VOLUME 18, ISSUE 1

Trusted Health MAGAZINE

Trusted Health Information from the National Institutes of Health



MEET NIH DIRECTORS

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Dr. Anthony S. Fauci, NIAID Dr. Griffin P. Rodgers, NIDDK Dr. Lindsey A. Criswell, NIAMS

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What to know about hearing aids and hearing health

Hidden costs of living with sickle cell disease

Zain Verjee: No longer hiding from psoriasis

COVER STORY

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Paralympic athlete and author **Amy Purdy** reaches new heights on prosthetic legs

In this issue

WELCOME TO VOLUME 18, ISSUE 1 OF NIH MEDLINEPLUS MAGAZINE.

This issue includes articles about prosthetic devices and other medical technology, autoimmune diseases, hearing loss, sickle cell disease, and environmental risks to your health. We also feature interviews with celebrities who share their own health experiences and with NIH Directors about their institutes' work.

Champion snowboarder, author, and motivational speaker Amy Purdy shares her story about using prosthetics. She talks about the experience of adapting her body and how gratitude helps her power through challenges. Plus, we share new research on NIH-supported ankle prosthetic technology.

Before he retired after more than 50 years at NIH, we snagged some time with Anthony Fauci, M.D., former Director of the National Institute of Allergy and Infectious Diseases. We look back on his career filled with groundbreaking research and what it means to him as a scientist.

Another Director featured in this issue is Griffin P. Rodgers, M.D., who leads the National Institute of Diabetes and Digestive and Kidney Diseases. He talks about the importance of training the next generation



of researchers and about his groundbreaking work on sickle cell disease treatment. Former sickle cell patient Tesha Samuels also shares her story of undergoing gene therapy to overcome this painful disease.

Have questions about autoimmune diseases? We have answers from all angles. International journalist Zain Verjee shares her story on psoriasis and how she found self-acceptance. We also have a helpful overview of autoimmune diseases and different NIH initiatives around them. Plus, Lindsey A. Criswell, M.D., M.P.H., D.Sc., Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, discusses the challenges of researching this important area of health.

Learn all about these and many other vital health topics in this issue of NIH MedlinePlus Magazine!

NIHMedlinePlus MAGAZINE

WHO WE ARE

The National Institutes of Health (NIH) is the **nation's premier medical research agency**, with 27 different Institutes and Centers. The National Library of Medicine (NLM) at NIH is a leader in biomedical informatics and data science research and the world's largest medical library.

NLM provides **free, trusted health information** to you at <u>MedlinePlus.gov</u> and in this magazine. Visit us at <u>www.magazine.medlineplus.gov</u>.

Thanks for reading!

CONTACT US

Email

NLMCommunications@nlm.nih.gov

Phone 301-496-6308

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National Institute of Allergy and Infectious Diseases



Anthony S. Fauci, M.D.

Anthony S. Fauci, M.D., former Director of the National Institute of Allergy and Infectious Diseases (NIAID), served the American public for more than five decades. A doctor, scientist, and infectious disease expert, he contributed to groundbreaking discoveries that saved countless lives. He retired from public service in December 2022.

Over the years, Dr. Fauci spoke with NIH MedlinePlus Magazine about antibiotic resistance, vaccines and community immunity, and the COVID-19 pandemic. He sat down with us again to reflect on his long career with NIH, discuss the challenges of science communication, and share his advice with young people who are interested in a career in science.

You've served the American public for more than 50 years. What has this work meant to you?

I've had the privilege and opportunity to spend my entire professional career—a total of 54 years—at NIH. It has been an extraordinary and rewarding experience that has allowed me to wear many different hats over the years. I first came on as a trainee, where I learned fundamental basics that I would use for decades. I was introduced to the disciplines of infectious diseases and immunology and the interface between them. I gradually worked my way to senior investigator, to section head, to lab chief, and finally to the Director of the institute.

It has meant everything to me; it's been my entire life.

What is your favorite memory from your time at NIH?

There are so many memories, or landmarks, that come to mind when I think about my long career here at NIH.

One that comes to mind is my early work on developing therapies for inflammatory vasculitis syndromes [a group of disorders that cause

inflammation of the blood vessels]. I worked with my original mentor Sheldon Wolff [M.D.] to develop a gamechanging therapy to successfully treat a disease that previously had a very high mortality rate.

Then when HIV came along, I turned my efforts to studying how it affected the body. This was important because understanding the virus better allowed us to begin developing interventions to prevent and treat it. So that's another memory that I hold dear.

When I became the Director of NIAID, we started an effort to develop safe and effective drugs for treating HIV. I'll never forget the moment [in 1996] when the results of the trial of the triple combination of drugs (including the protease inhibitors) came out. The feeling was just extraordinary: to see the results of a trial that now made it possible for persons living with HIV to live an essentially normal life.

Another very memorable point in my career-and in my life-was when [former President] George W. Bush asked me to help build the President's Emergency Plan for AIDS Relief (PEPFAR) program. I spent eight months working on that program which now, 20 years later, has led to saving 20 to 25 million lives.

MEET THE (FORMER) DIRECTOR

"

NIAID is truly an extraordinary institution. [Their] groundbreaking work... led to important discoveries that have saved many, many lives...

Most recently, there are the extraordinary results of the COVID-19 vaccines, which our group at the <u>NIAID Vaccine</u> <u>Research Center</u> played a major role in developing and which have saved the lives of millions of people.

There are painful memories as well. In the first few years of HIV, almost all of my patients admitted to the <u>NIH</u> <u>Clinical Center</u> died because we had no intervention. In fact, we were taking care of patients before we even knew that HIV was the cause of AIDS. When the virus was discovered in 1983 and 1984, then we were able to start doing things to counter this mysterious virus.

You've led and contributed to groundbreaking discoveries in infectious and immune-mediated diseases that have saved countless lives across the world. What does that mean to you?

It's very humbling to know that the work you are doing leads to saving actual lives, particularly being involved in something as expansive as PEPFAR. It's not something that you would brag about, but it's something that you feel honored to have had the opportunity to participate in. And [I'm] thankful for the many colleagues who helped along the way. Dr. Anthony Fauci, standing, presenting on HIV/AIDS to former President Bill Clinton, right, and former Vice President Al Gore, left, at the White House, 1996.



Dr. Anthony Fauci consulting with an AIDS patient, 1987.

What is something that you wish more people knew about NIAID?

NIAID is truly an extraordinary institution. The groundbreaking work by our own scientists—and the work that we funded through grants and contracts—led to important discoveries that have saved many, many lives not only here in the United States, but all over the world because of the global nature of infectious diseases.

You've spoken before about the importance of knowing your message, knowing your audience, and delivering that message to them clearly and concisely. Why is this so important, especially in science communication?

The purpose of communicating is for your audience to understand what you are talking about. You need to know who you are speaking to, and you've got to have a crystalclear message. If people don't understand what you're talking about, you are wasting your time and theirs.

Often, scientists instinctively want to show people how knowledgeable they are, [so] they speak in complicated terms and people have no idea what they are talking about.



I've learned that in any endeavor or aspiration in life, you will be more effective, accomplish a lot more, and feel better about what you do if you are passionate about it.

Dr. Anthony Fauci testifying at a U.S. House Appropriations hearing, 1987.

How do you balance the public's desire for quick results in solving health problems with the slow nature of research?

You communicate with them. You try to explain that the scientific approach often isn't linear, it's up and down and up and down. This isn't always intuitive to people. Science comes up with answers, but it isn't going to be quick. There are as many failures as there are successes on the road to understanding a particular issue related to a disease. Scientific discovery isn't all victory, and there are often a lot of disappointments.

What was the hardest lesson you learned in becoming a public figure for medical research?

You have to deal with an extraordinary amount of misinformation and disinformation that's being spread throughout the world. Social media in particular makes it possible for confusing bits of disinformation, conspiracy theories, and outright untruths to spread almost instantaneously. When you are a scientist, your goal is to use the scientific method to gather information, data, and evidence to improve people's health and lives. It is very difficult to fight against misinformation and disinformation. You've said that the next phase of your career will focus on advancing science and public health and on mentoring the next generation of scientific leaders. What would you say to young people considering a career in science, medicine, or public health?

A career in science and public health can be extraordinarily rewarding and gratifying. I've learned that in any endeavor or aspiration in life, you will be more effective, accomplish a lot more, and feel better about what you do if you are passionate about it.

If you are interested in a career in science, I encourage you to choose an area that you feel strongly about and that excites you. That excitement will generate the energy for you to perform at an even higher level than you would imagine.

Is there a final message that you would like to convey to the public that we haven't covered here yet today?

Yes—what an extraordinary institution NIH is. There is an electrifying, energizing atmosphere here on campus among so many bright, committed people. I don't think the rest of the world can fully appreciate how extraordinary this is and how fortunate those of us who have had the opportunity to be here are.

This interview has been edited slightly for length and clarity.



Paralympic snowboarder Amy Purdy isn't slowing down

The athlete and author discusses life with prosthetics and overcoming challenges

About 24 years ago, Amy Purdy lost her legs, spleen, and hearing in one ear from a deadly blood infection. Since then, she has won three Paralympic medals for snowboarding, advanced to the final round on Dancing with the Stars, and wrote the bestselling book On My Own Two Feet: From Losing My Legs to Learning the Dance of Life. She spoke with NIH MedlinePlus Magazine about her life's journey, using prosthetics, and her advice to others.

> Amy Purdy medaled in the 2014 and 2018 Winter Paralympic Games.

What happened that led to your needing prosthetics?

At the age of 19, I lost both of my legs to septic shock when I contracted a rare and deadly blood infection called <u>bacterial meningitis</u>. My body went into septic shock after just 24 hours of feeling like I had the flu, and I fought for my life in the hospital for two and a half months. I ended up losing my spleen, kidney function, hearing in my left ear, and both legs below the knees.

Was it difficult getting used to your prosthetics?

It will always take adjusting because your body changes, and so do your legs. It's not like you get your [prosthetic] legs fitted once and that's it, then, for the rest of your life. With prosthetics, you forever go through changes and making and adjusting legs. It's part of the process. However, mentally I adjusted right away to my new reality.

Do you use different prosthetics for different activities?

Yes. Different prosthetics work in different ways. When you run, you need prosthetics that are made of carbon fiber and can spring you forward. For snowboarding, there's an entirely different ankle motion needed, so you need a whole different type of foot to balance and bend at the ankle. And when you swim with prosthetics, there is an entirely different motion needed. Almost every activity—including walking—requires a different foot. "It's been a journey but another reminder for me of how incredible and adaptable the human body is."

How have your prosthetics changed since you began using them?

There have been some improvements over the last 20 years with how they fit the legs and what materials they use. I personally haven't seen a huge jump in technology for below-the-knee amputees [like me]. However, for above-the-knee and arm amputees, there are now very high-tech computerized limbs that have dramatically improved people's quality of movement and life.

You recently had to recover from several operations. How are you doing now?

In 2019, I severely injured my left leg, creating a massive blood clot. I almost lost my leg above my knee. It's been a massive journey over the last four years. I've endured 10 surgeries, including two new leg amputations, all to fight to save my leg. I am grateful to be doing well now. My body miraculously created an entirely new pathway for blood, and I'm now in the process of getting my prosthetic leg to fit properly. It's been a journey but another reminder for me of how incredible and adaptable the human body is.



By the numbers

- 2018 PyeongChang Paralympics—Silver medalist (snowboard cross), bronze medalist (banked slalom)
- 2017 World Championships—Bronze medalist (banked slalom)
- 2014 Sochi Paralympics—Bronze medalist (snowboard cross)
- 2012 World Championships—Silver medalist (snowboard cross)

SOURCE: Team USA

"Just continue to take one baby step at a time, and eventually you will get where you are meant to be. Keep going."

What is your message to everyone about facing physical and mental challenges in life?

When we compare ourselves to others or even to our old selves, it's the most self-sabotaging thing we can do. No matter what circumstances you're facing, you must remember to stay present. Take things day by day, one baby step at a time. Find things in your life to be grateful for and know that every day brings new light and opportunity.

How has gratitude been important to your success?

Gratitude is the key to happiness and success. You could have everything in the world, but if you don't have gratitude, you feel empty. You may have only a few things in your life, but if you are grateful for them, you live abundantly. Every morning, instead of thinking of all the negative things happening in your life, focus on all the positive things. This could be as simple as being grateful for your health or for your loved ones. That's a great daily practice because when you feel that gratitude in your heart from the moment you wake up, it influences your entire day.

Do you have specific advice for others who use or will use prosthetics?

Like everything else in life, it's a journey. Don't get discouraged. Just continue to take one baby step at a time, and eventually you will get where you are meant to be. Keep going.





When not on the slopes, Amy Purdy works as a motivational speaker, podcaster, and writer.

What does the future hold for you?

I am truly grateful for having accomplished so much in my life and living my dreams over and over again: winning three Paralympic medals, motivational speaking across the world, a New York Times bestselling book, and a wonderful life and marriage.

The next thing for me is to continue to help others do the same. I'm at the beginning of writing my second book, and I have plans to help people find their voice and use their own stories to impact the world.

Different prosthetics are needed for all types of physical activity.









Some examples of prosthetics for different physical activities.

How a prosthetic ankle improves balance control

Research funded by NIBIB discovers how a prosthetic ankle uses brain signals to improve posture and stability

hen someone loses a leg or other limb, a prosthetic device (a tool designed to replace a missing part of the body) can play a role in improving their quality of life by helping with mobility and stability. However, while most prosthetic devices are beneficial, current lower-limb devices can't provide continuous control of balance or posture. Without proper neural (brain and nerve) control, people with lower-limb devices are more likely to fall or have difficulty walking on certain surfaces.

Researchers funded by the National Institute of Biomedical Imaging and Bioengineering (NIBIB) are working on an ankle prosthetic that can use the remaining muscles—and the muscles' neural signals to improve amputees' stability and ability to hold an upright position.

How important are lower-limb prosthetics?

About 2 million people in the United States are living with an amputation, with lower-limb amputations being the most common. Many people choose to use a prosthetic device to help with walking and other types of movement.

What types of prosthetics are there?

There are a few kinds of lower-limb prosthetics:

- **Passive devices** are designed to support the body, but they generally do not move on their own. They can be static or adjustable and are usually designed to look like a natural limb. These devices are not powered and do not have a natural range of motion. Most lower-limb prosthetics are passive devices.
- **Powered devices** are designed to function more naturally. They can be controlled to move based on the movement of an amputee's residual limb (the part of the limb that remains after an amputation) or based on other signals from the body. These signals are measured with sensors, which feed information to a computer model to control balance and movement.

ARTIFICIAL LIMBS



Researchers are working on a brain-controlled ankle prosthetic that can improve mobility and postural control.

What is the research?

Electrical, or neural, signals that travel from our muscles to our brain help us move our entire body, including our limbs. Even after amputation, these neural signals play a major role in moving residual limbs. He "Helen" Huang, Ph.D., and her research group are developing a new computer model to control a lower-limb prosthetic device that anticipates the person's intended balance or motion. This system uses direct electromyographic (dEMG) control. In 2021, the research team released a <u>case study report</u> that evaluated how well a dEMG-controlled ankle prosthetic worked on a person with a transtibial amputation (where the limb is removed below the knee).

After an amputation, a person no longer has neural signals that once moved the entire limb, so they will generally need to build new signals to use their muscles in the residual limb differently. In Dr. Huang's system, dEMG sensors detect these new neural signals from the residual limb muscles. When initially using the dEMG-controlled ankle prosthetic device, the limb will move unnaturally while the computer model learns how the person intends to move it. People using a dEMG-controlled prosthetic would work with a physical therapist to help "train" their residual muscles to work with the device. This training will help the computer model better control the device to create a more natural balance and movement.



FAST FACT One of the first known prosthetics was a wooden and leather toe found on an Egyptian mummy that dates to **950-710 B.C.**

SOURCE: UNIVERSITY OF MANCHESTER



Even after amputation, electrical signals travel from our muscles to our brain to move residual limbs.

How does this dEMG prosthetic work?

- Researchers place surface electrodes (sensors) on the person's residual limb. These sensors detect electrical signals—the EMG—in a person's residual muscles.
- When the person contracts their residual muscle (like flexing their foot), the EMG activity is sent to a computer model.
- The computer model learns how to interpret the person's movement intentions to create a tailored dEMG prosthetic system.
- The dEMG controls the pneumatic artificial muscles (part of the prosthetic device that uses pressurized air to contract or extend), which allows the person to naturalistically control their ankle based on their intentions.

What were the study results?

The research team evaluated one person's stability when he used his passive prosthetic ankle and, after finishing physical therapy, when he used the dEMG-controlled prosthetic ankle. The study found that his stability while wearing the dEMG-controlled prosthetic ankle noticeably improved. He even had improved control when standing on a foam surface and with his eyes closed. The synchronization between his residual limb and the dEMG prosthetic was also much higher than it was with his usual passive device.

Researchers are now expanding this study to include several more people who have lost their lower limbs.

Meet the Director: NIH



National Institute of **Diabetes and Digestive** and Kidney Diseases



Griffin P. Rodgers, M.D.

How does an expert on blood diseases become the head of a "diabetes institute"? That's a question Griffin P. Rodgers, M.D., Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), hears a lot. Since 2007, he has led NIDDK's staff of nearly 600 people. He also made his own monumental contributions to sickle cell disease research. NIH MedlinePlus Magazine asked Dr. Rodgers about entering medicine and addressing health disparities, and he told us what advice he would give young researchers starting in the field today.

What drew you to study medicine?

I grew up in New Orleans. My father was a high school health and physical education teacher. My mother was a public health nurse, so I developed a love for science and health at an early age. Many of my mother's patients were from low-income households and often unable to come to clinics during the work week. She would sometimes visit their homes on weekends to provide care, give vaccinations to their kids, and that sort of thing. Seeing her give quality and compassionate care to all instilled in me a spirit of service to others, particularly to those who are medically underserved.

Then in high school, I had three close friends who had sickle cell disease. At that time, little could be done for this condition. Patients [with sickle cell disease] typically have periodic bouts of extreme bone and joint pain. All that could be done at that time was to give them strong pain medicines. Blood transfusion was also sometimes given to patients [for sickle cell anemia]. But very little could prevent or cure the disease. One of my friends died while I was still in high school, and the other two while I was in college. This experience drove me to medicine and hematology [the study of blood diseases].

In the Director's words

NIDDK's mission is to research some of the most common, chronic, costly, and impactful diseases nationwide: diabetes, obesity, kidney disease, metabolic disorders, liver disease, digestive diseases, nutritional disorders, urologic [related to the urinary system] conditions, blood diseases, and others. We want to **improve the health** and quality of life for people affected by these conditions. Learn more about this mission.

How did you end up at NIDDK?

During my medical residency at Washington University in St. Louis, Missouri, several mentors there suggested that I come to the National Institutes of Health. It was a cool place to do research in many fields, including in sickle cell disease. I contacted the head of the sickle cell disease branch in the Extramural Research Program at the National Heart, Lung, and Blood Institute, and they referred me to Dr. Alan Schechter [Chief of the Molecular Medicine Branch at NIDDK]. He had published an

"Seeing [my mother] give quality and compassionate care to all instilled in me a spirit of service to others, particularly to those who are medically underserved."

article on the status of research on sickle cell disease. I interviewed with his boss, I was offered a position that I accepted, and the rest is history.

How did your research impact therapies for sickle cell disease?

Dr. Schechter and I worked together to help develop hydroxyurea. This was the first effective, FDA-approved therapy for sickle cell anemia in adults. It dramatically improved patients' lives and their overall survival. The FDA approved hydroxyurea for adults in 1998 and then for children in 2017, because the earlier results were so promising. Thinking back now, had this drug been available when I was in high school, I still might have my friends to talk to today.

If people respond to it, hydroxyurea is a great drug for reducing a number of symptoms, including pain frequency, and increasing life expectancy. But it doesn't actually cure the disease. To cure sickle cell disease, you have to replace the stem cells in the bone marrow. [From 2004 to 2013, our team, led by Dr. John Tisdale and Dr. Matt Hsieh] developed <u>ways to use bone marrow stem cell transplants</u> to expand the possibility of curing the disease.

You were recognized for this work while also serving as Director of NIDDK. What have you learned about yourself as a leader?

What I've discovered is that it is good to be able to multitask. When you're a researcher in the laboratory, you focus on particular conditions that you may—if you're lucky—be able to make a major imprint on. Being an administrator for science, grants, contracts, and more, you can make a lasting contribution potentially to millions, perhaps hundreds of millions, of people worldwide.

Boosting health equity at **NIDDK**

Strategic Plan for Research

Published in 2021, this five-year plan is meant to guide NIDDK's mission to better understand biological and environmental contributors to health and disease. Many diseases under NIDDK's mission are connected. Understanding outcomes of one condition could teach researchers about another. The plan also makes recommendations to diversify the biomedical workforce, and to diversify participation in clinical trials. <u>Read the</u> <u>full plan here</u>.

Health Disparities and Health Equity Research Implementation Plan

Expected to publish this spring, this is the first plan of its kind from NIDDK. Researchers and community members nationwide are working together to identify needed research on health equity and health disparities. This research can impact NIDDK's work tackling specific diseases and conditions. The plan will also include strategies to put this research into action. Learn more about this plan.

To read Dr. Rodgers' advice for aspiring researchers and how he unwinds from work, check out his full interview online at <u>NIH MedlinePlus Magazine</u>!

HEALTHY

shares reliable information in quick bites

NIDDK's weekly wellness radio series reaches audiences across the nation

etting the word out about science-based, healthy lifestyle tips is a challenge. People are short on time and bombarded with information from unreliable sources. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) wants to cut through the noise.

Every week, the *Healthy Moments* radio broadcast shares valuable information in one-minute episodes. NIDDK Director Griffin P. Rodgers, M.D., hosts the series and often features special guests. The show covers topics related to NIDDK's mission and the conditions they study.

Healthy Moments premiered in 2008 on one station in Washington, DC. Episodes have focused on diabetes, healthy eating and weight management, digestive diseases such as irritable bowel syndrome and celiac disease, liver disease, and prostate health, among others. Episodes have also covered what it's like to participate in clinical trials at NIH. Listeners can learn how NIDDK works to improve equity and diversity in health care and in the biomedical research workforce.

Over the past decade, we've **grown** to about **60 million** listeners.



NIDDK Director Dr. Griffin P. Rodgers hosts *Healthy Moments* each week.

"Over the past decade, we've grown to about 60 million listeners. *Healthy Moments* is syndicated on stations across the country, particularly in areas with the highest rate of conditions within NIDDK's mission," Dr. Rodgers said.

Past celebrity guests include Barbra Streisand, Sugar Ray Leonard, Debbie Allen, and Laila Ali. NIH researchers and directors also share their expertise in an easy-to-understand, quick format.

The show airs on <u>select radio stations</u> in Atlanta, Baltimore, Cleveland, Dallas, Houston, and Washington, DC. Episodes also air alongside these nationally syndicated radio shows:

- Rickey Smiley Morning Show
- Willie Moore Jr. Show
- Get Up! Mornings with Erica Campbell
- Keepin' It Real with Rev. Al Sharpton

If your local radio does not broadcast *Healthy Moments*, you can <u>stream episodes</u> on NIDDK's website. Check out some videos—including some Spanish-translated episodes—on the institute's <u>YouTube channel</u>. NIDDK also provides text transcripts of each episode.

Listen now and understand your health better!

Meet the Director:



National Institute of Arthritis and Musculoskeletal and Skin Diseases



Lindsey A. Criswell, M.D., M.P.H., D.Sc.

Despite major progress, much is still unknown about the nature of disease. Lindsey A. Criswell, M.D., M.P.H., D.Sc., Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), encourages researchers she supports to think outside the box. Dr. Criswell talked with NIH MedlinePlus Magazine about how diverse ideas can help us better understand conditions such as autoimmune diseases (when the immune system attacks healthy cells by mistake) and initiatives that promote diversity and inclusion in research.

How does your background influence your approach to leading NIAMS?

When I was young, I was interested in nature and biology and how the world works. I was fascinated by the concept of nature versus nurture. All those things inspired me to initially pursue science and then genetics specifically. Then I pursued medicine so that I could help take care of people affected by rheumatic diseases (which cause inflammation of the bones, muscles, joints, and internal organs). But I also wanted to contribute to these fields as a researcher.

As my career and training evolved, I learned that working as part of a team was the best way to do good research. You need collaboration and a culture that recognizes contributions to keep people productive. You also need to have good leadership.

I was not initially drawn to leadership, but I realized that I had insights about the environment and culture and the values and priorities that help people work well together. Leadership opportunities came up, and someone had to do them. I cared deeply for the success of these efforts, so why not me?

How would you describe the mission and focus of NIAMS?

The name "NIAMS" clarifies the scope of the institute, which is very broad as it includes arthritis, the musculoskeletal system, and skin. That's a lot of the body. Within each of those categories are many types of conditions, some that are rare and some that are common. Some appear earlier in life; others appear much later in life. Most of those conditions are influenced by <u>social</u> <u>determinants of health</u>, including some that are more likely to affect underrepresented racial and ethnic minority groups.

Even though most of the conditions NIAMS studies are not deadly, they have a profound impact on individuals, families, and our communities.

Leadership opportunities came up, and someone had to do them. I cared deeply for the success of these efforts, so why not me?

What is the most challenging part of researching genetics and autoimmune diseases?

One of the challenges is that conditions that affect humans are complicated. Even diseases that we think are caused by a particular infection, abnormalities, or variations of a gene are complex. They do not behave the same in individuals who are affected by them. So, even when we think we have a good handle on the root cause, many other factors influence who is going to be affected—how ill people become, their long-term outcomes, and how they respond to treatments all vary.

While genetics are important, they're also very complex. Hundreds of genes contribute [to illness] in subtle ways and in ways that we don't fully understand. New tools and technologies are being developed every year, which is fantastic, but it's a challenge to keep up with how to use them. We're constantly thinking in new and creative ways about how to answer some of these questions [about disease], how to solve some of these problems.

Progress requires teams of people with different backgrounds—clinical, data analytics, patient engagement. Pulling together this diverse team is hard, but it also makes work in this area fun and rewarding.

What would you like people to know about arthritic, skin, and musculoskeletal diseases?

It is important to make the public aware of these conditions and how to get an early diagnosis and timely treatment.

These conditions interfere with quality of life because they can cause tremendous pain, disability, and suffering. They are responsible for a lot of lost productivity, which has a major economic impact for individuals, employers, and the health care system.

We have a basic understanding of [these] diseases and conditions, but the way we define or distinguish conditions is based on incomplete knowledge of what causes them.



NIAMS Director Dr. Lindsey A. Criswell hiking Mount Whitney in the Sierra Nevada mountains, California.

We don't have a perfect correlation between the biology of the disease and how we define it. That interferes with effective research. So, we really need to think outside the box and think creatively about the diseases and conditions that we study.

How is NIAMS helping to eliminate health disparities?

It's striking how much some of the diseases within our mission affect individuals from underrepresented racial and ethnic minority groups or individuals with low socioeconomic status.

An example is <u>lupus</u> (an autoimmune disease where the immune system mistakenly attacks healthy cells). Lupus appears to affect individuals of non-European ancestry around the world much more frequently than those of European ancestry. But it's not as simple as what continent your ancestors came from. Social determinants of health [include] things such as nutrition status and exposures to toxic factors in the environment—both of which can have an impact even in the womb. Educational opportunities and access to timely and high-quality [health] care—those factors have an important role in lupus.

Outcomes are affected by how quickly a disease is diagnosed, how effectively it's treated, and the timeliness of the treatment. Even more difficult than figuring out how to understand these things is how to have an impact. How do we, as a health funding and training institute, impact social determinants of health? Can we have an impact through health care systems? If we can do that, what partners do we need to try to do that?

To learn more about NIAMS research initiatives and how Dr. Criswell takes a break from work, check out her full interview online at NIH MedlinePlus Magazine!

Zain Verjee

is no longe hiding from psoriasis

Long-time international TV news anchor shares her story

s a leading international journalist on CNN and other major television news outlets, Zain Verjee's face was visible to millions of people every day. But she "spent a lifetime hiding" as she dealt with psoriasis, a chronic skin disease that causes itchy or sore patches of thick, red skin with silvery scaling. She shared with NIH MedlinePlus Magazine how she manages both the physical and emotional impacts of the autoimmune disease and her advice for others facing the condition.

You've had psoriasis since age 8. How were you first diagnosed?

In 1982, I developed a lot of small red dots on my skin. At first we thought it was simply a rash. But when silvery scale started to emerge, my mother took me to see a dermatologist, and I was diagnosed with psoriasis.

What are some physical effects of your psoriasis?

The severity of the disease changes based on weather, treatment, and stress. The physical impact was largely when my arms and legs were covered in thickened, dry skin. It was not possible for me to wear clothing that exposed my skin. It was too embarrassing. At the time, there wasn't the understanding of the disease that there is now. To be honest, the impact was more psychological than physical, although the itching and constant physical discomfort was there.

We don't often discuss the mental health effect of physical health conditions. Would you talk about that?

Yes, the mental health effect is so important. I spent much of my professional career on international television with my face visible to millions of people each day. Yet I spent a lifetime hiding.

Zain Verjee speaks at the Unstoppable

Africa Conference in 2022.



FAST FACT Psoriasis may be triggered by stress, injury to the skin, cold weather, illness (if it affects the immune system), allergies, or certain foods and alcohol.

SOURCE: National Psoriasis Foundation

As a young woman in my teens, covered in dry lesions, I felt unattractive and grappled with issues of self-worth. I would bottle up a lot of rage and anger that sometimes turned violent because I was so frustrated. I would hit my skin and loathe it, which led to body image issues.

I felt like I was always lying and leading a dual storyline. I had a lovely face, which was what people related to, yet my skin was flaring up underneath. So who was the real me? I was constantly split and felt like there was always this ugly secret. There were always strategies to hide my skin when swimming or during the summer or at the beach.

I can also function perfectly well in total darkness, and sometimes I still forget to turn on the lights. I always kept the lights off because I never wanted to see my own skin. My family—particularly my mother—was the reason I was able to overcome all of this both physically and psychologically. The support from loved ones around you is critical from a mental health standpoint, and I was fortunate to be able to receive that.

How are you doing now? Are you still affected by psoriasis?

Yes, I am still living with psoriasis, but much less so. I use biologic medication to control my skin disease. While I fear the long-term impact of this, the medication does help. I do still get scale sometimes on my scalp, ears, or stomach and lately on the soles of my feet, although I don't know why.

What is your message to others who have psoriasis and related autoimmune diseases?

There are new treatments that work, so be optimistic. Reach out to friends, organizations, or professionals if you're experiencing severe mental health issues. Connecting with others who have the condition is important, too. It makes a difference because you can relate to the same feelings and experiences. Make self-care a priority. Diet, meditation, and exercise truly have had a significant impact on me in managing psoriasis.

You are not alone—you are beautiful just the way you are.



Zain Verjee, right, with Grammy Award-winning singer and UNICEF Goodwill Ambassador Angélique Kidjo.

"You are not alone—you are beautiful just the way you are."

By the numbers

- Approximately **7.4 million** adults in the United States have psoriasis.
- Psoriasis occurs in all age groups but the highest proportion of cases is between **ages 45 and 65**.
- Approximately **10% to 20%** of people with psoriasis experience joint inflammation that produces symptoms of arthritis (known as psoriatic arthritis).
- In 2013, the total direct cost of treatment associated with psoriasis in the United States was estimated to be between \$51.7 billion and \$63.2 billion.

SOURCE: <u>Centers for Disease Control and Prevention;</u> American Academy of Dermatology



Your immune system is supposed to keep you healthy. What happens when it turns against you?

Autoimmune conditions can cause symptoms like pain and swelling in the muscles and joints.

our immune system's job is to keep you healthy by detecting and fighting harmful intruders such as bacteria and viruses. If you have an autoimmune disease, your immune system mistakenly attacks your body's healthy cells, tissues, and organs.

There's no cure for autoimmune diseases—at least not yet—but there are treatments to help manage their symptoms. Getting diagnosed and starting treatment as soon as possible can help prevent more severe damage further down the road.

How do autoimmune diseases work?

The immune system is a network of cells and organs that work together to fight infections and protect the body against diseases. For example, the skin and mucus membranes help prevent harmful germs from entering the body, and the organs and tissues of the lymphatic system (including the spleen, tonsils, thymus gland, bone marrow, and lymph nodes) create and store the white blood cells that fight infection.

In a healthy immune response, the immune system creates lymphocytes (a type of white blood cell) and antibodies (protective proteins) that identify unfamiliar substances called antigens and attack them in order to protect the body.

Typically, the immune system can tell the difference between the body's own cells and tissues and potentially harmful intruders such as viral and bacterial antigens. In people with autoimmune conditions, the immune system gets confused and produces autoantibodies, a type of antibody that attacks healthy cells and tissues. This can lead to inflammation in different parts of the body, harm the body's organs and systems, and contribute to a wide range of symptoms.

Immune system



Your immune system's job is to keep you healthy by detecting and fighting harmful intruders such as bacteria and viruses.

What are the different types of autoimmune diseases?

There are more than 80 known autoimmune conditions, which together affect more than 23.5 million Americans. Each disease is different, but what they all have in common is a haywire immune response that turns the immune system against the body it is supposed to protect.

Some conditions target specific organs or tissues, such as the skin, heart, or blood vessels. Others are more general, targeting multiple tissue or organ systems throughout the body.

Examples of common organ-specific conditions include type 1 <u>diabetes</u> (pancreas), inflammatory bowel diseases such as <u>Crohn's disease</u> and <u>ulcerative colitis</u> (digestive tract), and <u>multiple sclerosis</u> (brain and spinal cord). Systemic conditions—those that attack multiple systems—include systemic lupus erythematosus, also known as <u>lupus</u> or SLE, <u>Sjögren's syndrome</u>, and <u>scleroderma</u>, which all affect tissues and organs throughout the body.

What causes them?

While scientists and doctors aren't exactly sure what causes autoimmune diseases, they are likely triggered by interactions between genes, the immune system, and the environment.

There's still a lot to learn about these relationships, but experts think that even if a person with certain genes or certain combinations of genes is at risk of an autoimmune disease, they probably won't develop the condition without something in their environment triggering it or turning it on. Environmental triggers may include:

- Infection (from a virus or bacteria)
- Stress
- Dietary components (such as gluten or dairy)
- Contaminants in food (such as mercury in fish)
- Environmental pollutants (such as certain pesticides)

Who is at risk?

Autoimmune diseases tend to run in families. You're more likely to develop one if you:

- Have a family member with an autoimmune disease
- Are already diagnosed with one or more autoimmune diseases

Also, your racial and ethnic background, assigned sex, and age may make you more or less likely to develop certain autoimmune diseases. For example, many kinds of autoimmune diseases such as lupus, scleroderma, and Sjögren's syndrome are far more common among women than among men.

Because specific viruses or environmental conditions may trigger autoimmune diseases, the risk of certain autoimmune diseases may be higher in people who are more likely to be exposed to those triggers.

What are the symptoms?

Autoimmune diseases can affect different parts of the body. Their symptoms can be similar and even vague, and specific symptoms may not even look the same for every condition. Many of the most common ones—such as fatigue, joint pain, and muscle pain—could also be symptoms of other conditions.

Most autoimmune diseases cause inflammation, so people with autoimmune diseases often experience heat, pain, or swelling (which are all signs of inflammation) in the part of the body that's affected. Other common symptoms include:

- Fatigue
- Low-grade fever
- Losing or gaining weight
- Dizziness
- Swelling or pain in muscles or joints
- Difficulty thinking clearly or paying attention
- Rashes
- Digestive problems (such as bloating, cramping, diarrhea, or constipation)

People with autoimmune conditions often experience symptoms in cycles, and symptoms can change over time. Even with treatment, there may be periods of time where symptoms worsen or new symptoms appear (flares), followed by periods of remission where they disappear or become less intense.

How are autoimmune diseases diagnosed?

For many people with autoimmune symptoms, getting an accurate diagnosis can be difficult, time-consuming, and stressful.



Autoimmune diseases affect more than **23.5 million Americans**. Certain groups of people are at greater risk for some conditions. For example, lupus is more severe for African American and Hispanic people, while type 1 diabetes is more common in White people.

SOURCE: THE OFFICE ON WOMEN'S HEALTH

To diagnose an autoimmune disease, a health care provider will do a physical exam and ask you about your symptoms, your medical history, and your family's health history, including if others in your family have been diagnosed with one or more autoimmune diseases. Depending on your symptoms and background, they may recommend blood tests, imaging, or other diagnostic tests.

How are they treated?

There's no cure for most autoimmune diseases, but there are treatments to help people who have them address and manage their symptoms. Treatments vary depending on the disease and how the individual is affected.

You and your health care team can work together to create a treatment plan that works best for you, your lifestyle, and your symptoms with the fewest possible side effects. This could include pharmacological (drug-based) medicines that:

- Reduce pain (such as nonsteroidal anti-inflammatory drugs)
- Control inflammation (such as corticosteroids)
- Inhibit the immune response (such as immunosuppressants) In addition to these treatments, there may be certain activities, diets, and long-term lifestyle changes that can help you manage your symptoms and feel better. ■



What kinds of doctors diagnose and treat autoimmune diseases?

In addition to your primary care provider, you may work with one or more specialists, including:

- Immunologists (for immune system disorders)
- Rheumatologists (for rheumatic diseases such as arthritis and other inflammatory disorders)
- Endocrinologists (for glands and hormones)
- Hematologists (for blood disorders)
- Neurologists (for nervous system disorders)
- Cardiologists (for diseases of the heart and blood vessels)
- Gastroenterologists (for the gastrointestinal tract)
- Dermatologists (for skin diseases)





Some autoimmune diseases target specific organs or tissue, while others attack multiple tissue or organ systems throughout the body. Here's what you need to know about five common conditions.

Disease or condition	What's affected?	Who can develop it?	What are the symptoms?	
Lupus A chronic (long-lasting) disorder that causes damage to multiple areas of the body.	Connective tissue in almost any organ or system of the body.	 Anyone can develop lupus, but it's most common in: Women People between ages 15 and 45 African Americans, Native Americans, Alaska Natives, Native Hawaiians, and people of Asian descent People who have a family member with lupus or another autoimmune disease 	 Common symptoms include: Joint pain or swelling Muscle pain and weakness Fever Sun sensitivity Red rash (such as "butterfly" rash on the nose and cheeks) Swollen lymph nodes Fatigue and general malaise (feeling unwell) Sores in the nose and mouth Other symptoms depend on what parts of the body are affected. 	
Sjögren's syndrome A chronic disorder that causes damage to the glands that create moisture and lubrication (particularly tears and saliva).	Primarily the eyes and mouth, but it can also affect parts of the body like joints, lungs, and muscles.	Most people with Sjögren's syndrome are women. It is usually diagnosed after age 40.	The most common symptoms are dry eyes and mouth, pain in the joints or muscles, and severe fatigue. Other symptoms may include itchy skin, nasal irritation and nosebleeds, and dry cough.	
Rheumatoid arthritis (RA) A chronic disorder that causes damage to joint tissue.	Primarily targets the body's joints (usually on both sides of the body) and the tissues around them. It may also affect other systems of the body, such as skin, eyes, lungs, heart, and blood vessels.	RA is more common in women than in men. The risk increases as you get older, but you can develop it at any age.	The most common symptoms are swelling, pain, and stiffness in joints (typically in the wrists, hands, feet, spine, knees, or jaw). RA causes swelling in the lining of the joints, which can lead to harmful structural changes in the bones and joints over time.	
Psoriasis A chronic disorder in which an overactive immune system causes skin cells to multiply and rise to the surface of the skin too quickly.	Skin.	Anyone can develop psoriasis, but adults have it more often than children.	Itchy or sore patches of thick, red, scaling on the skin.	
Psoriatic arthritis A chronic autoimmune form of arthritis that affects the skin and joints. It can worsen over time.	Skin and joints.	Psoriatic arthritis is more common in adults than in children. Most people who develop psoriatic arthritis already have psoriasis. It can be triggered by stress, physical trauma, or infections.	 Common symptoms include: Pain, stiffness, and swelling in joints (on one or both sides of the body) Pain and swelling in other parts of the body, such as hands, feet, and low back Itchy or sore patches of thick, red, scaling on the skin 	

From discovery to treatment: How NIH works to improve the lives of people with autoimmune diseases

NIH supports research and initiatives to improve our understanding of and treatments for autoimmune diseases

utoimmune diseases are a group of chronic disorders in which the body's immune system mistakenly attacks and damages healthy cells and tissues. These conditions can impact almost every part of the body and can be difficult to diagnose and treat.

Thanks to scientific and technological advances, we've learned a lot about how processes in the body and the environment contribute to autoimmune diseases. But there's still much more to discover. We need better tools to study, diagnose, and treat these challenging diseases.

Researching autoimmune diseases at NIH

Institutes and centers across NIH conduct and support research on different aspects of these complex conditions, including:

- Autoimmune conditions that affect different parts of the body such as:
 - The bones, joints, muscles, and skin
 - The heart, lungs, and blood
 - The nervous system
 - The eyes
 - The mouth, jaws, teeth, face, and head
 - The kidneys, digestive system, and endocrine (hormone) system
- The immune system and its role in immunological and allergic diseases
- Autoimmune diseases that become more common with age
- Genetic factors involved in developing autoimmune diseases

GETTY IMAGES

MAGE CREDITS:

- The role of environmental triggers in autoimmune disease development
- The link between cancer and the immune system



NIH-supported research and initiatives lead to new insights and treatments for autoimmune diseases.

"AMPing" up progress, together

NIH advances scientific progress for autoimmune conditions through the <u>Accelerating Medicines Partnership</u>[®] (AMP[®]) program. AMP brings together government agencies and other organizations to share resources and expertise to develop new treatments and diagnostic tools. The goal is to identify and test promising targets for drug development and get new, effective treatments to people who need them.

Sharing resources and data and identifying new targets for health conditions

Identifying promising treatment targets for autoimmune diseases can lead to more targeted and effective tools for diagnosing and treating them. Pooling resources, expertise, and data allows AMP teams to identify and study new biomarkers (measurable biological substances in the body, such as genes, proteins, and other molecules). Changes in certain biomarkers are associated with developing different diseases. Doctors and scientists can use this information to help diagnose diseases and study how people respond to treatments. Biopharmaceutical companies can use it to develop drugs that cure a disease or manage its symptoms.

An important component of the AMP program is making biomarker data available to the research community. Scientists use this data to uncover important clues about the specific cells, pathways, and processes that cause inflammation and disease, including:

- What they have in common
- How they contribute to individual diseases
- How they respond to different treatments

To build on this work, in 2021, AMP launched the <u>Accelerating Medicines Partnership® Autoimmune</u> <u>and Immune-Mediated Diseases</u> (AMP® AIM) program. AMP AIM expands a previous AMP program to include a total of five common autoimmune diseases: rheumatoid arthritis, lupus, psoriasis, psoriatic arthritis, and Sjögren's syndrome.

This program will lay the groundwork for new discoveries of what these conditions have in common, how they differ, and their similarities to other kinds of diseases.

Developing new tools to speed up discovery

Experts will use new, advanced research tools to discover how these diseases cause problems like inflammation, injury, abnormal function, and illness in the body.

Additionally, the AMP AIM project is developing tools and resources to help researchers access and analyze biological data and information about them.

These discoveries can contribute to the development of new treatments for autoimmune diseases by revealing new clues about the specific cells, pathways, and processes involved when someone with an autoimmune disease experiences symptoms such as pain, swelling, and stiffness.



NIH institutes, centers, and offices that support AMP AIM include:

- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- National Institute of Dental and Craniofacial Research
- <u>National Institute of Allergy and Infectious</u> <u>Diseases</u> (NIAID)
- Office of Research on Women's Health (ORWH)

Collaborating for a cure

Other NIH-supported programs work to deepen our knowledge of autoimmune illnesses and create effective treatments for them. Here are just a couple of examples.

The <u>Autoimmunity Centers of Excellence</u> (ACE) program brings together experts from diverse scientific and medical backgrounds. The ACEs encourage collaboration on research into different aspects of autoimmune diseases, including effective ways to prevent and treat them. Find an ACE clinical trial. The <u>Immune Tolerance Network</u> (ITN) is a collaborative network for clinical researchers. It develops and funds research about immune tolerance in autoimmune diseases, allergies and asthma, and organ transplantation.

Immune tolerance is the immune system's ability to tell the differences between "self" (substances that are part of the body) and "non-self" (harmful intruders). Immune tolerance treatments aim to change the immune system to stop it from attacking the body's healthy tissue without compromising its ability to fight disease. Learn about ITN clinical studies.

NIAID oversees the ACE program, which is also supported by the National Institute of Diabetes and Digestive and Kidney Diseases and ORWH. NIAID also funds the ITN.

IMAGE CREDITS: GETTY IMAGES

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When both parents have sickle cell trait, they have a 25% (1 in 4) chance of having a baby with sickle cell disease with **each** pregnancy.

SOURCE: <u>Sickle Cell Disease</u> <u>Association of America, Inc.</u>

The costs of living with sickle cell disease in the United States

Sickle cell disease is more than an illness—it's a financial strain, too

In the United States, more than 100,000 people are living with sickle cell disease. Sickle cell disease is a group of inherited blood disorders that affects hemoglobin (the protein in red blood cells that carries oxygen throughout the body). Sickle cell disease is a lifelong illness that can lead to stroke, eye problems, infections, and episodes of extreme discomfort called "pain crises." While people who have sickle cell disease are physically affected, this illness is also a financial strain. On average, Americans ages 64 and younger who live with

sickle cell disease pay almost four times more in out-of-pocket expenses for health care than those without the disease. In 2022, researchers supported by the National Heart, Lung, and Blood Institute (NHLBI) conducted a <u>health care spending</u> <u>analysis</u> that recognized the hefty medical costs of living with sickle cell disease.

The study also found that much of these costs peak between the ages of 13 and 24, a time when many people with sickle cell disease are transitioning from pediatric to adult care. This switch can lead to an increase in medical visits due to

RESEARCH HIGHLIGHTS

challenges connecting with the right specialists and providers. Research shows that many people with sickle cell disease experience stigma and racial disparities when seeking care for pain, which often causes them to switch providers, too.

It's important to note that these statistics are limited to commercial health insurance, which is only used by one-third of people



Red blood cells that are "sickle" shaped can block the flow of blood through the body causing recurring episodes of pain.

with sickle cell disease. Health care costs vary and could be higher for those using Medicaid or Medicare and for those who don't have health insurance.

Reducing the costs with new treatments

There are a few current therapies used to treat the symptoms of sickle cell disease, but they are not recommended for everyone. With limited treatment therapies available, the costs of living with sickle cell disease remain high. Researchers are seeking new ways

to help treat sickle cell disease while easing the financial burden on people living with it.

Gene therapies and treatments could greatly reduce the current costs of treating sickle cell disease. In 2018, NHLBI established the Cure Sickle Cell Initiative, a research partnership created to find curative therapies for sickle cell disease. The

initiative has also announced the launch of the Gene therapy to Reduce All Sickle Pain (GRASP) Trial, which is designed to test whether gene therapy can improve or even eliminate painful episodes. This therapy will be tested in a clinical research study between 2023 and 2028.

With new advancements in genetic therapy, researchers are finding ways to provide accessible treatment to the more than 100,000 people in the United States living with sickle cell disease.



MAGE CREDITS: TOP, DARRYL LEJA, NATIONAL HUMAN GENOME RESEARCH INSTITUTE; BOTTOM, GETTY IMAGES



Tesha Samuels advocates for others after living with sickle cell disease

Now in remission, Samuels shares her experience of living with her sickle cell diagnosis

After living with sickle cell disease for decades, Tesha Samuels underwent gene therapy at NIH.

ickle cell disease affects more than 100,000 people in the United States every year, and for three decades, Tesha Samuels was among them. After going through a gene therapy program funded by the National Heart, Lung, and Blood Institute (NHLBI), Samuels is in remission and relatively pain-free.

Pain is the most common complication of sickle cell disease. Sickle cells traveling through small blood vessels can get stuck and block blood flow throughout the body, which causes pain. Pain can occur in any part of the body but most commonly occurs in the hands, feet, chest, and back.

Now Samuels has a new outlook on life and is finally doing everything that sickle cell disease held her back from. She talked with NIH MedlinePlus Magazine about her experience with sickle cell disease and her life after treatment.

When and how were you diagnosed with sickle cell disease?

I was diagnosed in 1984 when I was 2 years old. I was born prior to the newborn screening mandate, so I wasn't tested at birth. At the time, I had a lot of health issues my first couple years, and I visited the doctor's office often. Finally, my mom took me to a physician who questioned if I had been tested for sickle cell disease. My mom didn't know what sickle cell was at the time. Both my mom and I were tested. She tested positive as a carrier, and I tested positive for sickle cell disease. The trait for sickle cell is quite strong on my maternal side—my mother, grandmother, and great-grandmother all have it. But I'm the only one in my family who has sickle cell disease.

What symptoms did you first notice?

I was very young at the time of my diagnosis, but I remember it was very easy for me to catch a common cold or type of infection. As an infant, my mother told me that despite having all of the basic needs met like food and

"I did a lot of masking. I masked the pain often, and I was in excruciating pain daily. Eventually you become numb, not to the pain, but to the way you respond to the pain."

hygiene, it was very difficult to comfort me. She also noticed that I would wince when picked up. I believe that I was experiencing pain even as an infant.

As a toddler, she noticed I also fell down a lot but until the diagnosis, there wasn't really an explanation. My family did a great job of helping and supporting before the diagnosis but I can imagine it was difficult.

How did your diagnosis affect your dayto-day life?

When you have sickle cell disease, you always know you're different. As a preteen and moving through my teenage years, I did a lot of masking. I masked the pain often, and I was in excruciating pain daily. Eventually you become numb, not to the pain, but to the way you respond to the pain. Sometimes the pain can keep you in bed, but I didn't make that an option for myself. Instead of allowing the pain to keep me in bed, I would ask myself, "What can I do to help myself feel normal? What can I do to have a sense of normalcy in my life?" I created routines that would help me respond to and cope with the pain. This routine carried me through my adult years. Most people I interacted with outside of my family didn't know how much pain I was really in.

What was your treatment like before undergoing gene therapy?

My treatment plan included a lot of pain medication not necessarily because I desired it, but because I really needed it. Unfortunately, as time goes on, it feels like the medication isn't as effective, so the dosage needed to achieve some level of relief needed to be increased. For



Red blood cells that are "**sickle**" shaped block blood flow through the body, causing recurring pain episodes.

> SOURCE: National Heart, Lung, and Blood Institute

me, the pain was so bad and deep that it could almost take my breath away if I didn't have some pain medication to relieve it.

In addition to medication, blood transfusions were a part of my treatment. When I was 13, I had a *transient ischemic attack* (similar to a stroke). After that, I was doing routine blood transfusions to try to prevent that from happening again. The transfusions helped increase my *hemoglobin* (a protein in the blood that carries oxygen from the lungs to other organs) and *hematocrit* (the ratio of red blood cells to total blood volume). These provided more oxygen to the blood and gave me more energy. I would feel great for about two to three weeks, but of course, blood cells die off. I could literally feel my energy being depleted as my blood cells depleted. I did blood transfusions right up until the year I started undergoing gene therapy. I was doing monthly transfusions from ages 13 to 36.

"I've always had a zest for life, but it's always been in the background. But now I can go full steam ahead with my goals and ambitions."

Can you describe your experience undergoing gene therapy?

Gene therapy was a beautiful blessing, but between the <u>busulfan</u> chemotherapy and the other medications they give you to help offset potential problems, the process was also very grueling. I was just really tired all the time. I had no energy. The great thing is that I have an amazing support system and my treatment was right before COVID-19, so I was able to have visitors. But just like sickle cell disease, no one can truly understand the feeling of undergoing the therapy. Regardless, I felt that if I could live with sickle cell disease for 36 years, then I could survive three months of treatment.

It was a painful daily process to allow the treatment to do its job. The pain was deep and sharp, and I was experiencing the effects of the chemotherapy. There were issues like the inability to swallow from my esophageal lining (in the tube that connects the throat and the stomach) being inflamed or having a terrible nosebleed from the busulfan.

There were a lot of processes to experience. From the medical processes of undergoing the treatment, to the process of going home and learning the new normal. It's a transition from the physical to the mental. There's a shift in both, and that's a process that I grapple with daily. So, after living with this disease for 36 years, I now look forward to a life with new opportunities to finally do the things that I've always wanted to do. I've always had a zest for life, but it's always been in the background. But now I can go full steam ahead with my goals and ambitions.



Tesha Samuels leans into advocacy to ensure that sickle cell illness doesn't become a forgotten disease.

Since going into remission, do you still experience pain?

Very rarely, and when I do, I'm amazed that a simple over-the-counter medication is enough to be okay. I can just go to a regular drugstore, get ibuprofen, and be okay. When I do experience pain, I really try to understand that it's "normal" but nothing compared to what I've been accustomed to, and that's truly a blessing.

In what ways do you advocate for others with sickle cell disease?

I speak at events, and I think doing interviews such as this are ways to advocate for others. I'm also in the process of getting my nonprofit off the ground. We just hosted our first annual Walk for ExSCellence, and we raised over \$2,000 for the Sickle Cell Association of the National Capital Area, Inc. and other organizations that look out for the well-being of people with sickle cell disease.

Sometimes I battle with survivors' guilt because I wake up and feel completely different from how I did five years ago. I have a lot of friends who are still suffering and have tried different therapies with no results. It's hard because here I am, finally doing some of the things that I've always wanted to do, and I feel like I'm leaving them behind. Life every day is advocacy.

Precision Environmental Health's role in preventing disease

What is Precision Environmental Health?

Precision Environmental Health is a research area that helps scientists learn how interactions between the environment and genetics can affect a person's health. The goals are to prevent disease and help individuals reduce their unique health risks from environmental



This diagram illustrates how the <u>epigenome</u> changes the way DNA in our cells use genetic instructions.

exposures. Many environmental factors can influence human health.

Some factors, such as healthy diet and access to neighborhood parks, are good. Other factors, such as air pollution and exposure to certain pesticides, can lead to poor health. But how an individual responds to those factors in different ways is based on their unique biological makeup. Precision Environmental Health is about understanding those differences and developing disease prevention efforts that are based on a person's specific needs.

By supporting research in Precision Environmental Health, the National Institute of Environmental Health Sciences (NIEHS) plans to identify those who are most vulnerable to negative health outcomes from participants in North Carolina from diverse backgrounds. Researchers seek to use this information to understand the causes of diseases and the effects of environment, diet, lifestyle, and genetic factors on human health. Enrollment in PEGS is ongoing.

Another NIH-funded study, <u>Utilizing In Vitro Functional</u> <u>Genomics Advances for Gene-Environment (GxE) Discovery</u> <u>and Validation</u>, aims to better understand the connection between environmental exposure and human disease. In vitro refers to cell-based research, and genomics is the study of the complete set of an individual's DNA. The research program focuses on environmental agents such as industrial chemicals, metals, pesticides and herbicides, air pollutants, and biologically derived toxins (hazardous substances made from plants, animals, and microorganisms). The goal is to find new in vitro approaches to understand and treat human diseases caused by the environment.

environmental threats. That scientific knowledge will help to improve disease prevention efforts at the individual level.

What research is happening in Precision Environmental Health?

For the last 20 years, the NIEHS <u>Personalized</u> <u>Environment and Genes Study</u> (<u>PEGS</u>) has gathered health, exposure, medical, and genetic data from nearly 20,000

The NIEHS <u>Toxicant</u> <u>Exposures and Responses by</u> <u>Genomic and Epigenomic</u> <u>Regulators of Transcription</u> (TaRGET) Program

seeks to understand how environmental exposures lead to epigenetic changes that is, modifications to DNA that affect gene expression without altering the underlying genetic code. Toxic substances



such as heavy metals—for example, arsenic and nickel are associated with epigenetic changes that may lead to cancer, cardiovascular diseases, autoimmune diseases, and neurological disorders. The first phase of TaRGET focused on how environmental exposures affect epigenetic changes that influence the way our cells carry out their physiological functions.

The second phase focuses on characterizing epigenetic changes caused by environmental exposures in different types of cell tissues such as the brain, lung, liver, skin, and blood. It also focuses on using easier-to-access surrogate tissues to determine if we can observe epigenetic changes in blood that will predict or correlate with epigenetic changes in a particular type of tissue. Findings were done using mouse models, which will be used to inform human studies.

The NIH National Human Genome Research Institute's <u>Encyclopedia of DNA Elements</u> (<u>ENCODE</u>) was a project created to understand and analyze the

human genome. Researchers can use ENCODE data which has been combined with other data, such as environmental information—to better understand diseases and drugs, how an individual's genetic makeup interacts with the environment, and how those affect their health. Researchers and scientists aim to use the information collected by ENCODE to interpret the human genome sequence and apply it to better understand human biology and improve health, and thanks to a new understanding of how people's genomes and epigenomes work, ENCODE's data will help them do so.

ep•i•ge•net•ics /,epəjən'ediks/

noun biology the study of changes in organisms caused by modification of gene expression rather than alteration of the genetic code itself

> **SOURCE:** <u>National Institute of</u> <u>Environmental Health Sciences</u>



The future of water Why PFAS are harmful and how to avoid them

What are PFAS?

Per- and polyfluoroalkyl substances (PFAS) are synthetic chemicals that have been used in consumer products around the world since about the 1950s. Because they resist grease, water, and oil, PFAS have been used to make nonstick cookware, firefighting foams, water-repellent clothing, stain-resistant fabrics, and much more.

Why are PFAS harmful?

Experts around the world have linked PFAS to serious health risks. These include increased cholesterol levels, changes in liver enzymes, decreased vaccine response in children, impacts on infant birth weight, increased risk of high blood pressure or preeclampsia in pregnant people, and increased risk of kidney or testicular cancer. Over time, PFAS leak into the soil, water, and air. Since they break down slowly, if at all, people and animals are repeatedly exposed to them, and blood levels of some PFAS can build up over time. A recent Centers for Disease Control and Prevention study found that PFAS are present in the blood of 97% of Americans.

The National Institute of Environmental Health Sciences (NIEHS) funds the <u>Superfund Research Program</u> (SRP),

which aims to understand more about PFAS exposures

FAST FACT Per- and polyfluoroalkyl substances (PFAS) have been used in consumer products around the world since about the 1950s.

SOURCE: U.S. Centers for Disease Control and Prevention

and health effects, among other efforts. Research funded by the SRP has linked PFAS to altered hormones, increased body fat, thyroid issues, and cholesterol issues. Most of these findings come





A Purefast™ water pitcher filter by CycloPure, Inc., developed with support from the NIEHS Superfund Research Program.

from animal studies, but because many PFAS are thought to harm humans and animals in similar ways, their results can also be applied to people. People living in communities close to Superfund sites—which are contaminated with hazardous waste—were found to have similar exposures to PFAS as the animals in their research studies.

PFAS are found in drinking water all over the world, including throughout the United States, and are not currently removed using conventional water treatment strategies. More research is needed to find decontamination strategies for PFAS-polluted water, specifically the types and characteristics of PFAS that people are being exposed to and how to trace the sources of contaminants in the water.



Examples of how per- and polyfluoroalkyl substances (PFAS) enter the environment and water sources.

NIEHS-supported technology

MAGE CREDITS: GOVERNMENT ACCOUNTABILITY OFFICE

Another recent study has found a promising new PFAS decontamination strategy. NIEHS and SRP recently funded work with CycloPure, Inc. to research how its newly developed technology could remove PFAS from water. With this technology, CycloPure quickly and effectively removed more than 95% of two common PFAS, perfluorooctanoic acid and perfluorooctane sulfonic acid, as well as the other 38 types of PFAS targeted by the U.S. Environmental Protection Agency.

CycloPure's findings led to the creation of a water filter cartridge compatible with commercial Brita pitchers. These Purefast™ cartridges, which have been available for purchase since early April 2022, are an affordable and effective option to safely decontaminate drinking water. The filters cost \$45 and can filter up to 65 gallons of water. Each cartridge comes in a package with a prepaid return label to send used filters back to CycloPure, where the captured toxins can be turned into salts and be disposed of without causing any environmental harm. With the help of environmental engineering firms, CycloPure is testing its technology's ability to treat large-scale water sources and sustainably provide PFAS-free water.

It's not enough to just stop producing PFAS since the chemicals are already in the environment and take a long time to degrade. More ways to safely destroy PFAS and decontaminate the environment need to be further researched. With the support of NIEHS and SRP, CycloPure is piloting cutting-edge technology to decontaminate drinking water in a sustainable way.

Other NIEHS-supported research on exposure to toxic chemicals

Natural History of the Human Biological Response to Environmental Exposure and Injury



Environmental exposures such

as pollution, diet, and stress can make human disease more prevalent and severe. Researchers want to better understand environmentally induced injury and inflammation to help develop treatment methods. This study—which is currently recruiting participants—will collect a range of biological samples. Participants' household dust samples may also be collected. <u>Read more about this study</u>.

Study of Exposure to Chemicals in Consumer Products

Researchers recently completed a study to find better ways to



a study to find better ways to measure people's exposure to chemicals in household and personal care products. Because manufacturers do not always disclose the exact ingredients in their products, it can be hard to determine the extent to which consumers are exposed. Women ages 35 to 74 who use at least 15 consumer products per day were medically screened and their usage habits recorded by researchers. NIEHS and the U.S. Environmental

Protection Agency collaborated on this study.

Read more about this research.

Sunscreen in the winter? Sun damage is still a risk during colder months

Sunscreen is usually associated with beaches, pools, and sweltering summer days. We spend less time outside in winter, and when we do, we bundle up to protect ourselves from the cold. Ultraviolet (UV) levels (the amount of damaging rays from the sun) are lower in the winter because the earth tilts away from the sun. However, temperature and UV levels are less connected than you might think.

Aging is a natural and unavoidable part of the skin's lifecycle, but prolonged or serious sun damage can make your skin age prematurely. The sun causes as much as 90% of the visible skin changes commonly attributed to aging, and protection from UV radiation is the simplest way to avoid it.

Why we think we are safe from UV rays in winter

UV levels are invisible to the human eye, but the skin can still feel them—even in winter. Their radiation passes through and can damage skin cells. Skin cancer is the most common type of cancer in the United States. That is why the National Cancer Institute (NCI) recommends wearing sunscreen and limiting direct sun exposure during peak daylight hours (10 a.m. to 4 p.m.) all year round. And since clouds can only reduce UV levels by about 50%, it's also important to wear sunscreen on cloudy days. Be sure to put on sunscreen with an SPF of 30 or higher on uncovered areas like your face and ears when outside. Wearing a winter hat or earmuffs is another way to shield parts of the face and ears from damaging UV rays.

Sun damage runs deeper than sunburns

Sunburn is just one kind of sun damage and may fade in a matter of days, but overexposure to the sun can cause changes that only appear many years later. UV exposure can cause your skin's texture to change, wrinkle, bruise, and tear more easily. The sun also causes the appearance of tiny blood vessels in the skin, especially on the face.

Brown spots and large freckles, also known as age spots or liver spots, may appear on frequently exposed areas such as the hands and arms—especially in lighter-skinned people—and may appear as small white spots and red patches.



Did you know? Alaska Natives invented sunglasses thousands of years ago to shield their eyes from the reflection of sunlight off the snow.

Precancerous skin changes may include *actinic keratoses*, which are red, scaly lesions on the face, ears, and backs of the hands, as well as a condition called *actinic cheilitis* when it occurs on the lips. A doctor should also check for these and any other changes to your skin.

Skiing and sun damage

Snowsport lovers and hikers have a higher chance of skin damage during the winter months. The clear, dry air in the mountains can increase UV levels, which get higher as you go up the mountain. In the Swiss Alps, for example, UV levels can increase by roughly 6% for every 1,000 feet up the mountains. Snow also reflects UV rays, which can damage vision and potentially increase your risk for melanoma (skin cancer) of the eye. *Photokeratitis*, or snow blindness, is also a painful eye condition caused by exposure to UV rays reflected from ice and snow. Before hitting the slopes, make sure to wear UV-protection goggles or sunglasses to help protect your eyes from damaging UV rays.

Skin cancer: What to look for

It is normal to have moles or birth marks on your skin, but what looks like just another spot could be a sign of skin cancer. If you are concerned about a mole or spot, follow the "ABCDEs" to help identify an atypical mole.

A – Asymmetrical: Does the shape have irregular sides?

- **B Border:** Are the edges squiggly or bumpy?
- C Color: Is it more than one color?
- D Diameter: Is it larger than a pencil eraser?

E – **Evolving:** Has the size, color, border, or width changed in the past few weeks or months?

If you see any of the following, a new mark, or a change in an old mark—including moles on areas with less sun exposure—see your health care provider.



3

This basal cell carcinoma skin cancer is about 5 to 6 centimeters across and red in color, with defined borders and sprinkled brown pigment along its edges.



Melanoma skin cancer can appear beneath the fingernail as a black or bluish-black discoloration.



An example of malignant melanoma, a kind of skin cancer that spreads to other nearby tissues and body parts.



An example of squamous cell skin cancer, which can metastasize (spread) and should be removed surgically as soon as they are diagnosed.

Basal cell carcinoma skin cancer can appear as a small, pearly, dome-shaped nodule with small visible blood vessels.

NIH research on sun damage and skin cancer

Immunotherapy before Surgery Appears Effective for Some with Melanoma

A study by the <u>SWOG Cancer Research Network</u> found that giving melanoma cancer patients the immunotherapy drug pembrolizumab both before and after surgery substantially lowered the risk of the cancer coming back compared to patients who received the only drug after surgery. The findings do not show whether the drug improves patients' lifespans overall, but researchers believe guidelines for oncologists could be revised as a result. The SWOG Cancer Research Network is part of NCI's National Clinical Trials Network and its Community Oncology Research Program. <u>Read more about this study</u>.

The Effects of an Oral Dietary Supplement on Overall Facial Appearance Among Healthy Adult Women With Existing Skin Damage From Sun Exposure

The study hypothesis is that IMEDEEN[®] (a supplement brand) will affect skin health, including changes to skin appearance, skin density, moisture, and fine lines and wrinkles, when compared to a placebo over a six-month intervention period. Read more about this study.

Genomic and Epidemiologic Characterization of Spitzoid Tumors

A recent study led by researchers at the National Cancer Institute showed that individuals born with mutations in the *POT1* gene are prone to developing spitzoid melanomas (a rare subtype of melanoma that usually occurs in children). NCI is recruiting participants for ongoing research around spitzoid melanomas to learn how genetic and environmental factors contribute to development of the cancer and related conditions. Read more about this research.



Skin cancer is the **most** common type of cancer in the United States.

New cases up, deaths down

MAGE CREDITS: MEDLINEPLUS



From 2014 to 2018, the **rate of new cases of melanoma** increased by 0.5% each year for men and 1.8% each year for women.



From 2015 to 2019, the **death** rate from melanoma declined by 4.6% each year for men and 4.2% each year for women.



ulse oximeters have been used in hospitals and doctors' offices for decades. The small, painless devices measure blood oxygen saturation, which helps doctors decide how to treat patients. During the COVID-19 pandemic, which is in part a respiratory illness, over-the-counter oximeters became more popular for home-based use and were in increasing demand.

People using over-the-counter pulse oximeters should know the limitations of these devices and how to read them. It is also important to note that the accuracy of pulse oximeters can be affected by a variety of factors including skin pigmentation.

How do pulse oximeters work?

Pulse oximeters clip onto a fingertip and send beams of red and infrared light through tissues such as the nail, skin, and blood. The amount of oxygen in the tissue called oxygen saturation—affects how well it absorbs light. The clip's sensor measures how much light passes through without first getting absorbed by the tissue.

Oxygen saturation levels could be a sign of how someone's lungs are working. If blood oxygen levels are below normal (a condition called *hypoxemia*), patients could have headaches, dizziness, or shortness of breath. Hypoxemia can also lead to *hypoxia*, which occurs when the body lacks oxygen at the tissue level. This can cause headaches, trouble breathing, confusion, and bluish coloring in the skin, fingernails, or lips.

Getting an accurate read on pulse oximeters

What to know about using the devices and how their accuracy can be affected

Who uses pulse oximeters?

The U.S. Food and Drug Administration (FDA) <u>currently</u> <u>states</u> that there are two categories of pulse oximeters: those for prescription use and those that can be purchased over the counter.

- **Prescription oximeters** have been vetted by the FDA and are available only with a prescription. These devices have undergone clinical testing to confirm their accuracy and are typically used in clinical settings, although they can be prescribed for at-home use.
- Over-the-counter oximeters are sold directly to consumers and may use apps to estimate oxygen saturation. These products do not undergo FDA review and should not be used for medical purposes.

Doctors, nurses, and paramedics use prescription pulse oximeter readings as one factor to help decide how to best care for patients. Anesthesiologists use them to help determine how much anesthesia to give patients and to monitor their respiratory status. Medical providers may use a pulse oximeter or may prescribe one for home use for patients with any of these conditions:

- Asthma
- Lung cancer
- Chronic obstructive pulmonary disease (COPD)
- Influenza
- COVID-19
- Sleep apnea
- Carbon monoxide poisoning or injury from smoke inhalation
- Pneumonia
- Cystic fibrosis
- Heart disease
- A need for pain medications, including opioids, which could limit the ability to breathe

More people are buying non-FDAcleared, over-the-counter oximeters intended for fitness and general wellness to track their oxygen saturation at home. However, these versions of the device are not approved or cleared for medical purposes or decisions.

How can you read a pulse oximeter?

Read the manufacturer's instructions before using a pulse oximeter at home. The intended use of your pulse oximeter should be available in the manufacturer's instructions. Make sure your hand is warm and relaxed and is resting below your heart. Remove any fingernail polish or artificial nails on the finger being tested. Keep your body still. When the numbers on your device are steady and stop changing, record the levels, date, and time of the reading. Track how they change and tell your doctor if they do.

Pulse oximeters are most accurate when blood oxygen saturation is between 90% and 100%. Accuracy decreases when blood oxygen saturation is between 80% and 90%, and the devices are least accurate when saturation is below 80%. Keep in mind that readings may be off by a few percentage points. For example, if an FDA-cleared pulse oximeter reads 90%, then the *actual* oxygen saturation in the blood is generally between 86% and 94%. Most healthy people have blood oxygen levels between 95% and 100%, but this can be lower for people with lung problems.

Remember: The FDA only reviews the accuracy of prescription pulse oximeters, not over-the-counter oximeters meant for general wellness or fitness purposes. If you think your prescription pulse oximeter is not working, you can report problems with the device by using the FDA's <u>MedWatch online voluntary reporting</u> form.

What other symptoms of low oxygen levels should you look for?

FDA recommends that people who use pulse oximeters at home pay attention to other signs or symptoms of low oxygen levels and whether those symptoms change over time. These may include:

- Bluish coloring in the face, lips, or nails
- Shortness of breath, difficulty breathing, or a cough that gets worse
- Restlessness and discomfort
- Chest pain or tightness
- Fast or racing heart rate

Some patients with low oxygen levels may not show any of these symptoms. Only a health care provider can diagnose a medical condition such

How to read a pulse oximeter

The oxygen saturation level is a percentage usually abbreviated **SpO2**



The pulse rate, which is similar to a heart rate, is abbreviated **PR**

*Sometimes there is a third number indicating the signal strength. A weak signal may give an incorrect result. **There are many types of pulse oximeters, and yours may look different from the one pictured. Read the manufacturer's instructions for features specific to your device.



Pulse oximeters as we know them today were invented in the mid-1970s by **Takuo Aoyagi**, a Japanese electrical engineer. Aoyagi was inspired by the ear oximeters worn by military pilots in World War Il to signal when they were at risk of hypoxemia. Pulse oximeters began selling worldwide in the mid-1980s.

SOURCE: National Library of Medicine

as hypoxia. Because several factors can affect the accuracy of readings, the FDA recommends medical providers make treatment decisions based on pulse oximeter readings over time. The FDA also recommends checking the accuracy information on the device manufacturer's website.

What factors can affect pulse oximeter readings?

Any of these factors can affect pulse oximeter readings:

- Fingernail polish or artificial nails
- Skin temperature: A skin temperature of about 91.4°F is recommended
- Altitude
- Intravenous dyes: These are used to color blood serum for surgical or diagnostic purposes and can affect light absorption
- Poor circulation
- Skin thickness
- Tobacco use
- Skin pigmentation

MEDICAL TECHNOLOGY

"With the advancement in data mining tools and capabilities, trends in pulse oximeter accuracy can be [revealed] and analyzed, and recent evidence suggested
 that there might be a potential racial disparity in pulse oximeter accuracy."

- Dr. Qi Duan, a Program Director for NIBIB Division of Health Informatics Technologies

Are pulse oximeters less accurate for people of color?

Recent studies have suggested that prescription pulse oximeters may be less accurate for people with darker skin tones. Melanin (the natural pigment that gives skin, eyes, and hair their color) absorbs the red and infrared light from pulse oximeters, and the amount of melanin you have can change how much light is absorbed. People with darker skin tones have more melanin, and this could potentially lead some of the devices to give falsely high readings and medical providers to give these patients less supplemental oxygen in health care settings.

Qi Duan, Ph.D., a Program Director for the Division of Health Informatics Technologies at the National Institute of Biomedical Imaging and Bioengineering (NIBIB), said the increased use of pulse oximeters during the pandemic accelerated the publication of research including NIH-funded studies—around disparities in readings for patients of color.

What is being done about addressing disparities in pulse oximeters?

Researchers need more evidence to determine whether the racial disparities found in these case studies were specific to those hospitals or if this is a widespread problem. Better data science and collection of information from medical devices can help track patterns that lead to health disparities. "With the advancement in data mining tools and capabilities, trends in pulse oximeter accuracy can be [revealed] and analyzed, and recent evidence suggested that there might be a potential racial disparity in pulse oximeter accuracy," Dr. Duan said.

Health care providers can develop unconscious biases if they base treatment decisions on data that do not account for a wide range of backgrounds or conditions. Pulse oximeters are considered reliable technology, but manufacturers should test them on a diverse group of subjects. The FDA requires that medical-grade devices be tested on subjects with "darkly pigmented" skin, and the tests require at least two subjects or 15% of the trial group—whichever is more—be people of color.

The agency is considering new guidance around testing for skin tone disparities. On November 1, 2022, the FDA heard from a committee of medical experts, device manufacturers, and patient advocates about ongoing concerns that pulse oximeters may be less accurate in individuals with darker skin. The FDA will review the committee's recommendations and consider additional testing or labeling requirements for overthe-counter devices.

In addition to testing being more diverse, Dr. Duan said finding solutions to these problems needs to be inclusive as well.

"It may take a multipronged approach to address this apparent issue," Dr. Duan said. He noted that research studies need to better understand this problem and its causes, technological innovations to increase pulse oximeter accuracy and robustness, and outreach to health care professionals and caregivers to spread awareness about the studies' observations.

CASE STUDY

#1

Assessment of Racial and Ethnic Differences in Oxygen Supplementation Among Patients in the Intensive Care Unit

One <u>study</u> funded by NIBIB and the National Institute of Diabetes and Digestive and

Kidney Diseases looked at 3,069 Black, White, Hispanic, and Asian patients treated in the intensive care unit at Beth Israel Deaconess Medical Center in Boston, Massachusetts. The study compared 11 years of readings from pulse oximeters to actual blood oxygenation levels from arterial blood gas tests, which are considered more reliable. Researchers found that pulse oximeter readings were artificially higher than actual blood oxygenation levels in non-White patients. CASE STUDY

Racial Bias in Pulse Oximetry Measurement

Another <u>study</u> at the University of Michigan, supported by the National Library of Medicine and the National Heart, Lung, and Blood Institute, examined pulse oximeter readings from

White and Black patients between 2014 and 2015 and in 2020. This study found that Black patients were nearly three times more likely to have occult (hidden from view) hypoxemia than White patients. Researchers said relying on the devices to triage patients could place Black patients at increased risk of hypoxemia.

More NIH efforts to improve health disparities



A team from Johns Hopkins University developed the EquinOx pulse oximeter to help correct skin tone biases in blood oxygen readings.

New pulse oximeter design wins NIBIB 2022 DEBUT Challenge

A team from Johns Hopkins University in Baltimore, Maryland, won first place in the 2022 Design by Biomedical Undergraduate Teams (DEBUT) Challenge for their EquinOx pulse oximeter. The EquinOx is better able to estimate blood oxygen saturation levels using its new hardware that measures both skin tone and the device's raw data. The \$20,000 prize includes coaching to make the device commercially available. <u>Read more</u> <u>about the DEBUT Challenge</u>.

Technology Development to Reduce Health Disparities

This research project grant from NIBIB and the National Institute on Minority Health and Health Disparities (NIMHD) supports medical technologies aimed at reducing disparities in health care access and health outcomes. NIBIB and NIMHD seek technologies that are effective, affordable, culturally acceptable, and deliverable. Learn more about this funding opportunity.

NIH Minority Health and Health Disparities Strategic Plan 2021–2025

This five-year plan sets goals for NIH to address health disparities among racial and ethnic minority groups in medical research and clinical care. These goals include testing common health indicators to measure the scale of health disparities across different diseases, conditions, and populations. Another goal is to include more minorities and members of health disparity populations in big data sets, clinical research, and future big science initiatives. <u>Read more about the</u> <u>Strategic Plan</u>.



An alternative to pulse oximeters

An arterial blood gas test is more invasive and painful than using a pulse oximeter, but it's a more accurate way to measure oxygen and carbon dioxide in your blood as well as the balance of acids and bases. Having too much or too little acid in your blood can be harmful.

Know the difference between pulse oximeters

Pulse oximeters may be prescribed by a doctor or purchased over the counter. The FDA recommends knowing the difference so that patients use pulse oximeters safely.

	Prescription	Over the counter
Reviewed by the FDA	•	
Available by prescription only	•	
Underwent clinical testing	•	
Used for medical purposes	•	
Can be used at home	•	•
Available without a prescription (i.e., purchased in stores, online, or via mobile app)	•	
Used for general wellness or fitness activities		•

HEARING LOSS AND HEARING AIDS

Loud and clear What to know about hearing loss

New research and regulations for hearing aids improve access to hearing health care

earing loss affects approximately 37.5 million people in the United States ages 18 years or older. It affects one in three people ages 65 to 74 and nearly half of people ages 75 and older. But only about a quarter of those who could benefit from a hearing aid use one.

Barriers to use include high costs, stigma, limited access, and the belief that hearing aids are not worth the benefit. The U.S. Food and Drug Administration (FDA), which regulates the safety and efficacy of hearing aids, <u>recently approved a new category of over-the-counter</u> <u>hearing aids</u> for adults 18 or older with perceived mild to moderate hearing loss. The hope is that these devices will become more affordable and accessible.

What are some causes of hearing loss?

- Age
- Exposure to loud noise from machinery or residential tools such as lawnmowers and leaf blowers
- Excessively loud music
- Earwax or fluid buildup
- Punctured eardrum
- Health conditions such as diabetes, high blood pressure, stroke, brain injury, or a tumor
- Some medicines used to treat serious infections, cancer, and heart disease
- Heredity

What are side effects of hearing loss?

"Hearing loss, even if mild or moderate, significantly affects quality of life for tens of millions of adults in the United States," said Debara L. Tucci, M.D., M.S., M.B.A., Director of the National Institute on Deafness and Other Communication Disorders (NIDCD).

"Individuals with hearing loss need to work together with their family and friends to explain which listening situations may be difficult."

- Dr. Debara L. Tucci, Director of the National Institute on Deafness and Other Communication Disorders

This can make it hard to understand and follow a doctor's advice, to notice and respond to warnings, or to hear phones, doorbells, and smoke alarms.

Hearing loss has been associated with serious conditions such as depression, low self-esteem, cognitive decline, reduced mobility, and falls. It can also make it hard to engage with others, which can lead to social isolation and avoiding stimulating activities.

Age-related hearing loss can worsen over time. That impacts how well you understand speech, especially in noisy environments such as restaurants. As people get older, some experience tinnitus (a ringing sensation in the ears). Many individuals experience a type of dizziness called *presbyastasis*, a condition that affects our inner ear and sense of balance as we age.

How can I get a hearing aid?

Hearing aids are available with a prescription or over the counter. A rule change by the FDA in August 2022 made over-the-counter devices available without needing an examination by an audiologist (a hearing health professional). These hearing aids can help adults ages 18 and older with perceived mild to moderate hearing loss. Prescription hearing aids are available from a professional who will help select, program, and maintain the devices. Children and individuals with more severe or complex hearing loss should always work with an audiologist.

If you think you have hearing loss, talk with an audiologist to learn more about over-the-counter and prescription devices. They can help you determine whether hearing aids are right for you. Know the return policy for any hearing aid you purchase, whether it's over the counter or by prescription, in case you decide the device is not for you.

A hearing aid can help people hear more sound in both quiet and noisy situations. It can process sounds based on their pitch, frequency, or what direction they come from. The user can also change some of these programs to fit their needs.

Why did the FDA make this rule?

<u>The new rule</u> comes after decades of research by NIDCD and others, Dr. Tucci said. Since 2009, NIDCD has supported more than 60 research projects to make hearing health care more available and affordable. These projects



Hearing aids come in three basic styles. BTE hearing aids are used for mild to moderate hearing loss and are appropriate for people of all ages. ITE devices are used for mild to severe hearing loss and are appropriate for everyone but young children. Canal devices are used for mild to moderately severe hearing loss and are also usually not for young children.

SOURCE: National Institute on Deafness and Other Communication Disorders



FAST FACT: Hearing loss affects approximately **37.5 million people** in the United States ages 18 years or older. One in three people ages 65 to 74 and nearly half of people ages 75 and older have hearing loss.

SOURCE: NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS

included research on adults with possible mild to moderate hearing loss. A committee of experts in 2016 <u>wrote</u> that the confusing hearing health care system made it hard for people to get the care they need. The experts also did not find any evidence that requiring a medical evaluation before getting a hearing aid was clinically beneficial for patients.

"NIDCD-supported clinical research has shown that over-the-counter hearing aids for adults with perceived mild to moderate hearing loss can work as well as prescription hearing aids purchased through an audiologist," Dr. Tucci said.

Cost of hearing aids

The FDA expects that this new rule will increase market competition for hearing aids and could also reduce costs for prescription devices.

Currently, prescription hearing aids can cost hundreds to thousands of dollars. Some health insurance companies might cover the cost of hearing aids, but not all do. Medicare does not cover hearing aids for adults, but it can cover hearing loss exams as part of a treatment plan.

It is too soon to know how insurance plans will accommodate over-the-counter hearing aids. Check your individual health insurance plan to know whether it covers or will cover over-the-counter hearing aids.

By the numbers

9 years How long on average it takes people to seek help after a diagnosis of hearing loss

Number of adults in the United States who could benefit from hearing aids

How much more likely it is for men to have hearing loss compared to women.

Who are over-the-counter hearing aids for?

Over-the-counter hearing aids are for adults ages 18 and older who believe they have mild to moderate hearing loss, even if they have not had a hearing exam. <u>Some signs</u> you might have mild to moderate hearing loss include:

- Speech or other sounds seem muffled
- You have trouble hearing when you're in a group, in a noisy area, on the phone, or when you can't see who is talking
- You have to ask others to speak more slowly or clearly, to talk louder, or to repeat what they said
- You turn the volume up higher than other people prefer when watching TV or listening to the radio or music

SOURCE: NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS

Comparing hearing aids

Over the counter

- For people ages 18 and older
- For those with perceived mild to moderate hearing loss
- Does not require medical exam, prescription, or fitting by an audiologist
- Sellers do not need to be licensed

Prescription

- For people of all ages
- For those with any degree of hearing loss
- Requires a prescription
- Sellers must be licensed in some states

Speak up about your hearing loss

Hearing loss affects more than the individual. Dr. Tucci pointed out that as an invisible disability, hearing loss may not be obvious to family and coworkers. Poor communication between someone with hearing loss and others may cause friction and arguments. This may lead people to limit their social interactions or affect their performance at work.

"Individuals with hearing loss need to work together with their family and friends to explain which listening situations may be difficult," Dr. Tucci said. She offers some advice for people with hearing loss:

- Ask friends and family to face you when they talk so you can see their expressions and lip movements.
- Ask people to speak louder (but not shout). You may need to ask them to speak more slowly or more clearly.
- Turn off or turn down the volume of background noise, such as the TV, when you're trying to have a conversation.
- Be aware of noise around you that can make hearing more difficult. For example, when you go to a restaurant, don't sit near the kitchen or near a band playing music. Ask for seating in a quiet area. Sitting in a booth can also help soften or block noise.

How do hearing aids work?

Hearing aids are small electronic devices worn inside or behind the ear. The device uses a **microphone** to pick up sounds and converts them to electrical signals. These signals are sent to an **amplifier** (or processor), which increases the signals' power and sends them through a **speaker (or receiver)** located on or in the ear.



More NIDCD research on accessible hearing health care

NIDCD supports scientists and clinical researchers nationwide to overcome barriers to care and to improve the quality of life for adults with hearing loss.

Development and Assessment of a Spanish-Language Toolkit for Hearing Loss Self-Management

This project is recruiting participants. Researchers will develop and evaluate Spanish-language hearing education materials for adults. Materials should improve understanding of hearing loss and resulting difficulties. They should identify options for self-management with culturally and linguistically appropriate patient education. Learn more about this research.

Factors that Contribute to Hearing Handicap and Hearing Loss Treatment Decisions of Older Adults

This study investigates how individual differences in nonauditory factors contribute to and define hearing loss. "Nonauditory" means factors besides hearing, including personality and cognitive ability. Researchers will study how these influence hearing aid use. <u>Learn more about this research</u>.

Hearing Healthcare Assessment in Rural Communities

This study assesses hearing health care among adults living in rural Appalachian counties in Kentucky. Researchers will partner with rural health clinics to create a culturally responsive patient navigation program to promote hearing health care. Learn more about this study.



Deafness is not a burden

NIH's David Rice learned to be an advocate for himself and others

David Rice wants to increase the Deaf and hard-of-hearing workforce at NIH.

eing deaf is not the same for everyone with the condition. Deafness means partial or complete loss of hearing in one or both ears and can range from mild to severe to profound. It can happen at any age and can be hereditary, genetic, or caused by environmental factors such as occupational noise. The ways in which people who are Deaf communicate also vary, and this affects how they move through the world or connect with other people.

For David Rice, being deaf meant not only learning to navigate a hearing world physically and socially but also discovering how to advocate for himself and others. As the Acting Branch Director for the Special Emphasis Program Branch at NIH's <u>Office of Equity</u>, <u>Diversity</u>, and Inclusion, advocating for others is his job. He talked to NIH MedlinePlus Magazine about his experience and some things people may not realize about the Deaf community.

Deafness has a spectrum. Where do you fall within it?

I am severely deaf in both of my ears. However, I do have some hearing within my right ear; I can hear between 80 to 120 decibels in the right. In my left ear, I don't hear anything.

The hearing is not necessarily created equal, either. Pitches make a big difference—the higher the pitch, the less I hear. I can hear more clearly the lower tones and the lower pitch range. I do occasionally use a phone, and the majority of that is with people I know: my wife, my mom and my dad, my siblings. For the most part, I can hear them very well on the phone. I grew up with them; I know what their voices sound like.

But I rely heavily on American Sign Language (ASL) or lip reading. Lip reading is also not created equal in the Deaf and hard-of-hearing world. Although I may be able to lip-read fairly well, we can't assume that all Deaf people lip read. And lip reading is not perfect as some words have similar mouth movements but completely different meanings.

How did you learn to lip read?

In the late 1980s and early 1990s, closed captioning was not automatic like it is today. You had to buy a <u>closed</u> <u>caption decoder</u> box that sat on top of a television the sound went into the box, and the box would produce the captioning.

Mister Rogers' Neighborhood was my favorite TV show of all time, and if you look, you realize most of the time the camera was on his face. I credit watching hours and hours of *Mister Rogers* with the captioning box with helping me develop lip-reading skills when I was very young.

With Zoom meetings today or on Microsoft Teams, if I know the individual very well, I generally can rely on lip reading to have the conversation. But if I don't know the individual well and I'm not familiar with their voice, I like to have the interpreter there to make sure I don't miss anything and that I get the full conversation.

But lip reading is not 100% accurate. There's a lot of filtering that goes on in my head, and I use context clues to decipher what a person is saying.

How did you learn ASL?

I had a sign language interpreter with me from kindergarten all the way through 12th grade. I was the only Deaf person in the school. I had no one to communicate with in ASL. So I did not know the language the way I know it now—I consider myself fully fluent in ASL now. But I used the interpreter in grades K–12 really to be a lip reader for me. At that time, I did what they called Signing Exact English, which uses typical English sentence structure. The sentence structure is different in ASL. In my junior or senior year of high school, I took ASL as a second language credit. It was "Zoom" before Zoom, with video classes through the University of Cincinnati.



"I credit watching hours and hours of *Mister Rogers* with the captioning box with helping me develop lip-reading skills when I was very young."

Then when I went to college at the Catholic University of America in Washington, DC, they had a level in the dorm building for students who were communicating in ASL. I got to stay there, and that helped me learn the language. I took more classes in it. But the pivotal moment was, when I could no longer play baseball in college, I found a coaching job [at the Model Secondary School for the Deaf]. I did that for eight or nine years, and that is how I learned to speak ASL fluently—being able to interact with the students every day and being involved in the community. I volunteered with the <u>Deaf in Government</u> nonprofit, and that helped me advance my skills more than in a classroom setting.



American Sign Language (ASL)

- Developed in the 1800s; shares elements of French Sign Language and local sign languages
- Uses fingerspelling of words as well as facial movements
 - Complete, natural language
 - Unique grammar, pronunciation, and sentence structure separate from English

Signing Exact English (SEE)

- Developed in the 1970s; 1:1 visual representation of spoken English
- Uses fingerspelling of words
- Not a language
 - Follows English sentence structure; uses some ASL as well as unique signs

SOURCES: NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS; AMERICAN ANNALS OF THE DEAF

How do you prefer to communicate with new people who may not know you're deaf?

It depends on the setting. If I'm meeting a hearing person, like at the store or giving a speech, generally I use my voice. I golf a lot, so if I don't know the people I'm golfing with, I say "Hey, I'm deaf. If you think I'm ignoring you, I'm not. I just didn't hear what you said." I've gotten a lot more comfortable doing that.

If I'm meeting a Deaf or hard-of-hearing person, I'll go straight into ASL. In the Deaf community, it's very easy to identify who's Deaf or those who are part of the Deaf culture. This includes interpreters or children of Deaf adults.



David Rice gives the opening remarks during the NIH 2018 National Disability Employment Awareness Month kick-off event.

In a mixed group of hearing and non-hearing people, I prefer to speak because my verbal language is really my first language. I prefer to have an interpreter sign for me than for me to try to speak and sign at the same time. Interpreters are really skilled at this—my wife used to be an interpreter, and she's really skilled at speaking and signing at the same time.

Can you explain the concept of "language deprivation" and how that affects Deaf children's communication?

Language deprivation is denying [language] access from any individual. There's a critical period of time in the development of a child—from the day that they're born to a certain age—where language sets the foundation going forward. A lot of Deaf and hard-of-hearing children miss that window. And a lot of that has to do with the fact that some people don't think ASL should be part of the language development of a child who is Deaf and hard of hearing.

The Deaf community believes that spoken language and ASL should work together to help a child develop their language and comprehension skills. If you just focus on spoken language, they're going to fall behind. We need to study this more than what's currently out there.

FAST FACT: "Severe" hearing loss is the ability to only hear sounds once they are at least **71 to 90 decibels** (for example, a vacuum cleaner or alarm clock). "Profound" hearing loss is the ability to only hear sounds **at least 91 decibels** (such as a subway, passing motorcycle, or gas lawnmower). **SOURCE:** <u>AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION</u>

What are some things you have to do in daily life that a hearing person maybe would not?

Right now, I'm wearing headphones so I can hear through those, but I don't hear anything else around me. It's very directional. There could be danger behind us, and I would not know. I have to rely on my vision a lot more. I take my hearing aid out to go to sleep, so I use a vibrating alarm on my phone to wake me up.

When I make phone calls to people I don't know, I use a video phone. I call and use my own voice, but an interpreter is there to sign what the person says. I have to get on an app, wait for an interpreter to come on, and then dial the number, so there

are extra steps. Another example is I have to set my own vibrating alarm for when the stove goes off.

On mass transportation, such as in an airport or on the subway, if they make an announcement over the loudspeaker, I will not hear that. I have to watch the reactions of other people around me. I don't go to movie theaters anymore because it's hard to find screenings with open captioning. The physical captioning screens some theaters have are too cumbersome to use.

Also, with podcasts today, everyone can learn things or read books just by passively listening. I have to download and read the transcript. I have to make time to sit down and read it, so I don't follow podcasts as much as, say, my coworkers do.

What effect do you think the Food and Drug Administration's <u>rule change</u> for over-thecounter hearing aids will have for people who are deaf and hard of hearing?

Getting hearing aids over the counter at a CVS [without needing a prescription], for example, could be a game changer—especially for older people who are losing their hearing due to age. I think it's tremendously powerful to have that ability.

For me, my parents could not afford a hearing aid [when I was a child]. So while I still recommend going to the doctor and getting your hearing checked or fitted for a hearing aid, that's still not a reality for a lot of people. Who knows... if this rule was in place when I was younger, maybe I would have had access to hearing aids then?

To read more about David Rice's story and how he works to increase diversity, equity and inclusion at NIH, check out his full interview at <u>NIH MedlinePlus Magazine</u>!

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