said Chidi. “We’re providing permission.”

They advise health providers to consciously over-com-



California has lower maternal death rates than the country as a whole, but large racial inequities persist. California data is from 2013; nationwide data is from 2016.

pensate to give better care in situations in which Black women’s health is known to be frequently neglected — such as listening to and acknowledging Black women’s preferences about labor pain management, considering that research shows their pain is often under-treated. Other advice includes checking Black women’s blood pressure more frequently during pregnancy because they have higher rates of hypertension-related complications of pregnancy.

Feedback on *The New York Times* article has been overwhelmingly positive, said Chidi, and many physicians have asked for permission to use the article in their practices. Chidi and Cahill recently received two small grants, from the Stanford Center for Clinical and Translational Research and from the Stanford Maternal and Child Health Research Institute, to survey new Black mothers about whether they think the guide would have helped them. It’s a first step in what they hope will be much more research on the effectiveness of their work.

Igbinosa, the maternal-fetal medicine fellow, who was not involved in Chidi and Cahill’s project, wants the medical system to be pushed harder to listen to Black women and meet their medical needs upfront.

Because many birth complications develop when health providers are slow to respond to a patient’s concern about her symptoms, Igbinosa regularly talks with her patients about how to advocate for themselves. “A lot of these stories boil down to, ‘A woman wasn’t heard,’” Igbinosa said.

Of course, she wishes such conversations weren’t necessary. “We’re putting the onus on the patient, and that’s too much of a burden to bear,” she said. **SM**

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HOW CONSIDERING RACE  
SABOTAGES CARE — AND WHY CHANGE IS IMPERATIVE

# UNEQUAL TREATMENT

WHEN MEGAN MAHONEY, MD, WAS IN MEDICAL SCHOOL, STUDENTS WERE EXPECTED TO IDENTIFY THEIR PATIENTS BY AGE, RACE AND GENDER — IN THAT ORDER. Mahoney began to wonder: If she were a patient, how would they describe her, a biracial, light-brown-skinned woman with a white father and a Black mother? Might they see her anatomy differently or prescribe different courses of treatment than they would for a patient identified as white?

“I was just concerned that — and this is backed up by studies — as soon as I stated the patient’s race, there would be bias,” said Mahoney, a clinical professor of medicine and chief of staff at Stanford Health Care. “You can have the same case, the same words or presentation, and once you attach white or Black to it, you will see wildly different recommendations.”

Racial classification is deeply embedded in medical practice — in clinical care guidelines, in research protocols and in medical training. Mahoney is among a growing number of medical professionals who argue that including race in health care decisions can lead to poorer treatment for nonwhite people. They believe it’s time to take race out of health care and are urging medical centers across the United States to do so.

BY RUTHANN RICHTER AND  
JESSICA BEST

ILLUSTRATION BY BRIAN STAUFFER







The American Medical Association gave impetus to the movement in November when it declared racism a public health threat and said race should not be used as a proxy for biology or genetics in patient care, research and education. Rather, medical professionals and researchers should focus on the social factors — such as employment, education, housing, environment and racial trauma — that play a far greater role in determining health, the association said.

“When race is described as a risk factor, it’s more likely to be a proxy for influences of structural racism than genetics,” said Willarda Edwards, MD, a Baltimore internist and AMA board member who served as the chair of its Task Force on Health Equity.

She said the policy grew out of a discussion that began in 2003 when the Institute of Medicine published a report, *Unequal Treatment*, that detailed racial and ethnic disparities in the quality of health care. But interest in the issue reached a peak last summer during the widespread protests demanding racial justice. The pandemic also laid bare gross inequities in health care, as people of color have suffered and died from coronavirus at disproportionately high rates, she noted.

In light of these pressing issues, Stanford Medicine in November established the Commission on Justice and Equity with a goal of dismantling systemic racism and discrimination within the community. The commission is considering ways to make the culture of Stanford Medicine more diverse, equitable and inclusive and will recommend approaches to address health disparities that impact marginalized groups locally and nationwide.

In addition, the Stanford Medicine Health Equity Committee is gathering data on Stanford’s patient population, including information on race/ethnicity, sexual orientation/gender identity and socioeconomic status, to understand where disparities exist so it can ensure equitable access to care for all.

## EMBEDDED IN THE SYSTEM

**T**he use of race to inform clinical practice guidelines is pervasive.

In pulmonology, specialists measure lung capacity with a machine called a spirometer that is programmed to automatically apply a race-based “correction factor” to the reading, lowering a “normal” reading for a Black person by 10% to 15%. So a result that would be considered normal for a Black person could be considered unhealthy for a white person. Thus the Black patient may suffer a delay in care and receive inadequate treatment. The practice is based on the

# AMERICAN MEDICAL NOT BE USED AS A PROXY

faulty assumption that Black people have inferior lung function, according to Lundy Braun, PhD, a Brown University researcher whose 2014 book, *Breathing Race into the Machine*, traces the history of the device to the slavery era. Former President Thomas Jefferson, a slave owner himself, epitomized the thinking with his observation that Black people had a “difference of structure in the pulmonary apparatus,” Braun notes.

Another example is the algorithm used to gauge kidney function, known as the estimated glomerular filtration rate, or eGFR. The algorithm for the blood test is adjusted based on several variables — age, race, gender, height and weight. For race, it calculates two results — one for Black patients, in which case the rate is adjusted upward, and one for non-Black patients. This 50-year-old practice is based on the assumption that Black people have greater muscle mass, another myth of slavery times, Mahoney noted. The result is that Black patients could be classified as having less severe disease, disqualifying them for a transplant or leading them to postpone treatment until it’s too late to intervene.

“Even now, when I look at somebody’s kidney function, I use the race-correction kidney function because it’s ... baked into how the data is presented to us,” Mahoney said.

Some academic medical centers have stopped using race as a factor in the eGFR measure, and use of the practice is under debate at Stanford Medicine.

Black patients are also significantly less likely to get a kidney transplant than whites because of the eGFR and because of bias in seeking out Black donors who could be a good match, studies show. Black patients face obstacles to transplant every step of the way. They are less likely to be identified as a transplant candidate, to be referred for evaluation or to be put on a waitlist; and when they do receive a transplant, it’s likely to be a lower quality kidney, according to the American Society of Nephrology.

Other practices reflect racial bias in health care workers’ behavior toward Black patients. For instance, studies have documented that Black patients are less likely to be prescribed pain medication than white patients, and when they do get it, they are prescribed lower dosages than whites. In a 2016 study published in the *Proceedings of the National Academy of Science*, researchers at the University of Virginia

# ASSOCIATION: RACE SHOULD

FOR BIOLOGY OR GENETICS IN PATIENT CARE, RESEARCH AND EDUCATION.



MEGAN MAHONEY SAYS THAT INCLUDING RACE IN TREATMENT DECISIONS CAN TRANSLATE INTO POORER CARE FOR PATIENTS.

found that half of medical students and residents believed that Black and white people are biologically different, and that Black people are more tolerant of pain. The assumption was perpetuated during the slavery era when it was believed that Black individuals have thicker skin or feel less pain than whites, the researchers said.

Many race-based medical beliefs that attribute disease risk to genetics or biology fail to consider the context and contributing factors of disease, such as social and environmental factors. Mahoney remembers learning in medical school that Pima Indians had a higher genetic risk of Type 2 diabetes. But the Pimas in Mexico, who are genetically related, have relatively low levels of the disease. It is now known that the Pimas in the United States were more prone to diabetes because of the loss of their agrarian way of life, which forced

them to subsist for years on high-fat, high-carbohydrate foods the U.S. military supplied them.

Since the beginning of the COVID-19 pandemic, some have speculated that genetics plays a role in why minorities represent a disproportionately high number of patients who have suffered and died as a result of the coronavirus. Stanford population geneticist Carlos Bustamante, PhD, is involved in studies to understand how genetics influences immunity and response to COVID-19. Variation in the genes linked to COVID-19 are not specific to a racial or ethnic groups, but rather shared across groups, said Bustamante.

Furthermore, he pointed to the importance of social factors. “We think a lot of it has to do with who can shelter in place and who can’t shelter in place,” said Bustamante,

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# 'It makes you a little proud to be a human'

AS HIS DISABILITY PROGRESSED, ERIC SIBLEY'S COMPASSION FOR PATIENTS  
AND WILL TO CHAMPION DIVERSITY GREW STRONGER

**At first, the symptoms were so subtle he hardly noticed them.**

Sometimes his foot would catch on the ground as he walked. "I would stumble a little bit," said Eric Sibley, MD, PhD, professor of pediatric gastroenterology at the School of Medicine, now 59 years old. "Gradually it became more pronounced, until it was an obvious limp."

But Sibley was a busy man. He was a leader in pediatric gastroenterology, flying to conferences around the world. He was also running a successful science lab at Stanford making landmark discoveries about the molecular underpinnings of the lactase enzyme

BY JULIE GREICIUS AND TRACIE WHITE

ILLUSTRATION BY JEFFREY DECOSTER







necessary for digesting milk, and treating children with gastrointestinal ailments at Lucile Packard Children's Hospital Stanford.

Sibley was married to his college sweetheart — also a physician — and they had two young children. The Harvard College graduate had toiled through more than a dozen years of advanced education, picking up a doctorate and medical degree along the way, and he was reaping the rewards.

It was the early 2000s, and Sibley was among the elite in academic medicine. He was also one of few African Americans on a U.S. medical school faculty. In 2018, African Americans accounted for a mere 3.6% of full-time medical school faculty, according to an Association of American Medical Colleges report.

He didn't know yet that he would eventually be one of an estimated 2% to 10% of practicing physicians with a disability, according to the *American Journal of Physical Medicine & Rehabilitation*.

Sibley, who has multiple sclerosis, said the changes developed over many years.

"Initially, my disability was not visible," Sibley said. "Then my gait got worse. The weakness went from my right leg, then right arm, then left leg. I went from one crutch to two, then a wheelchair. ... Now my wheelchair is my desk."

The decline in mobility was slow. First he lost the ability to walk, then pain in his hands took away his ability to work in the lab. Just last year, when he could no longer hold up his head to look into his patients' eyes, he was forced to say goodbye to patient care.

A practical man, Sibley rarely pauses to look back at those losses. Instead, he has forged ahead, making accommodations, developing new talents, creating new opportunities and performing at the highest level in his rarified role as a professor of medicine.

Sibley often reflects on African American role models who helped enable his success, and he's paying it forward by being a mentor to other minorities and a champion of diversity in medicine.

## THE EARLY YEARS

**SIBLEY GREW UP IN A MIDDLE CLASS LOS ANGELES NEIGHBORHOOD AND EXCELLED IN SCHOOL.** His father, William Sibley, MD, practiced family medicine in South Los Angeles, not far from the family's home in the View Park-Baldwin Hills neighborhood.

"View Park-Baldwin Hills was one of the few neighborhoods in the west side of Los Angeles where African American professionals and entertainers could purchase homes with less realty discrimination," Sibley said. "We lived across the street from the jazz singer Nancy Wilson. And Ray Charles was two blocks over. Ike and Tina Turner were one block over."

His mother, Mary Hall Sibley, managed the household, and Sibley and his two younger brothers played sports.

"We all played catch, usually football, outside in the street," Sibley said. "Once, in the third grade, I was going up for a catch and ran into the hubcap of a parked car. I broke a bone in my knee. I had to be helped up off the street and got a cast. That's when I first thought, since I really enjoyed sports, I wanted to be an orthopaedic surgeon."

Though he was aware of an undercurrent of racism throughout high school and college years, it was subtle for him. He heard racial slurs and knew he was a part of a minority that faced discrimination. But with his father to help guide him and educational opportunities that helped him excel, a career in medicine never seemed out of reach.

Sibley attended the Harvard School for Boys, an elite private school in North Hollywood, one of four African American students in a class of 120. He went on to Harvard College as a pre-med student. In his junior year, he served as president of Harvard's Percy Lavon Julian Science Organization, founded in 1972 to foster enthusiasm and interest in science, math and engineering among Black students.

The late S. Allen Counter, PhD, a professor of neurology at Harvard and the founding faculty adviser of the organization, was a mentor for Sibley, talking with him regularly about his career goals and helping students arrange for prominent African American scientists and physicians to speak to the group.

It was the early 2000s, and Sibley was among the elite in academic medicine. He didn't know yet that he would eventually be one of an estimated 2% to 10% of practicing physicians with a disability.

Sibley also found mentors among Black upper-classmen who told him that “if you’re pre-med, it was a good idea to try to get exposure to research and science,” he said. Based on that advice, he spent summers working in research laboratories at the National Institutes of Health and completed the research for his honors thesis in the molecular biology lab of Tom Maniatis, PhD, at Harvard.

Sibley met his wife, Carol Somersille, MD, on move-in day at Harvard.

“The funny thing is my mother saw her and said, ‘Oh make sure you meet her. She looks like a nice girl,’” Sibley said. His wife laughs at the story, insisting Sibley didn’t tell her about it until 15 years later, after they were already married.

They were both interested in the sciences and active in the Percy Lavon Julian organization.

“Eric was always involved in racial justice issues,” said Somersille, an OB/GYN physician in Mountain View and director of the El Camino Healthcare District Board. “But he worked on the academic side of things. He tried to get people of color the opportunities that other people had.”

After three years at Harvard, Sibley graduated in 1982 with honors and enrolled in an MD-PhD program at Johns Hopkins University. He was drawn to Johns Hopkins, in part, for the chance to interact with another African American role model, cardiothoracic surgeon Levi Watkins Jr., MD, the first Black student to attend Vanderbilt Medical School and the first surgeon to successfully implant an automatic heart defibrillator in a human patient.

At Johns Hopkins, Sibley began to develop his research interests in gastrointestinal physiology — his doctoral thesis in biochemistry focused on insulin receptor gene regulation. He also discovered his love for pediatrics during medical school rotations.

“I’d be on call in the pediatric ward at nights. They had



NOT ONE TO LOOK BACK ON LOSSES DUE TO MULTIPLE SCLEROSIS, ERIC SIBLEY HAS DEVELOPED NEW TALENTS AND CONTINUED TO WORK AT THE HIGHEST LEVELS IN MEDICINE AND RESEARCH.

a little basketball play room,” Sibley said. “Being that I was still a kid at heart, I so admired how, despite being sick, these children could still be so resilient.”

Instead of pursuing his original goal of becoming an orthopaedic surgeon, his next step was a pediatric residency at Harbor-UCLA Medical Center. In 1994, a year after residency, he and Somersille were married.

Sibley started his career at Stanford in 1993 as a postdoctoral fellow in pediatric gastroenterology in the lab of Garry Gray, MD, a professor of gastroenterology who was investigating lactase, the enzyme responsible for the digestion of the milk sugar lactose, and how that enzyme may be regulated differentially during maturation. Gray’s group was just beginning to explore regulation of the lactase gene.

“I was interested in understanding if the lactase enzyme activity decreased in mammals as they weaned,” Sibley said. “That decline happens in humans but not those of Northern European descent so they can tolerate milk. African Americans are among those groups who have lactase deficiency, and it causes symptoms. I guess it was on my radar for that reason.”

Initially, grants from the Robert Wood Johnson Foundation’s Minority Medical Faculty Development Program enabled Sibley to dedicate 70% of his time to research. That increased to 75% after he received a career development award from the National Institutes of Health followed by multiple independent investigator R01 awards, which supported his research for the next 20 years. Among other findings, Sibley’s laboratory was the first to show how a specific DNA polymorphism that had been linked to lactase played a key role in keeping the enzyme active in some adult mammals.

His lab continued to make discoveries and publish papers with Sibley at the helm even after MS began to slow him down.



## CAREER INTERRUPTED

IT STARTED IN 1999, AFTER A ROUND OF GOLF AGGRAVATED WHAT SIBLEY THOUGHT WAS AN OLD SOFTBALL INJURY IN HIS SHOULDER. When the pain didn't go away, he saw a doctor. An MRI didn't show much in his shoulder, but looking toward Sibley's spine, the doctor noticed demyelinating lesions — evidence that the protective covering, called myelin, around his nerve fibers was damaged.

It wasn't enough for a diagnosis of multiple sclerosis — a brain and spinal cord disease in which the immune system attacks the myelin wrapping of nerve cells — but it was suspicious.

Sibley's official diagnosis didn't come until many years later: severe primary progressive multiple sclerosis, the most aggressive form of the disease. His illness would lead to a worsening neurologic function — with primary symptoms of pain and weakness of the extremities — but it was unclear how quickly this might occur and what type of losses he would face.

The adjustment to becoming a patient was challenging. “Until I developed MS, I was thinking, ‘OK, I’m going to be able to do everything,’” Sibley said. “It was a big psychological evolution to be able to accept that, yeah, there are going to be limitations on what I can do and how people are going to perceive me. The first real hurdle was using a crutch at all.”

Before his diagnosis, Sibley's career gained remarkable momentum. He was appointed to assistant professor in 1999 and three years later won his first NIH R01 grant. He became editor-in-chief of the *Journal of Pediatric Gastroenterology* in 2005 and in 2006 he was promoted to tenured associate professor. In 2010, his achievements in academic medicine were recognized by induction into the American Clinical and Climatological Association.

“All those things were lining up, and if I had been able to continue at that pace healthwise, I was on a trajectory to continue as a leader in my field,” Sibley said. “So that became a bit of a frustration, to have everything lining up perfectly, but then have the realization that I can't keep traveling to national leadership meetings. It's just too hard on the body.”

By 2011, he was using a wheelchair and his condition was common knowledge.

“I noticed he was limping a little ... then one day he came to my office and told me about his diagnosis,” said Dorsey Bass, MD, associate professor of pediatric gastroenterology. “It just blew me away. I couldn't believe this was happening.”

Bass, who shared a Friday afternoon clinic with Sibley for

two decades, witnessed Sibley, a quiet, compassionate man, provide care to the sickest of children, many with chronic disabilities. Sibley maintained his practice, his compassion for his patients only growing as his own disability increased.

“The dominant theme of Eric's practice is caring about the people who need it most,” Bass said. Some of Sibley's patients, he said, were “very financially distressed and with multiple disabilities, kids with cerebral palsy and lots of complicated, difficult issues.”

“Eric's loyalty to them and their loyalty to him just always, well — it makes you a little proud to be a human,” Bass said.

“It was just completely inspiring how he could barely walk down the hall, and still be doing rounds and seeing outpatients, and never complaining. ... Maybe the most remarkable thing is: It didn't really seem to change who Eric was,” Bass said. “He addressed his disability, like, ‘OK, how are we going to work around this? How can I keep going?’”

## CHANGING THE PACE

TODAY SIBLEY'S LIFE IS VERY DIFFERENT THAN IT ONCE WAS. IT TAKES HIM TWO TO THREE HOURS TO GET READY EACH MORNING. Simply getting out of bed is a daily challenge. He is more dependent on his wife and his two children — Carl Somersille Sibley and Lauren Somersille Sibley, both grown now — for support. Carl is now a Harvard graduate himself and Lauren is headed to Stanford.

Sibley eventually hired aides when he needed more help. He has seen doctors, physical therapists and occupational therapists regularly, and uses rituximab, an anti-inflammatory medication, to slow the progression of his disease.

Over the years, he missed important conferences and lost job opportunities. He missed his kids' performances and the presentation of awards at school. Gates were often closed to him, both literally and figuratively: Handicapped access denied. He grieved for each loss, but then he moved on.

“It's been tough,” Somersille said. “He'd get frustrated. There have been times when he became too weak to drive and had to pull over. Our children have had to step up and make sacrifices.” She said he gave up many things, but one thing he never gave up on was coaching. Sibley remembers, with fondness, many years of coaching his kids' basketball teams, but it wasn't always easy.

“There's a videotape of where I'm coaching on the sidelines,

and I have a limp,” Sibley said. “At one point I was on the court and, because of the limp, I sort of tripped over myself and fell down. But I continued to coach even with two crutches.”

Perhaps it was the skills he developed coaching that spurred an interest in mentoring others. In 2011, the same year Sibley began using a wheelchair, he was appointed one of the four academic advising deans who together mentor between 110 and 120 students each. The role suited him, said Neil Gesundheit, MD, professor of endocrinology and senior associate dean for medical education.

“The thing about Eric is he is a very gentle person,” Gesundheit said. “There’s a natural kindness to him. He has the ability to understand student issues and not be judgmental. Some of the students who struggle the most in med school are from backgrounds without family members who have worked in medicine — people from different racial and ethnic backgrounds who haven’t had any role models. Eric’s been there for them, a quiet champion of diversity.”

Sibley found he could be the most helpful with the most vulnerable students — those with physical or mental health challenges: “That’s one area where my own health issues have made it a little bit easier for students to approach me for the support they need.”

In October 2016, while transferring from his bed to his wheelchair, Sibley fell and broke his leg. “Turns out I have osteoporosis from sitting instead of using my bones,” he said.

The bone had to be set with a titanium rod that ran the length of his right femur. During his rehabilitation, Mary Leonard, MD, professor and chair of pediatrics, called him to discuss two new departmental roles she hoped he would take: the inaugural associate chair for academic affairs, and liaison to the Office of Faculty Diversity and Development involved with faculty appointments and promotions.

These responsibilities fit him perfectly, and he threw himself into his work as adviser to young faculty and postdoctoral fellows. In promoting diversity in the department, he has led a push for systemic recruitment efforts to ensure inclusion of minorities and other underrepresented groups.

“Eric has challenged all of us to create a

more inclusive and diverse culture in each component of our academic mission,” Leonard said. “At his suggestion, we’ve implemented term limits for our most important committees to create opportunities for the next generation of leaders, and we’ve brought a new level of rigor to our searches to identify diverse candidates. It’s much more structured now. He helps me identify potential candidates and I contact those people to encourage them to apply.”

## MENTORING THE NEXT GENERATION

WHEN SHE WAS NEW TO STANFORD’S FACULTY, AIDA HABTEZION, MD, ASSOCIATE PROFESSOR OF GASTROENTEROLOGY AND HEPATOLOGY, was interested in applying for the Robert Wood Johnson Foundation’s Minority Medical Faculty Development Program, just as Sibley had done.

“It’s nice when you find people who resemble you in many ways — as an African American, a scientist and specifically a gastroenterologist — and who have been successful in the field that you are just starting. It gives you hope,” said Habtezion who is on leave from Stanford to serve as Pfizer’s chief medical officer. It provides invaluable encouragement, she said, and helps identify opportunities to pursue.

“Eric was a very important mentor who could guide me and give me advice, because he walked that path before me,” she said.

In 2018, his 25th year at Stanford, Sibley reached a long-awaited benchmark, a promotion to full tenured professor.

For Sibley, prevailing through adversity had a lot to do with people who cleared the way ahead of him and with knowing that he could do the same. “There were times later in my career when there was no one like me in a role ahead of me, there having been no prior record of an African American physician promoted to full professor in the university tenure line, no one Black or similarly disabled to advise or mentor me,” he said. “So it was important to me to be that role model, to be a person students and colleagues with similar challenges could look to for guidance and encouragement.” **SM**

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The thing about Eric is he is a very gentle person. There's a natural kindness to him. He has the ability to understand student issues and not be judgmental. ... Eric's been there for them, a quiet champion of diversity.



# IT'S NOT ROCKET SCIENCE, IT'S HARDER

STANFORD MEDICINE RAMPS UP EFFORTS TO INCREASE  
RACIAL DIVERSITY AND END DISPARITIES

Ahmaud Arbery. Breonna Taylor. George Floyd.

2020 was rocked by a series of killings of Black Americans. Subsequent protests across the country strove to call attention to the racial injustice that permeates every level of American society. Academic medical centers are not immune.

In 2019, the Association of American Medical Colleges reported that medical school faculty across the nation were 84% white or Asian. At the time, 79% of Stanford's medical faculty were white or Asian; only 1.7% were Black or African American, and 4.3% were Hispanic, Latino or of Spanish origin — despite the fact that these minorities make up about 32% of the population of the United States.

"You can't tell me there isn't a problem at Stanford," said Bonnie Maldonado, MD, the senior associate dean for faculty development and diversity at Stanford Medicine. "The problem is, we often refuse to see it. But there's no utopia anywhere. There's no completely equitable and fair place."

In October, Stanford Medicine launched the Commission on Justice and Equity to amplify efforts to dis-

BY KRISTA CONGER

ILLUSTRATION BY LINCOLN AGNEW





mantle systemic racism and discrimination against underrepresented groups within the institution and around the world. In a joint statement, the leaders of the School of Medicine, Stanford Health Care and Stanford Children's Health affirmed their intent to address racial inequality as an urgent public health issue. By championing diversity, celebrating inclusion and committing to equity at every level of the institution, the leaders are aiming for Stanford Medicine to become a pacesetter in the organizational and cultural change necessary to transform the medical playing field into one that everyone can access equally. The commission's initial recommendations are expected this spring.

"After the George Floyd murder, our Stanford Medicine community came together to declare, 'enough is enough,'" said Terrance Mayes, EdD, associate dean of equity and strategic initiatives and executive director of the commission. "We pledged that Stanford Medicine will no longer remain silent. We will do everything we can to effect meaningful change."

A place doesn't become equitable and fair simply by increasing minority representation, however. The numbers

**Efforts to address racial inequity at Stanford Medicine are not new.** In 2004, the medical school focused on gender and racial diversity, creating a new leadership position meant to attract women and underrepresented minorities to post-graduate and faculty positions — the senior associate dean for diversity and leadership. Professor of medicine Hannah Valentine, MD, was the first to hold the post.

Conversations with faculty of color revealed a lack of community and a feeling of being dismissed. "People felt isolated, not just socially, but also in their research lives," said Valentine, a cardiovascular specialist. "Some expressed feelings that others were not interested in their work, or that their contributions weren't valued."

From 2004 to 2012, the number of underrepresented minorities on the faculty increased from 51 to 92, or 5.9% of the total. From 2012 to 2019, the number increased from 92 to 161, or about 6.8% of the total.

"There's been a slow drift toward better representation, but it's far, far, far too slow," said Valentine.

Some of the most pervasive stumbling blocks to prog-

# 'WE PLEDGED THAT STANFORD MEDICINE LONGER REMAIN SILENT. WE WILL DO EVERYTHING WE CAN

are simply a proxy for an undertow of inequality and inequity that can leave underrepresented minorities fighting to stay afloat. To make a real difference, Maldonado emphasized, it's important to recognize the unconscious bias and invisible barriers faced by minority community members, and to dismantle systems and policies that allow inequities to persist and thrive.

"These are thorny issues," Maldonado said. "I really can't imagine a topic that's any harder to deal with, frankly. But our leadership has been very supportive."

"Diversity and inclusion have long served as institutional values here," said medical school dean Lloyd Minor, MD. "With these at the heart of what we do, we've made encouraging progress. But the road ahead remains long, and it's become clear that achieving change at the scale required demands that we take a more direct approach."

In answer, Stanford Medicine is calling for a tidal wave of change that will ripple outward and carve out a new landscape of public health in this country.

ress are difficult to remove because they are built into the fabric of higher education in the United States.

"We have to reject the myth of meritocracy, the idea that you can succeed if you just pull yourself up by your bootstraps," Mayes said. "Not everyone has bootstraps. We also have to interrogate what we mean when we use words like 'excellence,' which can be a very loaded word in academia, and we have to reject the notion that diversity and excellence are mutually exclusive goals."

In the years since Valentine's appointment, Stanford Medicine has implemented dozens of programs for students, residents, postdoctoral scholars, and young and established faculty members to promote diversity, equity and inclusion.

Building on this work, the new commission brings together a body of external experts like commission chair Rosalind Hudnell, former chief diversity officer at Intel, with internal stakeholders like Valentine and Mayes to facilitate these efforts. "There is a lot of good work already



TERRANCE MAYES: 'WE HAVE TO REJECT THE NOTION THAT DIVERSITY AND EXCELLENCE ARE MUTUALLY EXCLUSIVE GOALS.'

# WILL NO TO EFFECT MEANINGFUL CHANGE.'

underway," Mayes said. "The commission is not meant to stifle existing programs, but to complement, amplify and help accelerate outcomes."

In a talk to the Stanford Medicine community in November, Hudnell emphasized that the commission will work to ensure that existing efforts to promote diversity, equity and inclusion are aligned, integrated and consistent across every level of the organization, while also driving strategies that build on successive small achievements.

"We talk about 'dismantling racism,'" Hudnell said. "But what you really want to do is dismantle the processes and procedures and policies that enable racism to flourish. You can't say, 'OK, tomorrow everyone is not racist.'"

The commission began by initiating a series of conversations with members of the Stanford Medicine community, including Black student and faculty leaders, LGBTQ+ leaders, and leaders of the Stanford Medicine Abilities Coalition. They wanted to hear directly about challenges facing underrepresented groups at Stanford

Medicine — which included a lack of Black representation in leadership and faculty positions, frustrations with retention of underrepresented community members, and a lack of transparency and accountability when instances of racism are reported.

"One of the commission's many deliverables will be to contrast the reality we experience today with the vision of where we hope to be," Paul King, president and CEO of Stanford Children's Health, said. "The commission will identify that gap. We recognize that not all problems will be solvable overnight, but we are committed to taking strong action that will effect lasting change. Together, we will erase that gap."

## SUPPORTING STUDENTS

ONE ISSUE THE COMMISSION is exploring is how best to support minority medical and graduate students as they progress through every stage of their training, from residents and postdocs to young faculty members.

When Dorothy Tovar, a sixth-year graduate student in microbiology and immunology, arrived at Stanford in 2015, she felt isolated and lonely and had a hard time finding other students of color. The daughter of Haitian immigrants, Tovar chose Stanford for graduate school because she was impressed by the resources available to graduate students and the care with which the faculty shepherded their students during their training. But she quickly realized there were very few people who looked like her.

"When I finally spoke with other Black students on the medical campus about this, I realized they were feeling the same way," Tovar said. "There wasn't an intentional community to share our experiences and challenges."

The deaths of Philando Castile and Alton Sterling at the hands of police and the subsequent protests in the summer of 2016 left Tovar feeling further adrift.

"I would wake up and hear that another Black man was killed, but I would still have to show up in lab and go to meetings as if nothing was wrong. It seemed that the university, my professors and my peers were ignoring a racial reckoning that directly impacts minority students," Tovar said.

As Tovar's experience shows, it's critical to foster a sense of community and belonging.

Ayodele Thomas, PhD, associate dean for graduate and career education and diversity, understands this need. Thomas is a descendant of enslaved people on both sides of her family, and her parents and grandparents were active in the civil rights movement. After receiving her PhD in



electrical engineering from Stanford (the first Black woman to do so), she pivoted to a career focused on increasing diversity and combating racism in higher education.

Yet, “When I walk into a room, there’s never the assumption that I am the leader,” Thomas said.

To address what she sees as a need for a greater sense of community among minority students, Thomas teaches a graduate-level seminar called Graduate Environment of Support. Although the seminar is diversity

focused, any student can enroll.

“We talk about challenges like imposter syndrome and discuss how to approach problems and take advantage of resources,” Thomas said. “Basically, it’s all the things I wish I had known before I entered graduate school, with a focus on fostering a sense of inclusion and belonging.”

At times, students like Tovar have also taken things into their own hands. In 2016, Tovar and three other graduate students launched the Stanford Black Bioscience Organization to build the community they were missing. She and four other students also worked with the dean’s office and the Diversity Cabinet to obtain funding for the Diversity Center of Representation and Empowerment, or the D-CORE — a gathering and group-working space within Lane Medical Library for any member of Stanford Medicine interested in issues of diversity and inclusion.

## PAY IT FORWARD

### INCLUDING SOCIAL JUSTICE IN THE CURRICULUM

Efforts to rework the medical school curriculum to address racism in health care have been underway at Stanford for several years. But they recently gained more urgency.

“After the killing of George Floyd and the other events of the summer of 2020, we realized we needed a deeper and more sustained commitment to making the necessary changes,” said Daniel Bernstein, MD, the associate dean for curriculum and scholarship.

Changing the curriculum in a meaningful way isn’t as easy as adding one or two more classes, however. “Compared with when I went to medical school, the amount of knowledge we have to teach and the students have to learn is exponentially larger,” Bernstein said. “So how do we accomplish that while still remaining faithful to our commitment to teach social justice?”

The solution, Bernstein believes, is to incorporate discussions of health inequities and implicit bias into every aspect of teaching. A lesson about hypertension, for example, can include a discussion about the impact of poverty, lack of insurance or poor diet on disease prevalence. It could also include the fact that, although non-Hispanic Black patients have the highest rates of cardiovascular disease in the country, they are less likely than white patients to receive appropriate therapeutic interventions.

“Some of these easy, clear targets can have enormous impact,” Bernstein said. “We teach students molecular biology, genetics, anatomy — sciences that underlie our practice of medicine. But 50% of the determinants of health are societal and are affected by the patient’s race or ethnicity, their income, and even their ZIP code. If a patient has asthma and lives near a refinery — breathing pollutants — how do we incorporate that knowledge into our patient care? We haven’t done an adequate job of teaching students that half of the puzzle.”

Conversely, students need to be empowered to correct others in a clinical setting when necessary.

“These are physicians during their formative years, first gaining knowledge as medical students, and then learning how to apply that knowledge in the clinic as residents,” said Bernstein. “We need to do better in both of these arenas.”

### MENTORING STUDENTS, TRAINEES AND FACULTY

THERE ARE NO SUREFIRE WAYS to immediately increase diversity and equity throughout Stanford Medicine. Although the incoming medical and graduate student classes are far more diverse than in the past, that change is trickling up slowly. In 2020, 38% of the incoming medical class identified as Hispanic/Latino, Black/African American, or two or more underrepresented minorities. There is a similar upward trajectory in incoming graduate students.

“The incoming PhD cohort has been more than 20%

# ‘IS THERE A IS AFFECTED? IF SO, WE NEED TO

historically underrepresented minority students for several years,” Thomas said. “So we’re seeing a change in the face of the student population overall. But the racial composition of the faculty hasn’t changed at all for the most part. There’s a mismatch.”

The commission is identifying blind spots and pinpointing vulnerabilities that can lead to attrition of minority students, residents and faculty members at critical career pressure points, said Mayes. “What is it that we aren’t seeing, that we aren’t thinking about? How do we create a place where everyone can thrive,

regardless of their background?”

Attrition isn't unique to medical or graduate school, however. Frequently postdoctoral scholars, medical residents and young faculty members of color struggle to find mentors who not only look like them but also understand their struggles.

“The transition from a postdoctoral scholar to a faculty member is the most difficult,” Valentine said. “Many institutions focus on medical and graduate student classes and think they have done a good job. But these trainees are looking up through the ranks, searching for role models. And they are not always finding them.” Having a good mentor can make all the difference.

“As a first-generation American, I was the first in my immediate family to attend college in the United States,” said clinical associate professor of neurology and neurological sciences Reena Thomas, MD, PhD, whose mother is from El Salvador and father is from India. Thomas was looking for someone to help navigate the early phases of her career when she met Maldonado through a minority faculty networking event sponsored by the Office of Faculty Development and Diversity. Soon the two were meeting regularly to discuss opportunities and the next steps of Thomas' career, and Thomas became a liaison between the neurology department and Maldonado's group.

In August 2020, Thomas became the inaugural associate dean of diversity in medical education to support medical trainees along their path to positions in academia, from premedical students to medical faculty members.

level by raising awareness of the general issues and challenges,” said Magali Fassiotto, PhD, the associate dean for faculty development and diversity. “Culture is characterized at the top levels of an institution, but it really lives at the local level.”

## ANTI-RACISM IN MEDICAL PRACTICE

**DIVERSITY IS MORE THAN JUST a numbers game. Increasing the prevalence of minority physicians and researchers and the awareness of all medical providers about racial inequality in medicine has a direct effect on public health.** In 2017 Fernando Mendoza, MD, associate dean of minority advising and programs (now emeritus), gathered a group of medical school faculty, including Daniel Bernstein, MD, the associate dean for curriculum and scholarship, to discuss ways in which medical school education could better address issues of anti-racism, social justice and health inequities in the doctor-patient relationship. [See related story on opposite page.]

But efforts to increase awareness about racial inequities in health care don't stop with students.

The Stanford Medicine Health Equity Committee, co-chaired by Maldonado and anesthesiologist Amy Lu, MD, is gathering data on Stanford's patients to better understand health disparities arising from the unequal treatment. Lu witnessed such treatment firsthand when, as a child, she translated for her Chinese-speaking grandparents at a public hospital in California.

# PARTICULAR POPULATION THAT UNDERSTAND WHY ... AND GET TO THE ROOT OF IT

“I love connecting with medical students and clinical subspecialty trainees who share a similar background as mine and helping them into the next phase of their careers, just as Bonnie did for me,” Thomas said.

The office also offers skill-building workshops and leadership programs for faculty on leading diverse teams; implicit bias; the roles of diversity, equity and inclusion in professional development; and the Department Diversity Liaison program, which focuses on empowering faculty members leading DEI efforts in their departments.

“We want to make lasting changes at the department

“Is there a particular population that is affected? If so, we need to understand why, what is the case, and get to the root of it. Is it because we are delivering care inequitably? Are certain kinds of care being withheld? Are patients who are coming to give birth being offered less pain medication if they are African American?” said Lu, the associate chief quality officer for Stanford Health Care.

There's no shortage of ways to improve.

But challenges remain.

“We're talking about building a culture of addressing

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# a voice for the incarcerated

Criminal justice reformer Shaka Senghor spent 19 years in prison for murder.

He grew up in Detroit in a middle-class Black family, was a smart child and did well in school, he told contributing editor Paul Costello.

But when he was 13, he ran away to escape abuse in his home and ended up involved in the illegal drug trade.

At 19, he shot and killed a man — a result, he said, of the horrible consequences of that dark and dangerous life.

Incarcerated for the crime and released from prison in 2010, Senghor is a different man today. He is a strategist, mentor, motivational speaker and author — his best-selling memoir, *Writing My Wrongs*, about life, death and redemption in prison, was published in 2016. He has dedicated himself to helping young people avoid the mistakes he made that landed him in prison, to enabling others to see the humanity of incarcerated people, and to closing down the pipeline of young Black men into the criminal justice system.

The U.S. Sentencing Commission has found that Black men serve longer sentences than white men for the same crimes. Black people make up a disproportionate amount of the nation's prison population, representing 12% of the total U.S. population but 33% of the federal and state prison population, according to a Pew Research Center report of 2018 data.

With COVID-19 ravaging incarcerated populations — according to an April 10 *New York Times* report, one in three inmates in U.S. state prisons are known to have had the virus — Senghor is also working with Stanford Medicine researchers to stem its spread in jails and prisons in California.

Costello spoke with Senghor in November about his life, activism and the Stanford project. This Q&A was edited and condensed from that conversation.

**COSTELLO** As a young boy, you dreamed of becoming a doctor. What happened?

**SENGHOR** Being a doctor was rooted in my idea of helping people. When I was around 13, I was seduced by the drug culture and experienced all sorts of negative consequences. I was nearly beaten to death,

robbed at gunpoint, was shot at age 17; and eventually I shot a man, tragically causing his death. I was sentenced to 17 to 40 years in prison. I was released in 2010 after 19 years there, seven in solitary confinement. It's taken me years to reconcile what my life was back then.

**COSTELLO** How did you change your life after you left prison?

**SENGHOR** I began immediately to do work in my community that would help other young people who started with a dream avoid the nightmare that I experienced. I've been a mentor, a leader of several organizations as a strategist and partner in criminal justice reform and gun violence prevention. It's been an unbelievable 10-year journey.

**COSTELLO** You've been working with Stanford Medicine professors Jason Andrews and Jeremy Goldhaber-Fiebert in California correctional facilities. What does the work entail?

**SENGHOR** It's allowing us to track how the virus is spread in contained environments. We're currently doing antibody testing in county jails and trying to build that out to extend to prisons. It's been a little bit of an uphill battle to get access.

**COSTELLO** Why an uphill battle?

**SENGHOR** It points to this kind of clandestine way that prisons have operated in this country, where they limit access, whether it's to the media or outside agencies just trying to do good work and help public safety. It's sad that we have to fight these battles when this is really about public safety. It's not about shaming the system or having an "I got you" moment. It's saying, "Hey, if we can track and figure out how this is spread in the environment, maybe we can have something to share with society to better protect people from contracting the virus in the first place."



ERNEST SISSON PHOTOGRAPHY

**COSTELLO** A California State Appeals Court said in October that state officials acted with “deliberate indifference” to the health of prisoners at San Quentin State Prison, where 75% of the incarcerated men had COVID-19 at the peak of an outbreak there this summer, and more than 28 had died from it. Is California prisons’ management of the pandemic indicative of how it’s playing out in prisons in the rest of the country?

**SENGHOR** Unfortunately, we literally have a human rights crisis inside prisons throughout the country. The way it has been handled is problematic in several ways. We’re finding a consistent theme: Governing parties have been slow to act, and they have not been very transparent about the steps they’ve taken to prevent the spread of the virus.

In some instances, they’ve made very poor decisions, including

transferring people who contracted COVID-19 to prisons where there were no outbreaks prior to these transfers. There’s not a great deal of public oversight. Until we have that, we’ll continue to find ourselves reacting as opposed to being proactive in our approach to problem-solving.

**COSTELLO** You must often hear, “Prisoners deserve whatever happens to them. Prisons are not a societal priority.”

**SENGHOR** Well, if you scare people into believing that anybody who gets out of prison is going to cause further harm, it’s hard to be empathetic and compassionate. Over 90% of incarcerated people will get out. We have a responsibility as a society to ensure that they are coming home healthy and whole, and that they have the skill sets and tools to reenter society after being in a very barbaric environment.

**COSTELLO** A key to successful rehabilitation is a strong connection to family. COVID’s isolation has fractured that bond. What’s the impact?

**SENGHOR** It’s devastating. I talked to a friend recently who told me he hadn’t seen his wife in six or seven months. She’s constantly in a state of worry about his health and well-being.

The flip side of that is the concern incarcerated people have for aging parents or others in their family who are vulnerable to the virus. Often, if someone in their family becomes critically ill with COVID, there’s little chance to see them again before they die.

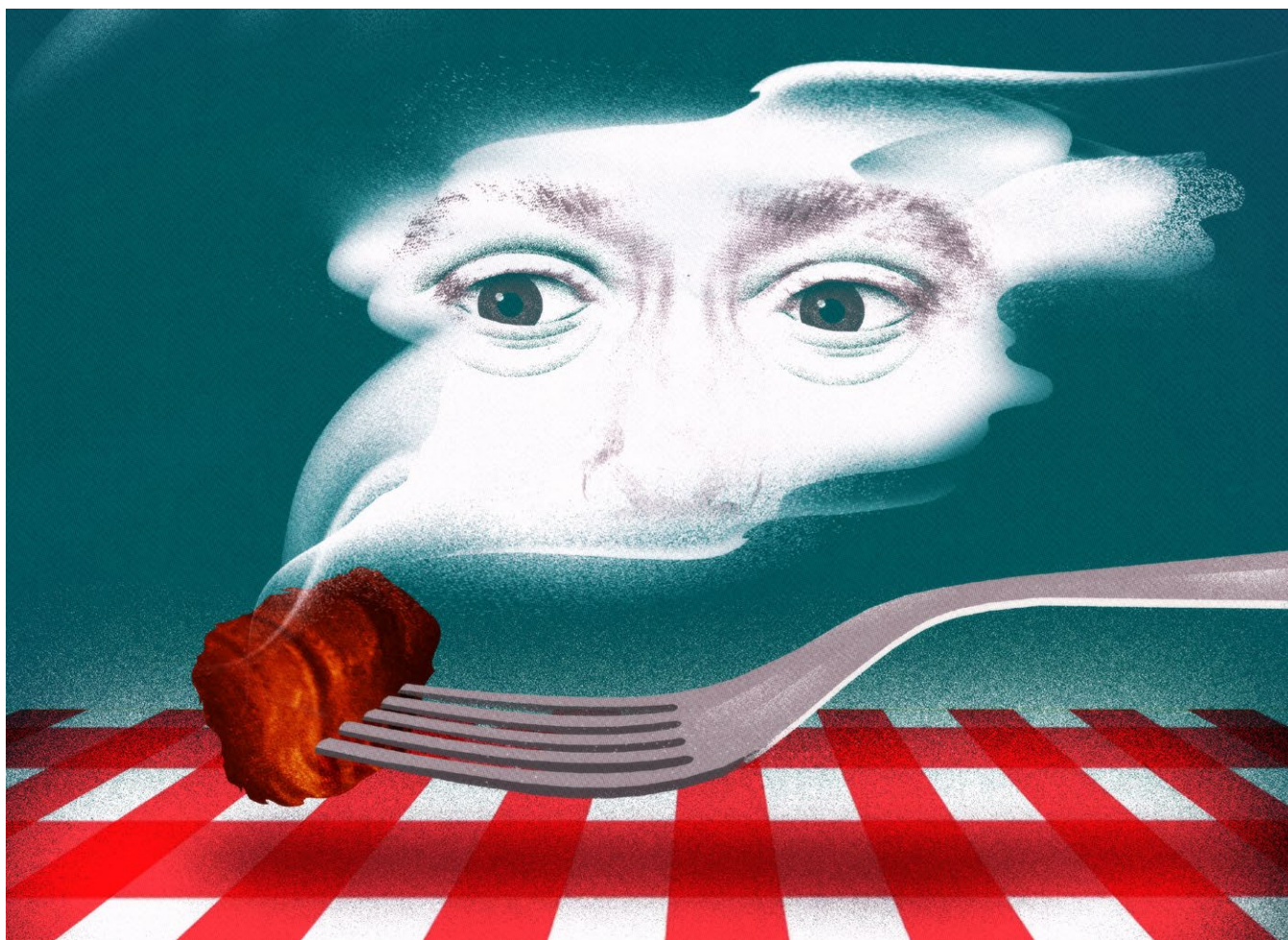
**COSTELLO** You often say, “No one is the worst thing they’ve ever done.” What does that mean?

**SENGHOR** I have an inherent belief that none of us arrives at our worst moment without a lot of bad things happening in our life. If you walk backwards from a person’s worst moment, you’ll realize they were victims of very traumatic experiences. Once a person reconciles with that moment, begins to take proactive steps toward healing and is accountable, society, at some point, has to create space for them to redeem themselves. **SM**



# plus

EXPLORING THE REALMS OF MEDICINE AND HEALING



## Adventures of the mind

BARBECUE WITH DAD, DEMENTIA  
AND HOW OUR SENSES  
CONTRIBUTE TO COGNITION

By Karl Lorenz

### PART I: FOR SALE — ONE TEXAS BARBECUE RIG

I SAW THE AD ON CRAIGSLIST, the site that hosts scheming Nigerian princes, soiled mattresses for sale and other random castoffs. The find was a real Texas barbecue rig, made of three-eighths-inch steel; a 10-foot-long main barrel; a separate offset firebox; and a tall, manly stack.

I imagined that sucker could hold 15 pork shoulders, maybe a dozen racks of ribs and more chickens than a Stanford math professor could count ... all for my consuming pleasure. It was a real wood-burning rig, only \$1,000 more or less, and shockingly, for sale about 5 miles from my house in oh-too-sophisticated Silicon

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Valley. It said, “Contact Fred in Belmont.” So I did.

I didn’t tell my wife, Elodie, about the purchase or announce the day of delivery. So when Fred drove up in a flatbed truck with that jillion-pound monster on the back, I went out front, trying to look like I was going to get the mail, and greeted him.

“Let’s roll it off — down the ramp, straight over that lawn and over to the gate on the right. We’ll stick it along the fence there.” Fred was nearly as robust as the barbecue rig, and it rolled easily ahead of him on a set of steel wheels. After pushing it across the hardened summer lawn, we parked it on the other side of the gate. I imagined — hopefully — that my wife missed the whole thing.

“What is that?!” Elodie barked, as I pseudo-innocently opened our back door. “Oh that? Just a barbecue,” I announced, as if the monstrosity was a 2-foot-tall Weber. “What in the heck? Why didn’t you tell me?!” she asked, as if there were an acceptable answer. “I’ve been wanting one. You know I loved Barney’s rigs, and you wouldn’t let me buy those. Besides, I got it on sale,” I replied. “On sale? How much?” she asked. “A thousand dollars ... isn’t that great?” I asserted, omitting the \$200 delivery fee. She snapped back, “You’re crazy. Was that guy in front the one who sold it to you? You just wait. In short order, you’re gonna look just ... like ... him!” I was halfway to that destination already, but ...

My Southern, food-centric brain drives my wife crazy. “Remember the wonderful reception for Catherine’s wedding? How beautiful it was outside at Green Cove?” she joyfully recalls. I don’t. I rarely do, but I don’t forget a good meal. “Did we bring ribs from the Pig Out up to the lake that weekend? Didn’t we do burgers on your grandmother’s dock?” I wonder aloud.

It might have been the same weekend, but I’m focused on the remembered taste of caramelized onions and mustard sauce on the side. “Your stomach is your brain,” she replies in disgust. Indeed, life has taught me that taste and other senses share important links to seemingly unrelated parts of the brain.

And thus it was inevitable that my mind turned to barbecue while tending to my father.

## PART II: HEART AND SOUL OF A FARMER

MY FATHER, Vernon Rudolph Lorenz, was a dairy farmer who moved to Georgia with my mother, Lois, from his home state of Wisconsin in the early 1960s, searching for opportunities. Things didn’t work out at the Atlanta farm that first hired him, so we moved to Macon, Georgia, where he took up a decadeslong career as a mortgage banker.

Even though my memories of Dad are associated with standard office wear of crisp white linen shirts and featureless black leather shoes, I think of him as a farmer. His displaced occupation and passion are reflected in my memories of his hands on a shovel, fingers dirty with composted soil, smiling at the size of a summer squash.

My father’s keen observations of nature taught me to look critically at the world around me and indirectly empowered me to undertake a career in medicine. We took long walks in the Georgia woods behind our house where I would search for arrowheads and pottery fragments in the clear water burbling over colored gravel. “This is a hickory tree, son. See the leaves?” he would query me as he held up the characteristically pointed leaves on a pinwheel-like branch.

My father’s keen observations of nature taught me to look critically at the world around me and indirectly empowered me to undertake a career in medicine.

As a farmer, he had to be constantly aware of changing weather, so nearly every day included a close look at the clouds and sky, speculation about the temperature and the chance of rain: “Looks like that front is finally moving in. A soak will be great for the garden.” After I moved to California, “How’s the weather?” was a regular start to our conversations, even though it was always 75 degrees and sunny.

He and my mother encouraged my own close attention to details. Dad took me digging in the pits of local kaolin mines. Macon is on the geologic fall line where ancient seas met land, and kaolin deposits reflected the historic coast. Probing in the kaolin pits, we dug out massive shark teeth, sand dollars and strange fossilized lumps.

One day, the excavation for the foundation of a new building revealed a 19th-century garbage dump, so we took up shovels to pull out glass apothecary bottles, porcelain doll heads and other artifacts. In both cases, he queried me about our findings, encouraged me to reflect on them, and helped me understand the importance of contextual clues in making sense of the world.

## PART III: A SWEET, CROOKED SMILE BEGINS TO FADE

SOME DECADES LATER, in early 2018, I found myself in Severna Park, Maryland, where my mother and father had moved to be close to my sister and her family. My dad ended his eighth decade of life in the fog of worsening dementia. Just a few months before, when I’d most recently seen him, his shaven, round face was still occasionally transfixed with a crooked, sweet smile. He was trying to crack typical corny jokes,



as best he could, even though his gait was faltering and I could see dementia haunting him, lurking just out of view.

Now, like a wraith, it was hiding just behind his eyes, pulling him slowly and more deeply into himself. His sweet smile was disappearing — gradually replaced by a plastic, expressionless mask.

In June that year, Elodie and I were driving to a restaurant in the Richmond neighborhood of San Francisco when my mother and sister, Melody, called. I had never heard such suffering in my mother's steady voice. Warbling on the edge of tears, she recounted how my father had tripped. He hated using his walker, and in a moment of neglect, his foot met an errant corner of something.

They had recently moved to a senior living community, and he was sent from there to a local emergency room. It was an "age-friendly health system" I recalled, on a list of systems lauded for making special efforts to gently care for older adults. Indeed, they treated him carefully, but my stalwart mother was crying. Her husband of over 50 years didn't recognize her.

"They want to admit him, but I'm not going to do that," said Melody. "It will just be that much worse, deconditioning and everything." Although he received timely care and minimal pain medication for a humeral fracture, the injury, combined with the sleeplessness of an emergency room stay and lack of food, pushed his mind into inner space. He was talking nonsense and didn't recognize anybody. My sister, who is a nurse, inherited my mother's steely backbone and insisted, "I'm taking him back to their apartment. He'll recover more quickly. I'll make a bed on the couch, and give you a call when we're settled."

Although he got better quickly, it

wasn't better enough. A quiet room, tender touch and a warm bed brought him to 80% of his baseline. By the second week of his convalescence, our mother was about to break. Dad never had problems at night before. But, without warning, he would now pee in his bed. Voiding before bed, fluid and caffeine restrictions, and other measures to prevent bed-wetting didn't work. And every time my father wet the bed, my mother arose, undressed him, and washed and dried his clothes and linens. She and my father lost hours of sleep. They and my sister were all nearly at wits' end.

"I'll come out and see what I can do!" I reassured my sister. How could I not try? I'm a general internist and a palliative care physician. So I flew out and camped on their sofa. I didn't get much sleep as I shared the night watch with my mother, and I couldn't keep Dad from wetting his bed either, at first. Because I imagined that sleep deprivation was making things worse, I tried a condom catheter to break the cycle, and thankfully, on the first night it worked. Everyone slept and in the morning, everyone was refreshed. Dad was still confused, but better. I showered and felt a stirring of hope, but it was gastronomy that really saved us.

#### PART IV: THE HEALING MAGIC OF ONE SAVORY BITE

MY FATHER LOVED barbecue as much as I do. Macon is steeped in Southern culture, and its necks, religion and politics are all red like the bloody clay. Macon is where Flannery O'Connor's short stories read more like newspaper articles than religious allegories run amok. I may live in California, where people think barbecue means hamburgers on a gas grill, but Macon taught me

Macon taught me that real barbecue is pork ribs, shoulders and chicken lovingly slathered and tended over fire for hours.

that real barbecue is pork ribs, shoulders and chicken lovingly slathered and tended over fire for hours. The happy result is a conjoined explosion of flavors and textures of spicy rub; softly yielding, smoky meat; and crispy burned edges.

One of my earliest memories with my father is heading out for barbecue. When I was knee high to a cockroach, we took a weekend trip to the Swamp-land Opry House. Yankee immigrants who write about it now ignorantly call it an "Opera House," but it hardly deserves such a sophisticated title. It was a place for foot stompin' local music, trucks and everyday folk.

What I remember about it was my first encounter with Brunswick stew, a soupy Georgia barbecue specialty of melted meat, summer corn, okra and other vegetables, swimming in a vinegary sweet liquid that all intertwined on the tongue.

The morning after Dad finally slept without wetting his bed, I felt the freedom to stretch our legs a little, and because of our mutual love, I suggested lunch at Mission BBQ. Although Mission BBQ isn't the down-home joint of my childhood, it was a place my parents adopted after moving to Maryland.

The staff at Mission adopted my parents, in turn, to the point where my mother would bake a special cake for Mission employees and they would reciprocate with a complimentary meal. Mealtimes there are distinctively weird, with photos of veterans and first responders on the walls, a fleet of Army green delivery Humvees parked outside, and patrons rising out of the blue to say the pledge of allegiance in unison.

Our trip there began with a slow, patient ritual of pulling on Dad's pants, helping him fasten up, and awkwardly getting his arms in his shirtsleeves. We walked slowly behind him, unsteadily making progress behind his walker,

and arrived at the apartments' atrium. Opening the door to a warm summer day, we folded the walker in the hatchback, gently helped Dad lower himself into the front seat and headed off down the road flanked by a ruptured canopy of waving green leaves and whitish gray clouds hinting of rain. We parked near the Mission BBQ entrance and helped Dad out, ambling up the disabled ramp to the door.

It was the forkful of pulled pork, or maybe the sauce on the pork, or maybe the combination that resuscitated Dad. The first flavorful bite turned on a switch, and his dull, withdrawn eyes popped awake like lightbulbs. He smiled and offered nearly his first coherent words of the week: "Hi, son," said with a weak smile. He scanned the room with growing awareness of his surroundings, and I nearly dropped my fork in astonishment.

Although he was still confused, I could see renewed expressiveness in his face and hear a restored clarity to his voice. During nights to come, he would finally get up to the bathroom with assistance, instead of peeing mindlessly in his sleep. It was the beginning of the end of the worst.

#### PART V: NAVIGATING LIFE BY THE POWER OF OUR SENSES

NOW, WHEN I GO OUT on morning runs, our retriever-mix, Charlie, reminds me of how profoundly essential senses other than sight are to our ability to navigate the world. As we head out on the Bayshore trail, Charlie apparently navigates our various routes by smell.

He seems to sense progress from one spot to another along bushes and posts where other dogs stopped and maybe marked the occasion. He's so good at consistently identifying these locations, even when I'm doing my best to pass them quickly, or when we're revisiting a route

we haven't taken for a while, that it seems like his mental map of the world might be inscribed with smells.

Before the coronavirus pandemic, I co-piloted a tandem bike with a blind rider who has become a good friend. I discovered as we were riding together that I could share my experience of the world by describing what I was seeing in tactile terms. My riding partner found it meaningful as we passed between huge palisades of trees in Golden Gate Park to hear that they looked like upside-down stalks of very long broccoli; or as we were passing along the beach in the Outer Sunset to hear that the clouds in the sky looked the way long, pulled-out tufts of cotton balls appear when floating in upside-down water.

And so I have come to increasingly recognize that our mental lives exist in a matrix of thought intermixed with smells, sights, tastes and touch. The command of our mental faculties might depend on the flavors of a well-loved meal or the plush seat of a familiar chair.

This brings to my mind synesthesia, a medical term I learned from neurology that refers to a blending of the senses. A person with synesthesia experiences and expresses one sensation in terms of another, as in, "My coffee tastes blue." My experiences made me wonder if synesthesia might represent overexpression of a higher potential that all of us possess: Having shared linkage of various senses to cognition might sometimes be adaptive. For example, sensory commingling might have aided hunter-gatherers who relied on senses to flexibly navigate the world — promoting survival when sight was diminished by injury or by travel in absolute darkness. In the case of my dog, my blind

Now, when I go out on morning runs, our retriever-mix, Charlie, reminds me of how profoundly essential senses other than sight are to our ability to navigate the world.

friend, and my father, different senses have triggered common cognition.

Whether related to synesthesia or not, this reminds me that appealing to multiple senses can be a powerful stimulus to mental awareness and that one sense may mitigate losing another. As a palliative care physician, I find this a crucial reminder of why sensory-rich environments can help maintain persons coping with dementia.

My wife and I still get into minor tussles about food. "You're so food-centered!" she will say in exasperation, especially when, after a long day of work, I still insist on taking the time to cook something appropriately delectable.

I notice my wine collection doesn't come in for a lot of criticism when she's drinking it, but she's often unhappy when I'm weighing the merits of particular Italian blends for a random Tuesday night pasta. A recent mealtime conversation focused on estate planning, including wills, trusts and advance directives. While it was difficult to work through, I knew one thing for sure. I'm attaching a note to my directive: When I'm dying and confused, push a plate of smoky ribs my way. **SM**

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KARL LORENZ, MD, *practices general internal medicine and palliative care at Stanford, is section chief of the VA Palo Alto-Stanford Palliative Care Program and co-directs the Stanford Palliative Care Center of Excellence (more info at <http://med.stanford.edu/palliative-care.html>). Vernon Lorenz's dementia worsened during COVID-19 isolation and he died in November 2020. Karl loves to use his smoker and enjoys a plate of barbecue whenever he can.*

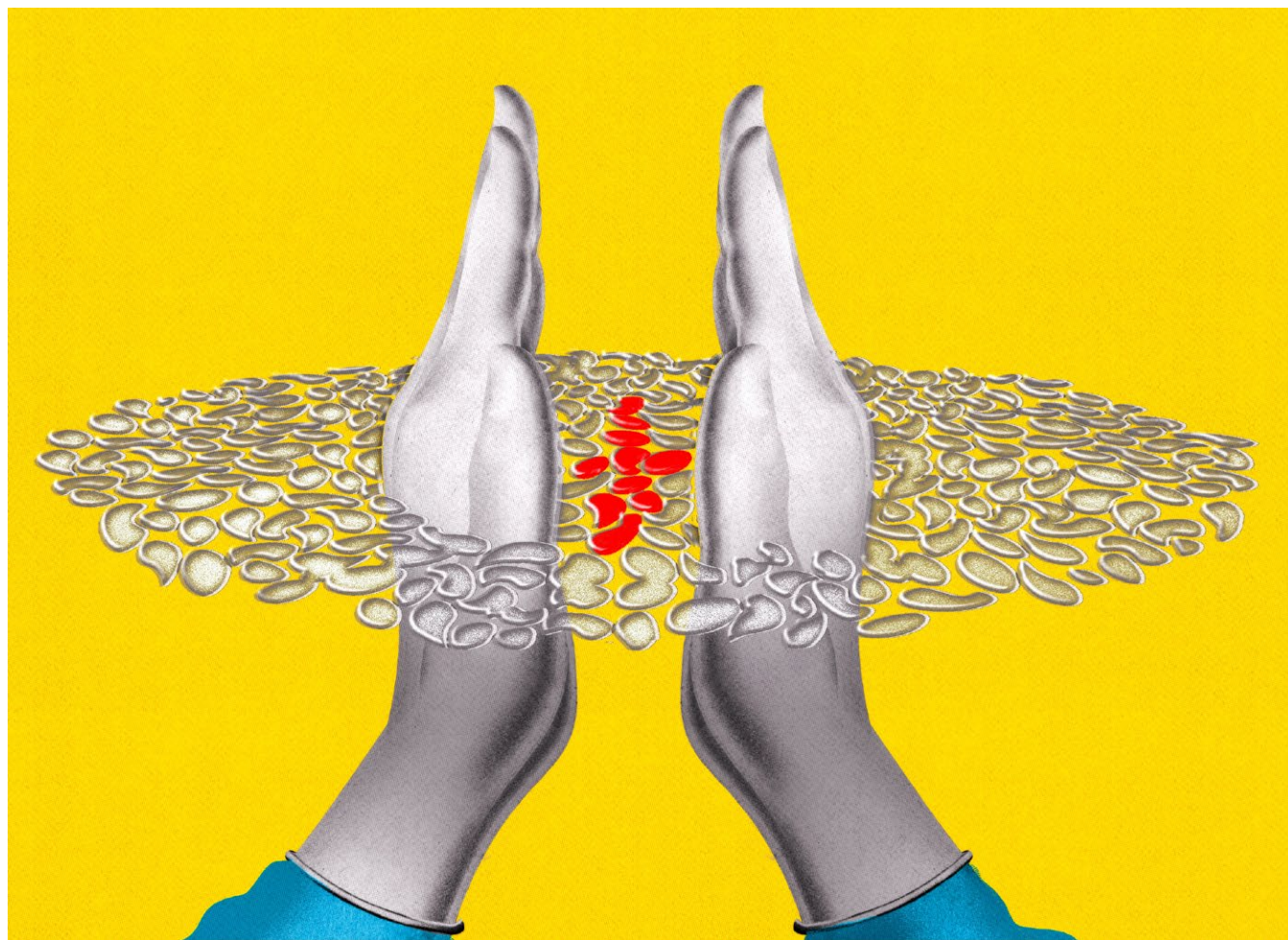
— Contact Karl Lorenz at [kalorenz@stanford.edu](mailto:kalorenz@stanford.edu)



# Resistance is futile

CLOSING CANCER CELLS' ESCAPE ROUTE

By Krista Conger



**I**T WAS A TRIUMPH. For the first time, people with an inoperable form of the most common type of skin cancer had a drug treatment option that was well-tolerated, quick and — in many cases — almost freakishly successful. Doctors breathed a sigh of relief. No longer would their patients have to suffer.

“How often in your life do you get to have worked within a field where you finally get to test a drug that actually changes people’s lives?” said Jean Tang, MD, PhD, professor of dermatology at Stanford and first author of the 2012 study announcing the success. “We were very excited about the results.”

But these doctors soon realized that for many patients the cancer returned after seemingly successful treatment with the new drug, vismodegib, which the Food and Drug Administration approved in early 2012 to treat advanced basal cell carcinoma. And when it returned, the tumors were likely to be resistant to the drug, leaving patients, once again, with limited options.

“We’d see the cancers melt away, but then the patient would return months later to say, ‘Hey, doctor, what’s this?’” said Anthony Oro, MD, PhD, the Eugene and Gloria Bauer Professor of Dermatology. By August 2012, Oro and professor of dermatology Anne Chang, MD, published a study showing that the tumors recurred in about 1 in 5 patients within a year of treatment.

The researchers realized that the new tumors were somehow evading the drug that seemed like a magic bullet the

BRIAN STAUFFER

first time it was used. But how? Recently, Oro and graduate student Catherine Yao learned that, like master spies, the cells dodge the treatment by shedding their identities to become a different type of cell entirely — one that is no longer susceptible to vismodegib.

The finding is the culmination of a research odyssey involving high school science fairs, an ailing father and years of study of the inner workings of mutant fruit fly embryos. But it could one day change the lives of people facing a deadly cancer.

“Finally, we’ve shown in great detail the escape route these cells have been using, and how it mirrors normal development,” Oro said. “If we can convince the drug-sensitive cancer cells to ‘stay in their lane’ by making it impossible for them to switch identities, or forcing them to switch back, we could transform the treatment of this disease.”

#### UNDERSTANDING MUTATIONS OF BASAL CELL CARCINOMAS

**M**ILLIONS OF PEOPLE each year are diagnosed with basal cell carcinomas, which occur primarily on sun-exposed skin. For the most part, the cancers are highly curable; they can be surgically removed or killed with radiation. But they become much more difficult to treat if they burrow deep into the surrounding tissues or spread to other parts of the body.

Basal cell carcinomas are unique among cancers because their growth relies almost exclusively on a cellular signaling system called the hedgehog pathway. Like a Rube Goldberg machine, in which a ball rolling down a track triggers weights to fall, dominoes to topple and pendulums to swing, cellular pathways comprise several successive steps that deliver a message or a signal from one location — often outside of the cell — to another — often the cell’s nucleus. Each step triggers the

next so a cell can respond quickly and efficiently to changes in its environment. Vismodegib helps stop basal cell carcinomas by blocking an early step in the hedgehog pathway.

Understanding how the hedgehog pathway works and connecting it to human cancer has been a decadeslong effort for researchers like Oro. The backstory of vismodegib’s initial success has its roots in studies of the earliest developmental stages of the tiny fruit fly called *Drosophila*.

Developmental biologists wondered how the fly embryo knows how to properly pattern itself during development — neatly ordering head, abdominal and thorax segments before adorning them with perfectly placed antennae, legs and wings. Without some kind of master regulators, they reasoned, you’d be just as likely to end up with a wonky Mr. Potato Head of the fly kingdom rather than the perennial pest that hovers around many of our kitchen counters and compost piles.

By the early 1980s, the researchers had identified more than 50 genes that, when mutated, disrupted the development of the embryo in macabre ways, including adding an extra set of wings, legs and antennae that sprouted from places they didn’t belong. Hedgehog was one of these genes, so named because mutant embryos had a spiny, hedgehog-like appearance.

#### FROM SCIENCE FAIRS TO HEDGEHOGS

**O**RO’S INTEREST IN dermatology solidified in 1984, after his father had suffered for years from a terminal slow-growing salivary gland cancer. While completing a summer internship at the National Cancer Institute, the then Stanford undergraduate resolved to apply for an MD/PhD program to

study the molecular basis of the disease that was killing his father.

He had a good background for it. In the early 1980s, Oro was among the first students at Gompers Preparatory Academy, a newly designated math and science magnet school in San Diego. The school became nationally known for the strength of its teaching and its

many national awards in academic competitions.

“We didn’t have a sports team, but science fair was like sports for us,” Oro said. “It was a very big deal at the school.”

One of Oro’s science fair projects used a technique called an Ames assay that

tests whether certain chemicals are likely to cause mutations in the DNA of bacteria. Rather than studying the impact of a chemical, Oro examined the potential of different kinds of UV light to cause mutations, with the goal of assessing how the loss of the ozone layer was likely to affect skin cancer rates.

“I didn’t realize at the time, but I guess I was a budding dermatologist even then,” Oro remarked.

Oro completed his medical and graduate school training at UC San Diego, where he studied how proteins in the nucleus of *Drosophila* affect pattern formation in the fly embryo. (At the time, the fields of developmental biology and cancer were beginning to merge as it became clear that the patterns of cell division and organization in a tumor often mirror those that occur during normal embryogenesis.)

He returned to Stanford in 1993 as a postdoctoral scholar in the laboratory of developmental biologist Matthew Scott, PhD. In 1984, Scott was one of several researchers to discover an important class of genes that shared a common DNA sequence called a homeobox. These genes carried the

If we can convince the drug-sensitive cancer cells to “stay in their lane” ... we could transform the treatment of this disease.



instructions for proteins that, when activated by the presence of the master regulators, turned on or off large swaths of genes involved in development and patterning in *Drosophila*.

“Once you start to understand how these regulators can flip a switch to control cell fate during development, it seems not so crazy that an adult cancer cell can also change fate,” Oro said. “It happens a lot in *Drosophila* genetics.”

The timing was fortuitous. That same year, researchers identified a hedgehog-like protein in humans, called sonic hedgehog, and Scott and Oro focused on understanding the hedgehog pathway in vertebrates, which is critically important during fetal development but rarely active in healthy adult cells. In 1997, the researchers showed that mutations in a protein in the pathway called patched are associated with developmental defects and human cancers, including basal cell carcinomas — a revelation that gave researchers around the world a new target for new cancer therapies.

Shortly afterward, Oro started his own lab, focusing on skin cancers as a model to learn more about how cancer cells change and grow.

“Just like in fruit fly embryos, where the effects of mutations are easy to spot, skin cancers are highly visible and easily biopsied, making them a great model to study broad themes in cancer development and evolution,” Oro said.

Discoveries by Oro and Scott and subsequent clinical trials at Stanford and elsewhere led to the 2012 approval of vismodegib, which inhibits another protein in the hedgehog pathway called smoothened. Though the pathway is inactive in most adult tissues, it is always active in basal cell carcinomas, sending constant signals to the cancer cell to divide relentlessly. Inhibiting smoothened acts as an emergency brake in the pathway, stopping the growth of the cancer.

“Tony and Matt really established the hedgehog pathway as the central pathogenic pathway in basal cell carcinomas and focused attention on the possibility of perturbing this process to treat these types of cancers,” said Paul Khavari, MD, PhD, the Carl J. Herzog Professor in Dermatology and chair of the department.

#### ROOTING OUT CANCER IN HAIR FOLLICLES

**S**URPRISINGLY, although basal cell carcinomas are skin cancers, they actually arise from stem cells in the hair follicles that pepper most of skin’s surface. Although the hedgehog pathway is inactive in most adult tissues, stem cells in the follicle toggle it on and off to regulate the rapid cycles of cell division and rest that drive the hair growth and loss that plague bathtub drains. Basal cell carcinomas arise when the pathway is always on.

Sometimes these cancers, Oro and Yao found, switch their careers in a phenomenon known as cellular plasticity, or the ability of one cell to morph into a related but different type of cell. This type of cellular transfiguration, akin to switching careers from a plumber to a carpenter or from a lawyer to a real estate agent, is one way that cancer cells evolve and change to promote metastasis or drug resistance.

Oro and Yao found that these basal cell carcinoma cells sometimes slide sideways along a common developmental pathway to more closely resemble another type of cell in the hair follicle called transit-amplifying cells. Normally, short-lived transit-amplifying cells die soon after secreting signaling factors to coordinate the growth and development of other cells inside and outside of the follicle. But the cancer cells that have assumed their identity continue to divide.

Although, like the stem cells, transit-amplifying cells and their cancerous doppelgangers also rely on the hedge-

hog pathway for their growth, they activate it differently. In the Rube Goldberg analogy, it’s as if they use a secret door to introduce a new ball below the emergency brake thrown by vismodegib — rendering the drug ineffective.

“Here, we can actually see cancer cells changing lanes or fates,” Oro said. “We give vismodegib, which inhibits smoothened activity, but the cancer doesn’t die. Instead it switches to a different type of cell that uses an alternative to the standard hedgehog signaling system. This allows them to live even though the upstream portion of the pathway is being blocked.”

After twirling a developmental cloak to evade vismodegib, the cancer cells exist in a murky limbo between ‘normal’ basal cell carcinomas and true transit-amplifying cells.

“Somewhere along the normal differentiation pathway, the differentiation program is hijacked by the cancer, which uses existing pathways in new ways to drive drug resistance,” Yao said.

The researchers soon discovered that this sneaky sidestep isn’t rare. In fact, the resistant cells have a unique pattern of proteins on their surface, which allows researchers to identify them in tissue samples from patients with basal cell carcinoma who came to Stanford for treatment. Also, the transformation isn’t always an evasive maneuver sparked by exposure to vismodegib or other smoothened inhibitors.

“Sometimes these cancers just change spontaneously,” Oro said. “Some untreated samples from patients have no resistant cells in their tumors, while other patients come to us with nearly half their tumor cells already resistant to vismodegib.”

Why? “Cancer biologists might say the cells want to hedge their bets while staying alive,” Oro said. “If you can diversify your portfolio so that a subset of your cells can withstand the treatment,

you're golden."

After working out the minutiae of the cells' drug resistance, Yao showed that simultaneously blocking smoothened with vismodegib and another protein called AP-1 dramatically decreased hedgehog pathway activity in tissue samples collected from people with basal cell carcinoma.

The finding suggests that a combination treatment targeting both arms of the pathway could be significantly more effective than inhibiting only smoothened, and it might even head off the transformation of drug-sensitive basal carcinoma cells into their resistant counterparts — in effect telling them to stay in their own lane — or re-sensitize resistant cells to vismodegib. Either would be a boon to patient care.

#### 'STAY IN YOUR LANE' COMBINATION THERAPY

**Y**AO AND ORO published their results in *Nature Communications* in October, and they are eager to translate their findings into patient care.

"Fortunately, we have here at Stanford a talented team of clinicians, translational scientists and basic scientists, as well as amazingly generous clinic patients who donate their samples for research," Oro said. "In particular, Sumaira Aasi, MD, who is the director of Mohs and Dermatologic Surgery, and dermatology faculty members Kavita Sarin, MD, PhD; Anne Chang, MD; and Jean Tang also lead their own independent research efforts."

Yao and Oro envision a future in which a patient's basal cell carcinoma could be evaluated for the cellular markers that indicated probable resistance to vismodegib and their treatment tailored to the results: treatment with a smoothened inhibitor like vismodegib alone if it is likely to be sensitive, or with a combination therapy including an AP-1 inhibitor if the cells have already begun to change lanes.

Interestingly, the implications of their finding could spread beyond basal cell carcinomas, including to the salivary gland tumor that eventually killed Oro's father.

"All skin cancers are a type of cancer known as an adenocarcinoma," Oro said, "as are cancers of the lung, pancreas, colon and salivary gland. Preliminary research indicates that we see the same cell surface markers delineating sensitivity or resistance on those cancers as well, and that they likely follow the same principle of lane-switching to evade treatment."

As with the studies that led to the approval of vismodegib, Oro and his collaborators are well-suited to move the findings into the clinic because they straddle the chasm that often separates basic science and clinical know-how.

"All the faculty members in the dermatology department are also practicing clinicians. We all speak the same language of medicine and of basic science; there's no translator needed," said Khavari. "This accelerates every step of the process. Tony not only made the initial observations in the laboratory but he deeply understands the clinical manifestations of the disease and what's needed to bring these types of advances into the clinic. This kind of work will provide additional options for treatment, which will be invaluable to our patients."

Oro knows what it's like to tell a patient there are no other options for their cancer. It keeps him hunting for new strategies.

"As a clinician, you might look up how to treat a specific kind of cancer and you use the recommended drugs. But if the cancer changes, well, those drugs aren't going to work," Oro said. "It's like trying to shoot a duck, but the duck changes into some other animal during the hunt. It's time for a different kind of weapon." **SM**

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#### FEATURE

### Righting decades of wrong

CONTINUED FROM PAGE 11

race and ethnicity data, 91% of the studies' patients were reported to be white.

Dermatologists are trained to recognize certain features or patterns associated with particular diseases — but signs of disease on skin can change with different pigmentations. If doctors learn to detect skin abnormalities only in people with light skin, they run the risk of incorrectly identifying conditions in people with dark skin or missing them altogether.

"As a field, dermatology's textbooks and educational materials, our databases and our publications are not representative of all skin types," Linos said. "Our goal is to hold ourselves and our colleagues accountable so that we ensure the same level of care, information and education for people of all backgrounds."

Their campaign has had some success. The cover of the October 2020 *British Journal of Dermatology* featured an image of COVID toes on dark skin. "We're on the lookout for the bigger picture and are seeking a more diverse set of images to represent disease across a spectrum of skin color," said John Ingram, MD, PhD, editor-in-chief of the journal.

Identifying the problem, said Linos, is an excellent start, but more is needed. "It is all of our responsibilities — primary care doctors, patients, dermatologists, researchers, journal editors. We all need to be aware that this is a problem so we can actively choose to be a part of the solution," said Linos. For example, doctors can photograph skin conditions on people of color, then, with patient permission, share the photos with researchers for scientific studies. "We must address it, and quickly, because ultimately the quality of patient care depends on it." **SM**

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#### FEATURE

### Unequal treatment

CONTINUED FROM PAGE 21

inaugural chair of Stanford's Department of Biomedical Data Science.

The modern concepts of race and racism originated in the 17th century, when European imperialists set out to build a power structure based on white dominance. This



hierarchy was later reinforced by the mass enslavement of Africans in the American colonies and the rise of social Darwinism, based on Charles Darwin's theory of natural selection in which only the strongest and the fittest survive, Charles Hirschman, a social demographer at the University of Washington, wrote in a 2004 paper, *The Origins and Demise of the Concept of Race*.

Under the veneer of modern science, the races came to be defined by physical characteristics and capacities, Hirschman said. This belief system continued well into the 20th century. Though slavery was abolished after the Civil War, "racism had developed a life of its own," Hirschman said. It provided a convenient framework for white people to justify suppression of Black people. And racist ideologies like the eugenics movement, based on the idea of "breeding out" inferior traits, gave justification for the Nazis to murder millions of Jews and other people they considered "undesirables."

After World War II, the ideology began to decline along with decolonization and the rise of social catalysts like the Civil Rights movement, the empowerment of minorities and the enactment of anti-discrimination laws.

The mapping of the human genome in 2003 brought a conclusive end to pseudo-scientific theories about race, proving that standard racial labels mean little when it comes to biology or genetics.

The genome project found that humans are 99.9% identical genetically and that more differences exist within historical racial categories than between them.

A year after the sequencing of the genome, Francis Collins, MD, PhD, leader of the international Human Genome Project and the director of the National Institutes of Health, said in a commentary that race and ethnicity are "poorly defined terms that serve as flawed surrogates for multiple environmental and genetic factors in disease causation, including ancestral geographic origins, socioeconomic status, education and access to health care."

Bustamante agreed, saying that race is largely a "social concept, something that doesn't belong to biologists."

"I would say my favorite definition of race is that it is not the property of an individual," he said. "It is the property of an interaction of an individual within a social context."

A better, albeit imperfect, way to characterize populations is to look to our geographic family roots, he said, because groups of people with ancestors from spe-

cific locations often share genetic variations. Bustamante is a Venezuelan-born U.S. citizen with ancestors from Spain. If he were forced to check a box about his racial identity on a driver's license application, he would choose Hispanic. But that says little about his biology, as Hispanics are a highly diverse group who identify based on their place of origin — and their genetics reflect this.

The inherited blood condition sickle cell anemia, widely seen as a disease of Black people, is a good example of how misleading racial categorizations can lead to poor decision-making in clinical care. In the United States, the disease is certainly most prevalent in Black people — 1 in 12 Black people carry the gene for the disease. But it occurs in other groups as well — for example, 1 in 100 Latinos carry the gene.

If clinicians assume it's a disease only of Black people, they could miss cases that occur among other patients.

**R**ECOGNIZING THE NEED FOR CHANGE, STANFORD'S SCHOOL OF MEDICINE HAS UNDERTAKEN A COMPREHENSIVE CURRICULUM REVIEW designed to build more equity into medical training and practice. The process originated several years ago, when officials considered changes to address racial disparities in care.

But the recent social justice protests and pandemic-exposed inequities made the issue all the more urgent, said Daniel Bernstein, MD, the associate dean for curriculum and scholarship.

"We teach the biology of disease very, very well," said Bernstein, the Alfred Woodley Salter and Mabel G. Salter Endowed Professor in Pediatrics. "But as the World Health Organization has noted, about half of the contributing factors of a patient's health are not related to biology. It's related to where people live, what their income is, how the color of their skin affects how they are treated by the medical community, and environmental factors. ... If students are only learning about 50% of health, they are missing a huge opportunity."

The AMA's statement on race and racism validated what some had been saying for a long time, said Italo Brown, MD, an assistant professor of emergency medi-

cine hired in the fall as the health equity and social justice curriculum lead.

"For many years, we've had to rely on one another to get momentum around challenging people to view health differently and not look at race, but rather to focus on underlying social determinants as the driver of outcomes," said Brown.

When instructors talk about asthma, for instance, they need to include discussion about the historical practice of redlining, which relegated minorities to neighborhoods where there is a greater exposure to harmful environmental toxins, he said.

"When you teach asthma to medical students, you have to talk about why cases revolve around communities of color," Brown said. "If you don't share that information, you're missing a very large piece of the puzzle."

Bernstein said that when teaching first-year medical students about hypertension and its connection to cardiovascular disease, the traditional approach is to focus on the physiologic mechanisms of the disease.

"How much of it is traditionally physiologic versus how much is related to environmental and social stress, based on working three jobs and wondering whether you can put food on the table, or whether you can afford the medicines," he said. "Students should not look only to the blood pressure cuff. They need to look at patients holistically and what is a contributing factor in terms of the effects of systemic racism, their socioeconomic situation, and the presence or lack of support systems in the community."

For Mahoney, that represents a wholesale change from her time in medical school decades ago, when few questioned a system where doctors categorized patients by race, to one in which trainees learn instead to ask patients how they would like to be identified.

"I think this moment represents the beginning of a paradigm shift — from the time we go through medical school and residency to the way in which we are seeing patients," Mahoney said. "Everything is starting to change with the growing diversity of our patient population. We are responding appropriately, but it will require a major transformation of the way in which medicine is being practiced." **SM**

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#### WEB EXTRA

"Race is a social construct, not a biological construct." See our video with Stanford Health Care's chief of staff, Megan Mahoney, MD, on the role of race in health care: [stan.md/race-in-medicine](http://stan.md/race-in-medicine) Also read our Q&A with Italo Brown about Black medical mistrust at [stan.md/italobrown](http://stan.md/italobrown).

## FEATURE

### It's not rocket science, it's harder

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real, systemic racial inequities at every level," Maldonado said. "No aspect of this is simple, straightforward or easy to measure."

One challenge is supporting the change-makers themselves. Tovar's extracurricular efforts to create D-CORE are an example of what's known as the minority tax, or the expectation by non-minorities that people of color should serve on diversity committees, mentor younger minority students, give talks about their personal experiences with racism, or carry out any of a plethora of other tasks — all without any direct benefit to their own career or professional development.

These overtures are often made with the best of intentions but without recognition of the impact of being asked to serve as "a token," according to Fassiotto. She recalls an instance in which a white male faculty member, intending to support his colleague's career, asked a female faculty member of color if she'd like to participate in a department committee. He was taken aback when she said she felt like she was valued more for her "otherness" than for her expected contributions.

"I suddenly realized that I didn't know anything," the male faculty member recounted to Fassiotto.

**A**N UNDERCURRENT OF SKEPTICISM OFTEN GREETED ANY NEW EFFORT TO PROMOTE DIVERSITY AND INCLUSION. So many committees over so many years. Why should this new push be any different?

"One of the blessings of the current moment is that people are asking questions and having conversations that they wouldn't have been willing to have several months ago," Ayodele Thomas said. "At least people are talking about it. In the past, someone would have said 'I'm not a racist' and just kept moving on with their life. But now we've been forced to slow down a bit and really think about the components of racism and how to address them."

Members of the commission have spent the past six months in conversation with people across Stanford Medicine to identify problems and brainstorm solutions.

"Addressing systemic racism must begin by taking a brave and honest look within, and fundamental to this process is the act of listening," said David Entwistle, president and CEO of Stanford Health

Care. "For months, the Commission on Justice and Equity has met with all community stakeholders to solicit their ideas and input. This dialogue must continue after the commission delivers its recommendations. Stanford Medicine has a tremendous opportunity to grow more inclusive through this journey and set an example for others."

"Diversity is not rocket science. It's harder," said commission chair Hudnell. "Stanford is trying to do, within the walls of its community, something that — it's clear if you just turn on the news — the world hasn't figured out how to do. But we have three leaders who are aligned in their mission. Now we need to devise strategies and actions that drive this alignment throughout the organization."

Preliminary ideas driven by the learning sessions include bolstering the organizational capability to promote diversity, equity and inclusion; working toward parity and equity for Black and underrepresented groups in the community; increasing trust and accountability around issues of equity and justice; and creating a coordinated, holistic approach to combating racial health disparities.

"Our leadership has put the institution's full weight behind confronting discrimination and creating a more just and equitable environment here at Stanford Medicine," said Priya Singh, the chief strategy officer and senior associate dean for strategy and communications. "Through the lens of our tripartite mission — research, education and patient care — the commission we've convened will help us strengthen our internal programs and identify opportunities to assert national leadership on addressing disparities that continue to harm the health of historically marginalized groups."

Mayes agreed. "Our country is different than it was a year ago; the campus climate is different; and the commitment by the three leaders of Stanford Medicine is sincere, authentic and unwavering. I do think this time we will see real, meaningful change. As an institution, we have committed to racial equity, diversity and inclusion, and we will continue to denounce racism in all its forms, including recent instances of anti-Asian violence," said Mayes. "But we aren't perfect. There is room to grow." **SM**

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# GROUNDING BY FAMILY

STORIES OF INDIGENOUS MIXTEC ANCESTORS HELP

MED STUDENT PERSEVERE IN COLLEGE

As a young child, first-year medical student Gianna Nino-Tapias frequently suffered from tonsillitis. Her mother called from their home in Oregon to Oaxaca, Mexico, to ask her own mother how to treat it. “Grill some tomatillos and add herbs,” Nino-Tapias’ grandmother said. “Place the mixture in a satchel and tie it around her neck. Have her sleep with it.”

The remedy didn’t help, so Nino-Tapias’ mother took her to a medical doctor. He recommended a tonsillectomy, but her mother refused. She mentioned the therapy she had tried, a tradition from her Indigenous Mixtec community.

“He was very dismissive. He mocked what she had done to try to cure me,” Nino-Tapias said, adding that it caused her to think about medicine as a career.

Pride in her Indigenous identity not only sparked Nino-Tapias’ path to medical school but it also carried her through rough spots in college. One day, she hopes, it will inform her care of other Indigenous people.



The women in Gianna Nino-Tapias’ family gave her courage to pursue her dream of being a doctor. ‘I learned I needed to find that tenacity, that persistence.’

The oldest of four children, Nino-Tapias was born in eastern Oregon, where her mother harvested crops. After Nino-Tapias’ sophomore year in high school, the family moved to a larger town in Washington, where she received help applying to college and was accepted to Stanford.

But in the scramble to satisfy her graduation requirements after transferring, she missed out on chemistry. She failed her first go at the subject in college and abandoned her plans for medical school.

“It almost destroyed me,” she said. “I felt like I didn’t belong, that I had gotten into Stanford by accident.”

Changing her career goal to public health, she traveled as part of a school program to Oaxaca, land of the Mixtec. They call themselves Ñuu Savi, people of the rain. “I went home. I learned where I was from, and that grounded me,” she said.

She visited her maternal grandmother, who never learned to read, grew up without running water and electricity, and wove palm leaves into baskets to sell. “I thought about all these women who came before me, and what they had to do to sustain their families,” Nino-Tapias said.

“My challenges in trying to get into medical school were very different but in some ways very similar,” she added. “I learned I needed to find that tenacity, that persistence.”

Deciding that she wanted to have a more direct impact on health, she took chemistry again and, she said, “I did fine.” She joined Stanford’s Natives into Medicine club and met Indigenous medical students who helped guide her through her undergraduate years. “They were amazing mentors,” Nino-Tapias said. “They taught me that I could pursue medicine as a career and not feel discouraged by an experience of failure.”

Last summer, Nino-Tapias found that a setback can lead to a windfall: Out of work because of the pandemic, she returned to Washington to pick blueberries alongside her mother. A tweet she sent out about farmworkers’ low pay went viral and, for a few weeks before school started, she became something of a celebrity, prompting donations to help her pay for medical school.

Now, as she delves into anatomy, biochemistry and physiology, Nino-Tapias reflects on the fact that her tonsillitis cleared up after a traditional healer rubbed an egg over her body and steamed herbs for her to inhale. She doesn’t know why she stopped suffering from bouts of fever and sore throat.

Regardless, she has resolved that she will respect the beliefs of her patients who turn to folk remedies. “I think the best way to serve them is to incorporate medicine with traditional healing,” she said. — MANDY ERICKSON

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# Seasonal shifts

BODIES DIVIDE THE YEAR IN TWO — AT LEAST IN PARTS OF CALIFORNIA

**Mother Nature's traditional signals** — think **crunchy leaves** or wildflower blooms — teach us that there are four seasons. But some bodies see it differently.

Stanford scientists have found that our bodies' molecular changes ebb and flow in patterns, but not necessarily in the way you'd think. According to their study of people from the San Francisco Bay Area and Southern California, the human body has two seasonal turning points: late spring-early summer and late fall-early winter.

The late-spring period coincided with a rise in molecules that play a role in allergies and arthritis. Come winter, scientists saw an increase in molecules that fight viral infection and in those involved in acne development. Signs of high blood pressure were also higher in the winter.

"Many of these findings open up space to investigate so many other things," said postdoctoral scholar Reza Sailani, PhD, a lead author of the study, published Oct. 1 in *Nature Communications*. "Take allergies, for instance," he said. Pairing readouts of molecular patterns with pollen count data could pinpoint specific allergy triggers.

More broadly, the findings provide insights for better drug trials. Researchers studying a drug for high blood pressure, for example, can factor in that blood pressure spikes in winter — so a Bay Area trial started then, rather than spring, would likely have a different result.



Researchers tracked molecular data from more than 100 people living in the Bay Area and three from Southern California over four years. In that time, more than 1,000 molecules waxed and waned over yearlong time spans, with participants experiencing the two key transitional periods.

"You might say, 'Well, sure, there are really only two seasons in California anyway: cold and hot.' That's true, but even so, our data doesn't exactly map to the weather transitions either. It's more complicated than that," said Michael Snyder, PhD, professor and chair of genetics, and senior author of the study.

One caveat, Snyder said, is it's likely that the molecular patterns of people in other parts of the country will differ, depending on atmospheric and environmental variations.

— HANAE ARMITAGE

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