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Women's Heart Health

Ta'Rhonda Jones

Star of Fox TV's *Empire*
delivers a healthy message in
Go Red For Women movement.

Reducing Health Disparities

10 NIH Research
Breakthroughs

Spotlight on Rare Diseases

Fibromyalgia:
Puzzling and Painful

Technology Opens Doors to Scientific Discovery



Photo: Michael Spencer, NIH

Susannah Fox, chief technology officer of the U.S. Department of Health and Human Services, wants to expand the public's access to health information.

The Friends of the National Library of Medicine (NLM) recently hosted NLM's Board of Regents, NLM senior staff, and other leaders from across the National Institutes of Health (NIH). The invited speaker was Susannah Fox, chief technology officer of the U.S. Department of Health and Human Services (HHS). During her talk, "At the Crossroads of Health, Technology, and Service," she focused on the innovative work under way at the HHS IDEA Lab and her efforts to make data information and tools more broadly available.

Fox has pioneered participatory research methods to explore how information technology and social media affect the health care industry and the consumer health care experience, with a special focus on people living with chronic and rare conditions. (Learn more about NIH's support for rare disease research starting on page 16 in this issue.)

"When I started my research into the social impact of the Internet back in the year 2000," she stated, "[the NLM was] already ahead of the game, making sure that people had access to the information and data that they needed."

One of her passions is facilitating expansion of the public's access to information that can help them better understand how to improve their health. Technology is playing a primary role, and she is a leader in this effort.

"The changes that technology is bringing to [HHS] and to government are positive ones. This moment we are living through is opening doors to innovative thinking and scientific discovery and in people's pursuit of health," she said.

Glen P. Campbell, Chairman
Friends of the National Library of Medicine

Portrait Unveiled of Former NLM Director Lindberg

On February 10, the National Library of Medicine was the scene of a special unveiling ceremony for a portrait of former NLM Director Dr. Donald Lindberg and his wife, Mary. Lindberg retired in 2015 after more than 30 years of service as NLM Director. During his tenure, the Lindbergs were a much-admired team, always closely involved with the people and activities of the Library. Commissioned and sponsored by the Friends of the NLM, this new painting now hangs in a prominent location at NLM.



Photo: Ernie Branson, NIH

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16 ▲ Patricia Weltin, with her daughters, Olivia and Hana (left and right), works to raise awareness of rare diseases.

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Photos: Cover: Sam Zachrich; (Top) Getty Images for AHA; (Center) James Gathany, CDC; (Bottom) Patricia Weltin

The National Institutes of Health (NIH)—the Nation's Medical Research Agency—includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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Sharing Advice From The Heart

Ta’Rhonda Jones, star of Fox TV’s *Empire*, delivers a healthy message about women and heart disease.

This year’s Red Dress Collection® was hosted by The American Heart Association’s Go Red For Women® and supported by the NIH National Heart, Lung, and Blood Institute (NHLBI) and Macy’s. This widely publicized event took place on February 11, 2016, and kicked off New York Fashion Week. More than 20 celebrities walked the runway in red gowns in an effort to raise awareness that heart disease is the leading cause of death among women. The NIH/NHLBI supported this event by providing evidence-based scientific messaging to special guests, more than 100 media outlets, and the public.

Ta’Rhonda Jones is an actress and recording artist best known for her scene-stealing role as Porsha Taylor on Fox TV’s *Empire* and as a TV personality on many other programs. Under her music alias, Lady Heroine, she is currently in the studio recording tracks for her upcoming album. She is part of this year’s Go Red For Women movement and discussed with *NIH MedlinePlus* magazine why she got involved.



Photos: Getty Images for AHA

The Heart Truth

The National Heart, Lung, and Blood Institute (NHLBI) sponsors The Heart Truth® education program in partnership with many national and community organizations. The program's goal is to raise awareness about heart disease and its risk factors among women and educate and motivate them to take action to prevent the disease and control its risk factors.

The program tells women that "The Heart Truth starts with you. Talk with your doctor, find out your risk for heart disease, and take action today to lower it." The Heart Truth's messages are highlighted by the moving stories of women who are taking action to have a heart-healthy lifestyle.

The centerpiece of The Heart Truth is the Red Dress®, which was introduced as the national symbol for women and heart disease awareness in 2002 by the NHLBI. The Red Dress® reminds women of the need to protect their heart health and inspires them to take action to lower their risk for the disease.

To hear more stories and learn more about how to lower your risk for heart disease, visit www.hearttruth.gov. The Heart Truth® is a registered trademark, and Red Dress is a service mark of the U.S. Department of Health and Human Services.

What inspired you to get involved in the American Heart Association's Go Red For Women movement and Red Dress Collection?

For me, heart disease is personal, so when the American Heart Association (AHA) approached me and asked me to participate in the Go Red For Women Red Dress Collection and wear up-and-coming Macy's Incubator designer Conrad Booker, of course I said yes. I want to bring awareness to the fact that heart disease impacts women, and African-American women, in a very real way. The AHA says that nearly 50 percent of African-American women have cardiovascular disease, but only 14 percent believe it's their greatest health threat. That's a problem.

You have had personal experience with a heart condition starting as a child. Can you tell us a little about that?

I was born with a heart murmur, and for the first few months after birth I had to wear a heart monitor. I was told that I wasn't going to be able to participate in a lot of activities because of my condition. But as I got older I became more active. I played softball, basketball, volleyball, and ran track! I think being involved in all these different activities helped me maintain a healthy lifestyle.

And your mother has a heart condition as well. Is this something she developed as an adult?

My mother was diagnosed with congestive heart failure three years ago. Both she and her doctor are currently determining the best course of treatment so that she can live a better, healthier lifestyle.

What message do you have for women, especially young women, about heart health and taking care of themselves?

I want women to know that you can lead a successful and productive life with heart disease, but as women, we have to make our health our priority. Women, especially young women, can do that simply by scheduling a well-woman visit with their doctor. It's never too early to have your heart checked, especially if heart disease runs in your family. A well-woman visit is a doctor's appointment where you can learn about the risks for heart disease and stroke and that visit could save your life.

TV Crime Reporter Missed Clues

Jennifer Donelan didn't realize the signs of her heart under distress until she was in a hospital bed recovering from a heart attack at the age of 36. A crime reporter for WJLA-TV in Washington, D.C., her life revolved around the traumas, disasters, and heartaches that plagued her community.

"I was extremely worried about breast cancer; I was not worried about heart disease," she said. "Heart disease was not even on my radar."

Jennifer's heart attack reset her priorities.

"Wait a minute, I thought to myself. 'I'm 36 years old, and I just got smacked by my reality.' I smoked. I didn't get good sleep. I wasn't exercising. I really didn't eat well. And the stress was, like, 120 percent all day long."

At the time, Jennifer's career was her primary focus. "But the heart attack stopped me dead in my tracks," she said. "After the heart attack, my first walk—I was afraid every step would be my last."

Jennifer now takes time to manage stress and nourish herself with healthy food. Jennifer urges all women to know their risk for heart disease and take action to lower it.

"Women need to wake up," she said. "Heart disease is the number one killer of women. Women need to know their numbers, their cholesterol, their history, and their BMI (body mass index). They need to watch their stress."

"If the story of what I've been through can help even one other woman, then it's been worth it," she added.

"The Red Dress® means I'm not alone."

— From *The Heart Truth*®, a program of the National Heart, Lung, and Blood Institute



Learn more about Jennifer's story at www.nhlbi.nih.gov/health/educational/hearttruth/about/stories-jennifer.htm

Find Out More

- ✓ National Heart, Lung and Blood Institute: www.nhlbi.nih.gov
- ✓ Heart Diseases: www.nlm.nih.gov/medlineplus/heartdiseases.html
- ✓ Heart Disease in Women: www.nlm.nih.gov/medlineplus/heartdiseaseinwomen.html
- ✓ American Heart Association: www.heart.org

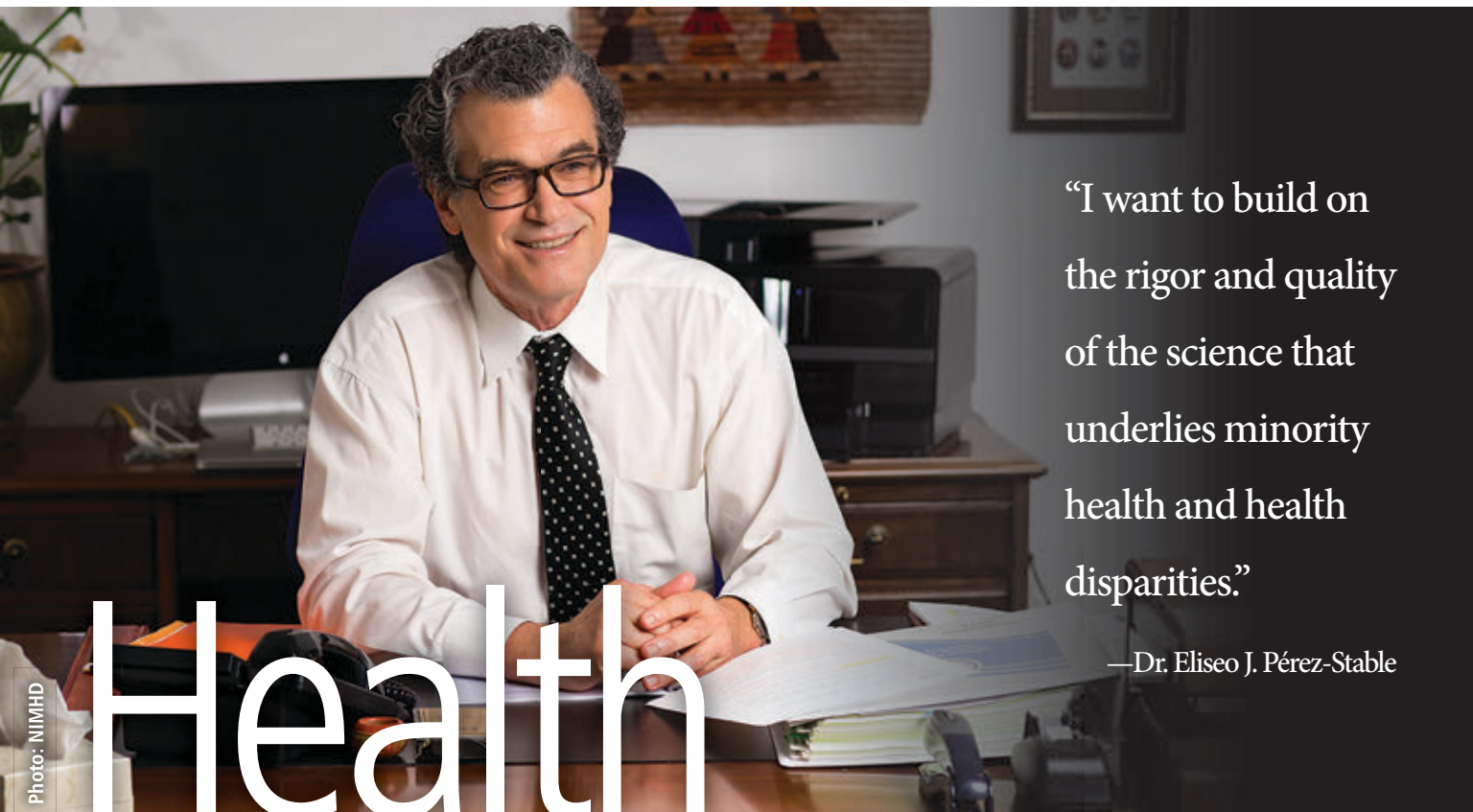


Photo: NIMHD

“I want to build on the rigor and quality of the science that underlies minority health and health disparities.”

—Dr. Eliseo J. Pérez-Stable

Health Disparities

Eliseo J. Pérez-Stable, MD, Director of the National Institute on Minority Health and Health Disparities (NIMHD), leads NIH’s efforts to improve minority health and reduce health disparities.

He recently discussed the work of NIMHD and minority health and health disparities with *NIH MedlinePlus* magazine.

What do you see as three of the major health challenges facing minorities in the U.S. today?

The first challenge is adequate access to high-quality health care that is based on evidence from the best research. The Affordable Care Act has made a substantial impact on decreasing insurance barriers for minorities who are uninsured or underinsured. However, the lack of diversity in the medical workforce and appropriate use of high-cost services, tests, procedures, and medications remain significant problems. Furthermore, even with expanded health care coverage, segments of the U.S. population remain uninsured, such as undocumented immigrants.

Minority women have higher rates of some risk factors for heart disease.

The second challenge is the obesity epidemic and its causes and consequences with regard to higher rates of diabetes, heart disease, cancer, and impact on quality of life. Excess obesity and severe levels of obesity affect all racial and ethnic minority groups in the United States.

Third, early life development from before birth to school age requires special attention to emotional engagement, improved nutrition, parenting, and skill building. Scientific advances have shown that adverse experiences during early life have significant consequences in adult health.

What are the most important goals you have as NIMHD's new Director?

I want to build on the rigor and quality of the science that underlies minority health and health disparities. This will promote innovative research on these topics to advance our understanding of mechanisms leading to health disparities and to develop and test interventions that will reduce these health disparities. We plan to expand the inquiry into the mechanisms in behavior and biology that lead to disparities as well as integrate the environmental, social, and cultural factors that affect these disparities. NIMHD will also establish a more robust research program in the health care setting where disparities may be reduced or exacerbated.

Why should all Americans—not just minorities—understand and care about minority health and health disparities?

This is an issue of social justice. Racial and ethnic minorities and the working poor have been traditionally disadvantaged and subject to discrimination. Furthermore, the interaction of environmental, biological, and behavioral factors studied in different population groups can contribute to advancing general knowledge about specific health conditions and outcomes. Finally, demographic projections indicate that by 2040 more than 50 percent of Americans will self-identify as belonging to a minority group and this topic will, in this way, affect all Americans.

How can improvements in health care settings for minorities improve care?

People who are working in or managing in health care settings can create a welcoming environment for minority populations by acknowledging the value of differences and diversity. For example, they can provide professional interpreters and appropriate signage and forms for persons who do not speak English and create a culture of respect for all persons no matter how different each of us is.

If a person of color walks into a clinic and the only people that look like him or her are custodians and maybe the front desk staff, this creates additional barriers that institutions need to recognize and actively address. There is much to be gained in providing universal quality care to all and treating all individuals with respect in our human interactions.

What should Latinos, African Americans, and other U.S. minorities understand about the need for more of them to participate in clinical research trials for a variety of diseases?

There is a saying that if one is at the table, it is not likely that one will be on the menu. We need to overcome historical mistrust, institutional barriers, and individual factors and be at the table.

The inclusion of all minorities in clinical research, both therapeutic trials and observational studies, is an issue of social justice and of advancing knowledge. Without the inclusion of minorities in therapeutic trials, we will not really know whether a treatment applies in a similar way to these groups. In the era of precision medicine, there may be genetic differences that track my individual ancestry that will determine response to a specific drug, greater susceptibility to a certain disease and possibly better outcomes for a common condition. Minority participation in studies will help us advance knowledge about health and disease, about what works for whom and how, and in this way reduce existing health disparities.

76%

of Hispanic women are overweight or obese

37%

of African-American women have high blood pressure

16%

of Native American women have been diagnosed with diabetes

—Sources: NHLBI, U.S. Department of Health and Human Services

Healthy Living Tips



Aim for a healthy weight



Have a healthy diet



Get regular physical activity



Don't smoke

What Are Disparities?

The diversity of the American population is one of the nation's greatest assets. However, one of our greatest challenges is reducing the profound disparities in health status of our racial and ethnic minority, rural, low-income, and other underserved populations.

Health disparities are the focus of the NIH's National Institute on Minority Health and Health Disparities (NIMHD). The Institute provides the leading edge in enhancing the scientific knowledge base and designing interventions to improve health outcomes to reduce and ultimately lead to the elimination of health disparities.

Health disparities refer to significant differences in the health status and outcomes of different groups of people. According to the National Institute on Minority Health and Health Disparities, some groups of people have higher rates of certain diseases, and more deaths and suffering from them, compared to others. These groups may be based on:

- Race
- Ethnicity
- Immigrant status
- Disability
- Sex or gender
- Sexual orientation
- Geography
- Income

To better understand the context of disparities, it helps to learn more about the U.S. population.

- Approximately 33 percent of the U.S. population, or more than 100 million people, identified themselves as belonging to a racial or ethnic minority population.
- About 51 percent, or 154 million people, were women.
- Approximately 12 percent, or 36 million people not living in nursing homes or other residential care facilities, had a disability.
- An estimated 70.5 million people lived in rural areas (23 percent of the population), while roughly 233.5 million people lived in urban areas (77 percent).
- An estimated four percent of the U.S. population ages 18 to 44 identified themselves as lesbian, gay, bisexual, or transgender.

Despite notable improvements in the overall health of the United States during the past two decades, there continues to be striking disparities in the burden of illness and death experienced by African Americans, Hispanics/Latinos, American Indians and



Photo: iStock

Alaska Natives, and Asian Americans, Native Hawaiians and other Pacific Islanders.

For example, heart disease is the leading cause of death in America, accounting for 32.3 percent of all deaths in 2009 and affecting some minorities more than others. In 2009, the overall rate of death due to heart disease was 236 per 100,000 deaths. The rates were 281.4 for white males, compared with 387.0 for African American males. In addition, avoidable deaths disproportionately occur among non-Hispanic blacks and residents of the South. For example, avoidable deaths are particularly high among black males; in 2010, the black male rate was approximately 80 percent higher than that of white males and black females.

Why Do Health Disparities Exist?

Disparities exist in nearly every aspect of health, including quality of health care, access to care, utilization of health care, and health outcomes. These disparities are believed to be the result of the complex interaction among biologic factors such as genetic variations, social and environmental factors, and specific health behaviors. Disparities in health care persist even when the data are controlled for gender, race and ethnicity, age, and socioeconomic status.

A health care workforce that reflects the diversity of patients and provides culturally competent care can contribute to reducing these disparities. Community health workers play a unique role in implementing culturally competent health promotion and disease prevention programs.

Research

Heart disease continues to be the leading cause of death in the United States, and racial and ethnic minorities and individuals with lower socioeconomic status are strongly affected. Several large observational studies are examining the occurrence of cardiovascular disease and its association with biological, demographic, social, environmental, and genetic determinants of risk in minority populations.

■ Strong Heart Study (SHS) of American Indians

strongheart.ouhsc.edu

The SHS is a study of cardiovascular disease and its risk factors among American Indian men and women supported by the National Heart, Lung, and Blood Institute (NHLBI) since Oct. 1, 1988, and is the largest epidemiologic study of American Indians ever undertaken.

■ Jackson Heart Study of African Americans

www.jacksonheartstudy.org

The mission of the Jackson Heart Study is to examine the reasons for the greater prevalence of cardiovascular disease among African Americans and uncover new approaches for reducing this health disparity.

■ Genetics of Coronary Artery Disease in Alaska Natives

www.ncbi.nlm.nih.gov/pmc/articles/PMC3869403

Although Alaska Native peoples were thought to be protected from cardiovascular disease, data now show that this is not the case, despite traditional lifestyles and high omega-3 fatty acid intake.

■ Hispanic Community Health Study of Americans of Mexican, Puerto Rican, Cuban, and Central American descent

www.csc.unc.edu/hchs

This multicenter epidemiologic study in Hispanic/Latino populations aims to determine the role of acculturation in the prevalence and development of disease, and to identify risk factors playing a protective or harmful role among Hispanics/Latinos.

■ Multi-Ethnic Study of Atherosclerosis (MESA)

www.mesa-nhlbi.org

This study seeks to validate methods to detect cardiovascular disease before it has produced clinical signs and symptoms in African Americans, Hispanic Americans, Asian Americans, and Americans of European heritage.



Photo: iStock

April Is National Minority Health Month

2016 Theme: Accelerating Health Equity for the Nation

The Office of Minority Health in the U.S. Department of Health and Human Services leads the observance of National Minority Health Month each year. It joins with federal, state, tribal, local, and territorial partners across the country in calling for a renewed commitment to eliminate health disparities and achieve health equity. For more information, look for new resources and information about National Minority Health Month events, tool kits, social media content, partner and stakeholder events registry, and more at <http://minorityhealth.hhs.gov/nmhm>.

Find Out More

- ✓ National Institute on Minority Health and Health Disparities: www.nimhd.nih.gov
- ✓ Health Disparities: www.nlm.nih.gov/medlineplus/healthdisparities.html
- ✓ U.S. Office of Minority Health: <http://minorityhealth.hhs.gov>



ROBOTS

for better health and quality of life

As part of the National Robotics Initiative, multiple federal agencies are supporting the development of a new generation of robots that work cooperatively with people. This year, the National Institutes of Health funded three innovative robots. Two are to improve the health and quality of life for people with disabilities. The third is a “social companion” to inspire curiosity, determination, and hard work in children.

Smart-walker “surrounds a person with confidence”

As we age, it’s harder to walk without assistance. Physical activity and quality of life decrease. To continue living at home, we often require costly modifications such as ramps or wheelchair lifts.

University of Alabama in Tuscaloosa mechanical engineer Xiangrong Shen is developing a four-legged robot to help the elderly remain active and independent—without relying on caregivers or expensive home renovations.

Says Shen, “We want to help people in their daily lives in their own homes. Our robot surrounds a person with confidence.”

The new robot has two modes: power-assisted walker and smart “mule.” In the first, you select the level of power to maintain a stable, steady pace. As the smart mule, the robot walks beside you while carrying “saddlebags” of groceries, for example. It uses a 3-D computer vision-based system to detect your motion and surroundings. It easily bypasses obstacles that wheelchairs cannot.

This project is funded jointly by the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Nursing Research, and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.



Photo: Xiangrong Shen, University of Alabama, Tuscaloosa

“Robots are rapidly being incorporated into all aspects of our lives, from GPS in cars, to speech recognition on smart phones,” observes Roderic I. Pettigrew, PhD, MD, Director of the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the lead institute for the National Robotics Initiative at the NIH.

“We want to encourage leaders in the field of robotics to apply their ingenuity to improve health care. Such innovations have the potential to help facilitate healthy independent living.”

Roderic I. Pettigrew, PhD, MD, Director, National Institute of Biomedical Imaging and Bioengineering, NIH



Photo: NIBIB



A preschooler interacts with a social-robot companion.

Photo: Personal Robots Group, MIT Media Lab

A social-robot “buddy” for kids

Thanks to *Star Wars*, R2D2 and C3PO captivated Cynthia Breazeal’s imagination as a child. She grew up to pioneer human-robot interactions, develop Jibo, the world’s first family “companion” robot, and found and direct the Massachusetts Institute of Technology Personal Robots Group.

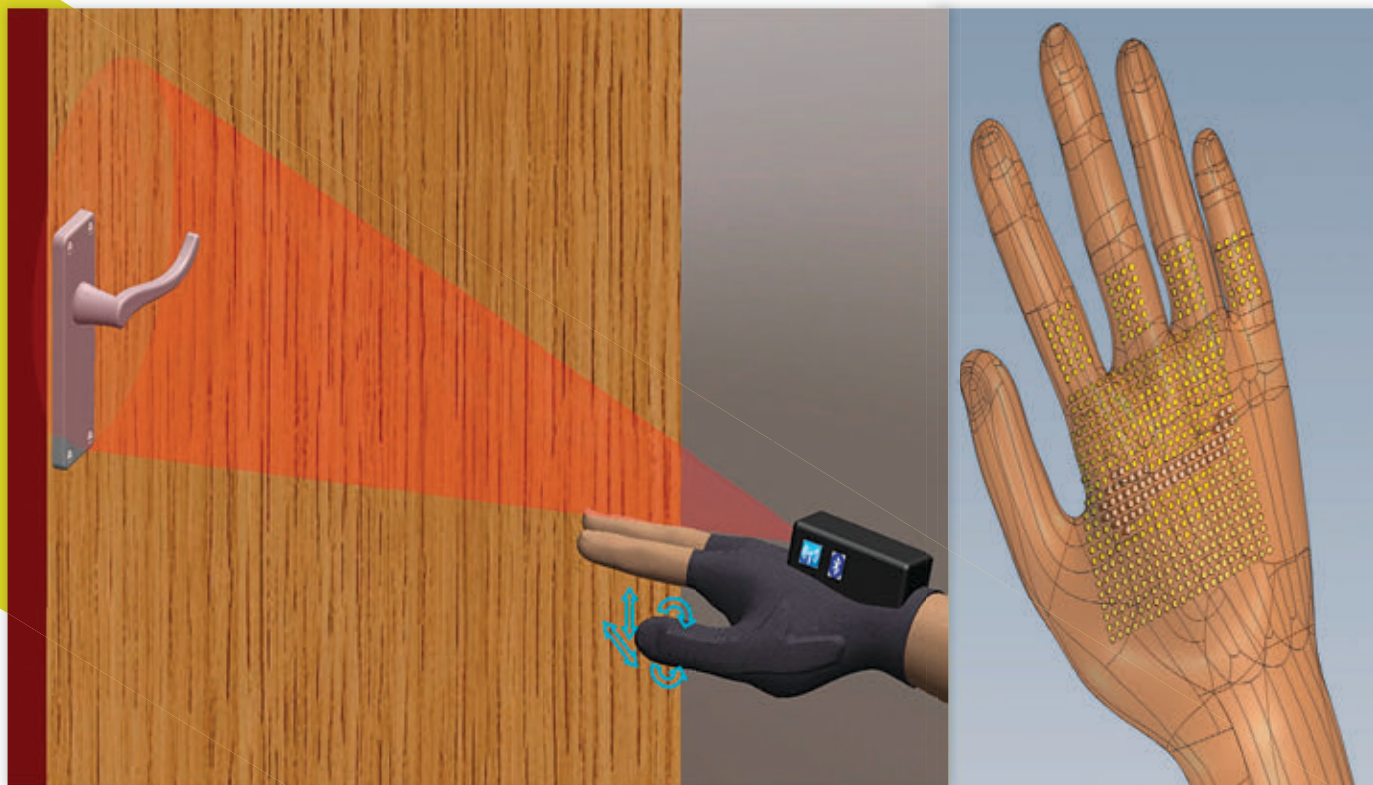
She and her team are working on an autonomous, long-term social robotic companion for children—an interactive “buddy”—to promote and assess a child’s curiosity and intellectual growth. Not only do dedication and hard work improve one’s basic abilities, Breazeal believes they also influence a child’s mental health, academic achievement, and general well-being. The researchers plan to evaluate the new “buddy’s” influence in a six-month study in which children learn and play while interacting with the robot companion.

This project is funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.

“If we’re ever going to see robots like *Star Wars*, it’s going to happen in a lab like this.”

— Cynthia Breazeal, Massachusetts Institute of Technology

Photo: Cang Ye, University of Arkansas at Little Rock



“Seeing-eye” glove for the visually impaired

Cang Ye is passionate about enlarging the world for the blind and visually impaired. “In the age of computers, we’re still using primitive devices—the white cane—to navigate our surroundings,” he says.

At his University of Arkansas laboratory, Ye and his systems engineering colleagues are creating a kind of “seeing eye” glove that combines a small, 3-D camera and computerized sensors to help people detect obstacles and grasp things. A blind person could use it to walk around a chair, for instance, or open a door handle.

“It’s a big challenge,” Ye says. “The glove needs to be both small and powerful.”

This project is funded by the National Eye Institute.

Find Out More

- ✓ **Eunice Kennedy Shriver National Institute of Child Health and Human Development:** www.nichd.nih.gov
- ✓ **National Eye Institute:** www.nei.nih.gov
- ✓ **National Institute of Biomedical Imaging and Bioengineering:** www.nibib.nih.gov
- ✓ **National Institute of Nursing Research:** www.ninr.nih.gov

Researchers Study Strategies to *Preserve Hearing*



Lisa L. Cunningham, PhD, Chief,
Section on Sensory Cell Biology

Photo: NIDCD

Focus on research: Dr. Lisa Cunningham

An estimated half million Americans experience hearing loss every year from ototoxic drugs—drugs that can damage hair cells in the inner ear that are essential for hearing. These drugs include some antibiotics and the chemotherapy drug cisplatin for cancer patients. Scientists at the National Institute on Deafness and Other Communication Disorders (NIDCD) are studying strategies to preserve hearing without interfering with the benefits of these often lifesaving drugs. Dr. Lisa Cunningham, Chief, Section on Sensory Cell Biology, spoke with **NIH MedlinePlus** magazine about the research.

What sparked your interest in hearing loss?

From my earliest days in school, I always liked science. I entered college as a pre-med student but switched to audiology in my junior year. After completing my first research project as part of my audiology training, I was hooked. I loved the feeling of discovery, and knew I would do research for the rest of my life. For my doctoral-level training, I studied neuroscience because I wanted to be able to study hearing at the cellular and molecular levels. My neuroscience training gives me the tools to carry out these fundamental studies, and my audiology background keeps me always searching for ways to translate our research into new therapies.

What are hair cells and why are they important to us?

Hair cells are the cells in the inner ear that convert sound into signals that are interpreted by the brain. They are called hair cells because they have a bundle of projections on them called stereocilia that look like tiny hairs. When sound waves cause the stereocilia to move, the hair cell sends a signal to the brain that tells the brain there was a sound.

What are ototoxic drugs and why are they important?

Ototoxic drugs are medications that cause hearing loss as a side effect. There are two major types. Cisplatin is a drug used to treat cancer—it saves many thousands of lives of both adults and children worldwide. Unfortunately, it also causes significant permanent hearing loss in a proportion of the patients treated with it. The second group of ototoxic drugs is a class of antibiotics called aminoglycosides. They are widely used to treat life-threatening infections. Like cisplatin, they cause hearing loss in many patients.

What Is Ototoxicity?

Ototoxicity describes something that is toxic to the ear (oto-). Ototoxic drugs can damage hair cells in the inner ear, causing hearing loss as a side effect.

How do these lifesaving medicines damage hearing?

Cisplatin and aminoglycosides kill the hair cells in the inner ear. Because our hair cells don't grow back after they die, the result is permanent hearing loss.

Have you discovered anything that may help to protect the hair cells?

Our lab and others have developed a variety of strategies to reduce hair cell death and hearing loss from ototoxic drugs in animal studies. For example, for the past several years my lab has focused on a class of protective molecules called heat shock proteins (HSPs).

What are heat shock proteins and how do they help my hearing?

HSPs are found in every cell type—yeast, bacteria, and plant and animal cells. They are robustly activated in cells exposed to dangerous levels of heat and to a wide variety of other cellular stresses, including starvation, oxygen deprivation, free radicals, and more. Once HSPs are activated in response to stress, they can help to keep cells alive and functioning. We have discovered that by activating them, we can protect inner ear hair cells from dying due to ototoxic drugs.

Testing to identify early signs of ototoxicity

At the National Institutes of Health, research audiologists like NIDCD's Carmen Brewer, PhD, evaluate the hearing of study volunteers being treated with known ototoxic drugs and experimental drugs.

"We start with a baseline-hearing test so we can monitor the effect of treatment on hearing function," she says.

"We test hearing at the most important frequencies for hearing and understanding speech, and for the extended high-frequency range (such as high-pitched whistles), which often shows early signs of ototoxicity. We also test for signs of early hair cell damage that cannot be detected by standard tests.



▲ Carmen Brewer, PhD, Chief Research Audiologist, NIDCD Audiology Unit

"Not every patient treated with ototoxic drugs develops hearing loss, and the extent varies from patient to patient."

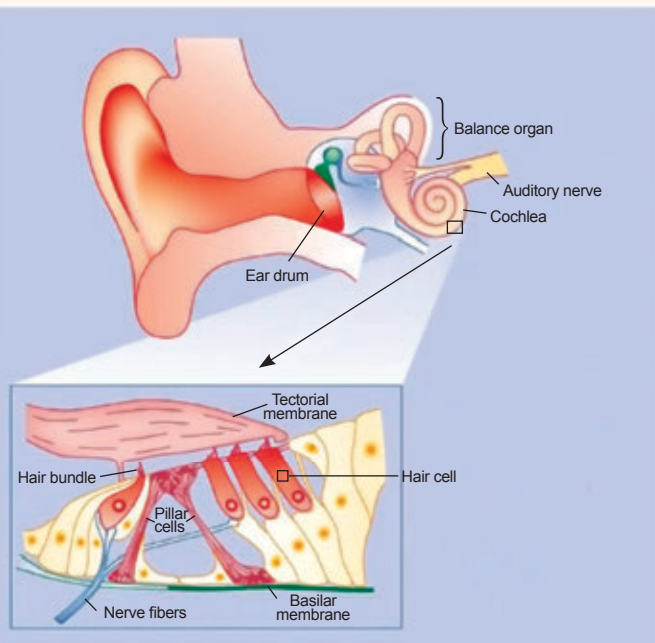
"We alert participants to the signs of hearing changes, such as ringing in the ears (tinnitus), a sense of fullness in the ears, and difficulty hearing in noisy situations.

"In some cases, the medical team may decide to change the patient's drug or how the drug is given. When needed, we also help participants and their families cope with hearing loss, including recommendations about hearing aids and other options to help improve the patient's ability to understand the sounds around them.

"In the longer term, we will collaborate with Dr. Cunningham to initiate clinical studies aimed at protecting the hearing of patients taking these drugs."

The Human Ear

Illustrations: Courtesy of Matthew Holley, adapted from *Nature*, 405(6783)



◀ View of the ear shows the cochlea—the organ of hearing—and hair cells. Some therapeutic drugs can kill hair cells, resulting in permanent hearing loss.

“Antibiotics Caused My Hearing Loss...”

When Gulab Lalwani of East Lansing, Michigan, was hospitalized with endocarditis, a serious infection of the heart, she was immediately put on a powerful antibiotic (gentamicin) to combat the infection. Thankfully, the medication did the job and stopped the infection after several weeks of treatment. But the news was not all good. The drug that saved her heart also substantially impacted her ability to hear. Ten years later, Lalwani, now 75, still has problems hearing, possibly due to age-related hearing changes combined with ototoxic hearing loss. “When I’m in a group or listening to the TV, I often can’t hear everything that is being said,” she says. “I think it is time for me to get hearing aids.”



Gulab Lalwani

Photo: Courtesy of Gulab Lalwani

Please describe the benefits of your findings.

Our results advance our understanding of the fundamental processes that occur when the inner ear is under stress. They point to a promising new direction for developing therapies to prevent hearing loss in patients who need lifesaving—but ototoxic—drugs. Our challenge now is to move this discovery from the laboratory to the clinic so it can benefit patients by protecting their hearing. We are working with our colleagues at the NIH Clinical Center to develop studies aimed at reducing hearing loss in patients taking ototoxic drugs.

What do you recommend for patients at risk from ototoxic drugs?

Patients should discuss the potential for drug-induced hearing loss with their doctor. It is very helpful to have a baseline hearing test before beginning therapy with ototoxic drugs. This allows the patient and his or her audiologist to monitor for changes in hearing and keep the medical team informed if these changes occur.

How important is long-term medical research like yours?

Medical research is the reason we have life-saving therapies in the first place. For example, the discovery of cisplatin was a major medical breakthrough. This drug saves the lives of millions of cancer patients and is remarkably successful at curing certain types of tumors in children. Unfortunately, it can also cause severe permanent hearing loss. This can be particularly troublesome for young children socially and in school because hearing is critical to their developing speech and language skills. Our goal is to improve the lives of these children and their families by developing therapies to protect their hearing.

Find Out More

- ✓ **National Institute on Deafness and Other Communication Disorders (NIDCD):** www.nidcd.nih.gov
- ✓ **MedlinePlus:** www.nlm.nih.gov/medlineplus/hearingdisordersanddeafness.html

The Zika Virus

A biting *Aedes aegypti* mosquito, which is responsible for transmitting Zika virus.

Photo: James Gathany, Centers for Disease Control and Prevention

NIH launches multiple research efforts to understand the Zika virus and find a vaccine.

Zika virus is a member of the flavivirus family. Other flaviviruses include dengue, yellow fever, and West Nile virus. Like its relatives, Zika virus is primarily transmitted to humans through the bite of infected *Aedes aegypti* mosquitoes.

It may also be transmitted from an infected pregnant woman to her baby during pregnancy or around the time of birth. Spread of the Zika virus through blood transfusion and sexual contact has been reported. Most people who become infected with Zika virus do not become sick. For the 20 percent of people who do become sick, the illness is generally mild with symptoms that include fever, rash, joint pain, or conjunctivitis (red eyes) and lasts several days to a week.

Microcephaly

There have been reports of a serious birth defect of the brain called microcephaly among babies born to infected women. Microcephaly is a condition in which a baby's head is abnormally small and can be associated with incomplete brain development. Currently, it is unclear what link, if any, Zika infection may have to microcephaly. International research organizations are investigating.

There have also been reports of Guillain-Barré syndrome (GBS) in some countries where Zika transmission is occurring. GBS is a rare autoimmune disorder in which damaged nerve cells cause muscle weakness and, sometimes, paralysis. Most people recover from GBS, but some have permanent damage and in rare cases GBS can lead to death.

“You could have a Zika virus vaccine in large-scale clinical trials in 2017, which is rocket speed for a vaccine.”

—NIAID Director Dr. Anthony S. Fauci

NIAID Zika Virus Research

The National Institute of Allergy and Infectious Diseases (NIAID) at NIH is accelerating research in areas such as:

- The natural history of the Zika virus
- Basic research on how it causes disease
- Diagnostics to rapidly determine if someone is or has been infected with Zika
- How to distinguish it from other flaviviruses
- Development of treatments and vaccines

Although Zika virus is new to the Western Hemisphere, NIAID scientists and grantees have long studied Zika relatives, such as dengue and West Nile virus. Those studies provide a springboard to accelerate investigations of Zika and may yield approaches to developing therapeutics and vaccines that will combat Zika virus.

NIAID is working with its partners in government, academia, and the pharmaceutical and biotechnology industries to better understand Zika virus, the disease it causes, and ways to combat it.

It is possible that an investigational Zika vaccine will be ready to enter early-stage human trials in 2016. An early-stage trial would examine whether an experimental vaccine is safe and generates immune responses in vaccinated volunteers.

“You could have a Zika virus vaccine in large-scale clinical trials in 2017, which is rocket speed for a vaccine,” said NIAID Director Dr. Anthony S. Fauci.



Photo: NIH

▲ Anthony S. Fauci, MD, Director of the National Institute of Allergy and Infectious Diseases.

Find Out More

- ✓ **NIH links:** <http://syndication.nih.gov/zika.htm>
- ✓ **Zika Virus:** www.nlm.nih.gov/medlineplus/zikavirus.html
- ✓ **Centers for Disease Control and Prevention (CDC) links:** www.cdc.gov/zika/index.html
- ✓ **NIH Seeks Research Applications:** www.niaid.nih.gov/news/newsreleases/2016/Pages/ZikaNotice.aspx

Putting a Face on *Rare Diseases*



Photo: Courtesy of Patricia Weltin

◀ Patricia Weltin (center) and her daughters, Olivia and Hana (left and right), who have a rare and potentially dangerous disease, Ehlers-Danlos syndrome.

Patricia Weltin says that her efforts to shine a light on rare and undiagnosed diseases is best expressed in the words of the late Swiss artist Paul Klee: “Art does not reproduce the visible; rather, it makes visible.”

That has been Weltin’s goal since she founded the non-profit Rare Disease United Foundation (www.rarediseaseunited.org) and began putting together the “Beyond the Diagnosis” traveling art exhibit—a collection of original paintings of children, each with a rare disease.

Weltin, a single parent who lives in Rhode Island, has two daughters with a rare and potentially dangerous disease, Ehlers-Danlos syndrome (EDS), a connective tissue disorder causing joint dislocations, tooth loss, and numerous other symptoms. EDS comes with life-threatening comorbidities like Chiari malformations, which are structural defects in the cerebellum, the part of the brain that controls balance.

In reaching out to other families who have children with rare diseases, she discovered that many of them feel invisible and isolated, as she did. But, altogether, there are between 25 and 30 million people in the United States with any one of more than 6,500 rare and/or undiagnosed diseases.

“It has become a global movement,” Weltin says. “I haven’t really called anyone. But CBS News found out about it and has recorded a segment for a couple of news shows. The exhibit will go to London in October.”

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FastFacts

- ✓ In the United States, a rare disease is generally considered to be a disease that affects fewer than 200,000 people. Rare diseases are sometimes called orphan diseases.
- ✓ There are more than 6,500 rare diseases. Altogether, rare diseases affect an estimated 25 million to 30 million Americans.
- ✓ The exact cause for many rare diseases remains unknown. For a significant portion, the problem can be traced to mutations (changes) in a single gene.
- ✓ Treatments for rare diseases are available for more than 200 of them at the present time.
- ✓ To find a rare disease specialist, start at <https://rarediseases.info.nih.gov/resources/pages/25/how-to-find-a-disease-specialist>.

—Source: Genetic and Rare Diseases Information Center (GARD)

“BEYOND THE DIAGNOSIS”

MAKING THE INVISIBLE PATIENTS VISIBLE

The “Beyond the Diagnosis” art exhibit’s focus is the rare disease patient. Artists have donated their time and talents to create paintings of rare disease patients for this groundbreaking portrait collection. The exhibit will travel to medical schools and hospitals across the country, encouraging the medical community to look “beyond the diagnosis” to

the patient. The exhibit has already been represented by displays in the Harvard Medical School’s Gordon Hall and the Clinical Center at the National Institutes of Health. The paintings are by artists from all over the world—the United Kingdom, Pakistan, Australia, India, and several European countries—as well as the United States. Katherine Belle and Case are two of the approximately 100 patients who have a painting either finished or under way.

Artist: Lori Jeremiah



Katherine Belle

“Born healthy in July 2011, Katherine Belle plateaued in her motor development at 13 months old and has never walked (age 3). After exhausting all tests, two doctors have given a 90 percent diagnosis of infantile neuroaxonal dystrophy. However, uncertainties remain, and further testing is under way. Katherine Belle is a beautiful, bright, and happy 3-year-old who loves cupcakes, books, mermaids, bunnies, Peppa Pig, and teasing her mommy and daddy. Katherine is our life’s greatest blessing.”

—Glenda, Katherine Belle’s mom

Artist: Charlie Hall



Case

“Case is 8 years old and faces every day with exuberant joy. He loves playing guitar, riding his pedal bike, bowling on Xbox Kinect, and swinging in his new sensory room. During his weekly four-hour infusion, his mom puts his pump and medicine in a backpack so he can jam to his favorite music videos. After being diagnosed with Hunter syndrome at 2, Case has endured (with a smile) more than 400 infusions, 100 flights to a clinical trial, 50 spinal taps, 10 surgeries, five Port-a-Caths, and one medical tattoo. He is quite proud of getting a tattoo at the tender age of 4.”

—Melissa, Case’s mom



On the Front Lines of *Rare Disease Research*

The Genetic and Rare Diseases (GARD) Information Center is a program of the NIH's National Center for Advancing Translational Sciences (NCATS). The GARD Information Center provides current, reliable, and easy-to-understand information about rare or genetic diseases in English and Spanish.

Dr. Petra Kaufmann is director of NCATS' Office of Rare Diseases Research, which includes GARD. She also directs NCATS' Division of Clinical Innovation. She recently discussed rare diseases and ongoing research with *NIH MedlinePlus* magazine.



Photo: Daniel Sone

Many people may not hear about research on rare diseases. Why is this research important for all of us?

There are more than 6,500 rare diseases, and only a few hundred have any treatment. While each rare disease affects fewer than 200,000 people, these conditions, in total, affect an estimated 25 million in the United States. Rare diseases are devastating and costly for patients, families, and the nation as a whole. This is partly due to the severity of these conditions, but also because diagnosis can be difficult and often only possible well after symptoms have appeared.

What motivated you to help explore research on rare diseases?

As a medical student, I saw my first patient with muscular dystrophy. The lack of available treatments prompted me to seek training and research opportunities so that I could help make a difference for patients with rare diseases, such as muscular dystrophies. I have since conducted laboratory and clinical research, and led rare diseases research programs, including clinical trials in academia.

As the director of the National Institute of Neurological Disorders and Stroke's Office of Clinical Research, I helped develop NeuroNEXT, a network for neurological trials, most of them in rare diseases. As a clinician, I have worked in the adult and pediatric neuromuscular clinics at Columbia University, and I currently volunteer as an attending physician in the Muscular Dystrophy

Association Clinic at Children's National Medical Center. This work gives me continued motivation to make a difference for patients with rare diseases and their families.

Is there progress being made on finding solutions for some rare diseases today?

NCATS tackles rare diseases through collaborative research to study the commonalities and underlying molecular causes of these disorders. There is indeed progress in understanding and discovering therapeutics for some rare diseases. For example, researchers at the Rare Lung Diseases Consortium, which is part of the NCATS Rare Diseases Clinical Research Network, developed a treatment approved by the U.S. Food and Drug Administration (FDA) last year for lymphangioleiomyomatosis, a rare lung disease that affects women of childbearing age.

▲ Dr. Petra Kaufmann and U.S. Rep. Joseph Crowley, co-chair of the Rare Disease Congressional Caucus, visit the "Beyond the Diagnosis" exhibit at the NIH Clinical Center. They are shown with a painting by artist Tom Hughes of Devon, who has atypical hemolytic uremic syndrome.

GARD is funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI).

In addition, in January 2016, Vtesse, Inc., announced that the FDA granted breakthrough therapy designation status to the company's drug candidate, VTS-270, for treatment of Niemann-Pick disease type C1. Researchers supported through NCATS' Therapeutics for Rare and Neglected Diseases program and the Eunice Kennedy Shriver National Institute of Child Health and Human Development, in close collaboration with Vtesse, patients, and patient advocacy groups, developed VTS-270 as part of a project focused on finding treatments for this lipid storage disease.

“Having four children myself, I can only imagine what it means for families when they find out that their child has a rare disease.”

—Dr. Petra Kaufmann, Director, NCATS Office of Rare Diseases Research and Division of Clinical Innovation

Additional NCATS programs and initiatives that support rare diseases research include but are not limited to the following: Genetic and Rare Diseases Information Center, Global Rare Diseases Patient Registry Data Repository, and our Clinical and Translational Science Awards Program.

How important is medical research on rare diseases to my family and me?

Having four children myself, I can only imagine what it means for families when they find out that their child has a rare disease. Medical research is critical, not only because it can advance the diagnosis and treatment for rare diseases, but also because it brings hope to people living with rare diseases. In addition, rare diseases research has the potential to speed the development of treatments for more common diseases at the same time.

Find Out More

- ✓ **National Center for Advancing Translational Sciences (NCATS):** ncats.nih.gov
- ✓ **MedlinePlus:** www.nlm.nih.gov/medlineplus/rarediseases.html
- ✓ **Rare Disease United Foundation:** rarediseaseunited.org

Rare Disease Day

Aims to Maximize Chances for Cures

Rare Disease Day takes place worldwide on the last day in February to raise awareness among policymakers and the public about rare diseases and their impact on patients' lives.

Each year, the National Center for Advancing Translational Sciences (NCATS) and the NIH Clinical Center sponsor Rare Disease Day at NIH as part of this global observance. Since 2010, the slogan for NIH's event has been "Patients & Researchers—Partners for Life."

This slogan aligns with NCATS' philosophy that researchers must work closely with patients, families, caregivers, and advocacy groups to maximize the chances for success in advancing rare diseases research. This philosophy has been put into practice in NCATS' Rare Diseases Clinical Research Network and the Therapeutics for Rare and Neglected Diseases program, among other efforts.

The European Organisation for Rare Diseases (EURORDIS) is the voice of 30 million people affected by rare diseases throughout Europe. EURORDIS is a non-governmental, patient-driven alliance of patient groups representing 705 rare disease patient organizations in 63 countries.



Photo: NCATS

▲ Aidan (center), with his father, younger brother, mother, and Rare Disease United Foundation CEO Patricia Weltin, has the rare disease ectodermal dysplasia. It is an inherited disorder that involves defects in the hair, nails, sweat glands, and teeth. The ectoderm contributes to the formation of the lens of the eye, parts of the inner ear, the fingers and toes, and nerves, among others. Ectodermal dysplasia may cause these parts of the body to develop abnormally. Aidan, his family, and Weltin attended the "Beyond the Diagnosis" art exhibit at the NIH Clinical Center on Rare Diseases Day. His painting is by artist Nan Kruzik.

Fibromyalgia: A Puzzling and Painful Condition

Fibromyalgia can take a powerful toll on health, well-being, and quality of life.

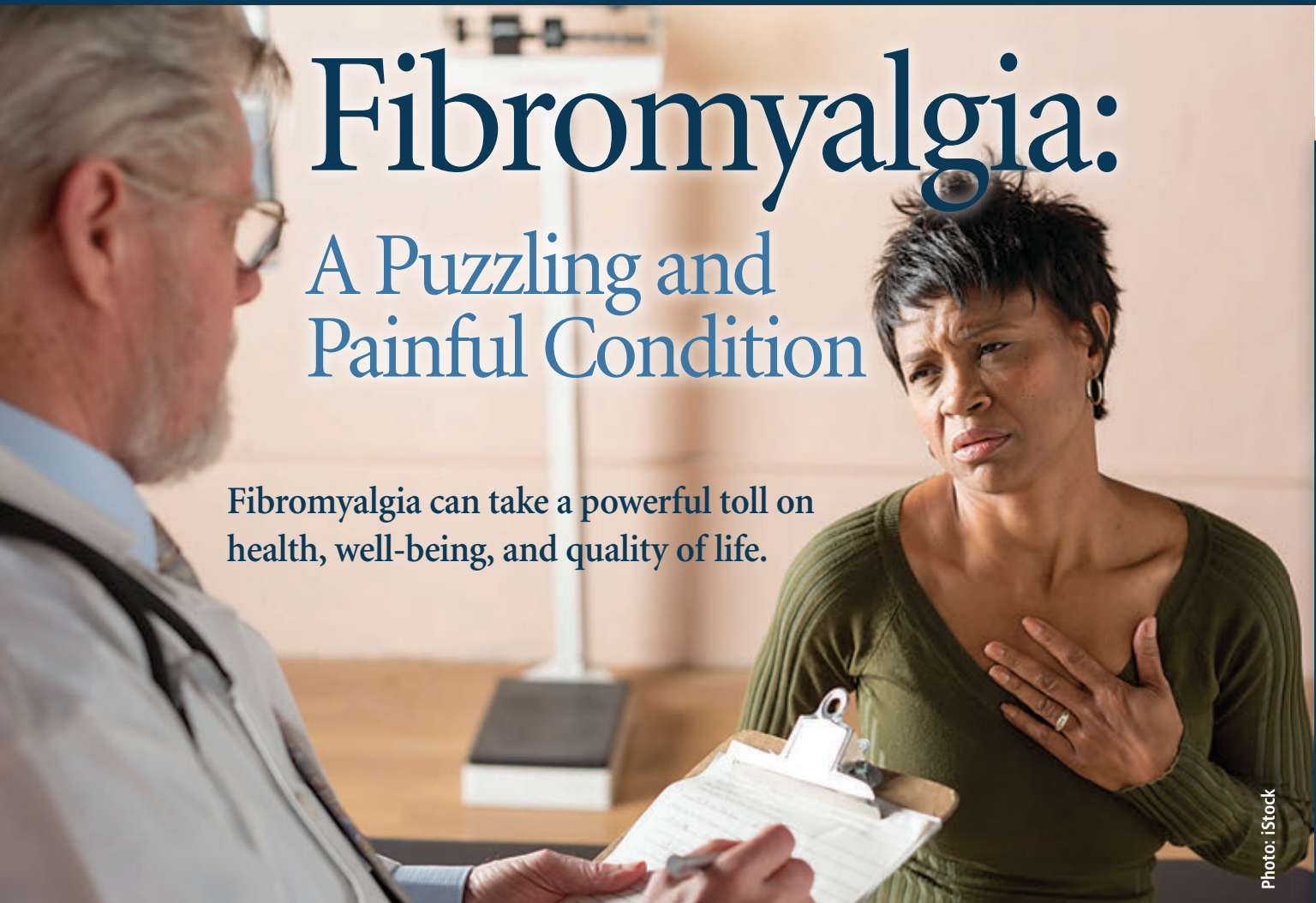


Photo: iStock

You've probably heard of fibromyalgia, but you may not know what it is. Fibromyalgia is a long-term (chronic) pain condition that affects 5 million or more Americans ages 18 and older. For unknown reasons, most people diagnosed with fibromyalgia are women, although men and children also can be affected. People with certain disorders, such as rheumatoid arthritis or lupus, may also have fibromyalgia, which can affect their disease course and treatment.

Fibromyalgia can take a powerful toll on health, well-being, and quality of life.

"People with fibromyalgia suffer from severe, daily pain that is widespread throughout the body," says Dr. Leslie J. Crofford, an NIH-supported researcher at Vanderbilt University. "Their pain is typically accompanied by debilitating fatigue, sleep that does not refresh them, and problems with thinking and memory."

Complex Diagnosis

People with fibromyalgia often see many doctors before finally receiving a diagnosis. The main symptoms—pain and fatigue—overlap with those of many other conditions, which can complicate the diagnosis.

"To make things more challenging, there are no blood tests or X-rays that are abnormal in people with the disorder," Crofford says. With no specific diagnostic test, some doctors may question whether a patient's pain is real. "Even friends, family, and

Wise Choices: Feeling Better with Fibromyalgia

- **Get enough sleep.** Getting the right kind of sleep can help ease pain and fatigue. Discuss any sleep problems with your doctor.
- **Exercise.** Research has shown that regular exercise is one of the most effective treatments for fibromyalgia.
- **Try a complementary health approach.** Practices such as tai chi, qi gong, yoga, massage therapy, and acupuncture may help relieve some symptoms.
- **Consider medicines.** Talk to your health care provider about an approved medication for treating fibromyalgia.

coworkers may have a difficult time understanding the person's symptoms."

A doctor familiar with fibromyalgia can make a diagnosis based on the criteria established by the American College of Rheumatology. Diagnostic symptoms include a history of widespread pain lasting more than 3 months and other symptoms such as fatigue. In making the diagnosis, doctors consider the number of areas throughout the body where the patient had pain in the past week, and they rule out other causes of disease.

Cause Not Fully Understood

What causes fibromyalgia isn't fully understood. Many factors likely contribute.

"We know that people with fibromyalgia have changes in the communication between the body and the brain," Crofford says. These changes may lead the brain to interpret certain sensations as painful that might not be bothersome to people without the disorder.

Researchers have found several genes that may affect a person's risk of developing fibromyalgia. Stressful life events may also play a role.

Fibromyalgia isn't a progressive disease, so it doesn't get worse over time and may even improve. It's never fatal, and it won't harm the joints, muscles, or internal organs.

Treatment

Medications may help relieve some—but not all—symptoms of fibromyalgia. "Drug treatments by themselves don't result in remission or cure of fibromyalgia," Crofford says. "We've learned that exercise may work as well as or better than medications. In addition, therapies such as tai chi, yoga, and cognitive behavior therapy can also help to reduce symptoms."

People with fibromyalgia often have the best results when treated with multiple therapies.

"It's critically important for health care providers to help patients develop an understanding of fibromyalgia, and to provide realistic information about treatments, with an emphasis on using exercise and other physical therapies in conjunction with medications," Crofford says.

Crofford and her colleagues are exploring whether a treatment called TENS (transcutaneous electrical nerve stimulation) can help people with fibromyalgia exercise more comfortably and reduce pain. She and other NIH-funded teams are also seeking markers of fibromyalgia in the blood that might ultimately lead to more targeted and effective treatments.

If you or someone you know has fibromyalgia, see the "Wise Choices" box for tips on reducing its impact.

—Source: *NIH News in Health*

Facing Fibromyalgia

“I feel like myself again.”



Amy Richardson with her daughter Lela.

Photo: Courtesy of Amy Richardson

Amy Richardson, a 30-year-old mom from Lodi, California, has dealt with the debilitating pain of fibromyalgia since childhood. Like many with fibromyalgia, she has another overlapping chronic pain condition, temporomandibular joint disorder (TMJ), which causes pain and dysfunction in the jaw joint and the muscles that control jaw movement. She spoke with **NIH MedlinePlus** magazine about her conditions.

When did you start having symptoms of fibromyalgia?

I actually think I've had it since I was a kid. After just doing normal kid stuff, I would wake up the next day and my ankle would hurt for the next two weeks. That kind of thing seemed to happen pretty often. I have had problems with my right wrist since the third grade.

Did your problems become more severe over time?

Yes, it seems like it became more noticeable on a day-to-day basis in high school. When I was 19, I was diagnosed with TMJ after I started having pain in my jaw when eating. Sometimes I had to go on a liquid diet to avoid the pain.

I have wondered whether my pregnancy impacted my condition, because since I got pregnant with my daughter I've had to think about being in pain every day. My daughter is now 8 years old. When she was little I felt terrible because often I couldn't read her a book at night because of the pain from TMJ.

What process did you go through to get diagnosed with fibromyalgia?

Many doctors saw me over the years. Some were dismissive of my symptoms. I had been tested for lupus over and over and arthritis.

I wasn't diagnosed with fibromyalgia until I was 26. A wonderful new primary care doctor was very thorough and referred me to the appropriate specialists. They did specific tests for fibromyalgia, including pressure point tests. They asked me where the pain was and I said it is easier to tell you where it is not.

“The diagnosis was correct.”

When you got the diagnosis, what was your reaction?

I had a split second of relief that I finally knew what it was, and then I just had a flood of emotions. Because of my history, I was skeptical. But after a few more visits it was clear that the diagnosis was correct.

What treatment did they prescribe for you? How has that helped?

The doctor started me on one medication, but that didn't help. Then they started me on gabapentin. It took four to five months to get the right dosage. I have a little bit of pain, but few side effects. I have been on this medication for almost three years now. And I feel like myself again. When I was having pain on a regular basis, I didn't feel like myself.

I am a school bus driver now. I know that without the medication I wouldn't be able to work. I tried to be more active but it just knocked me out.

What do you say to others who might be experiencing these kinds of symptoms?

Try to find the right doctor who is willing to work with you and listen to you. Keep trying to find what works for you even though can be a tiring and frustrating process. Medications are scary, and they don't work for everyone, but for me the right one made me feel like myself again.

What Research Is Being Conducted on Fibromyalgia?

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) sponsors research that will improve scientists' understanding of the specific problems that cause or accompany fibromyalgia, in turn helping them develop better ways to diagnose, treat, and prevent this syndrome. For example:

Scientists are seeking to determine the extent to which chronic pain in people with fibromyalgia is associated with the activation of cells in the nervous system and the production of chemical messengers, called cytokines, that regulate immune cell function.

- Researchers are using imaging methods to evaluate the status of central nervous system responses in people diagnosed with fibromyalgia.

Investigators are seeking to identify markers of fibromyalgia in the blood that might ultimately lead to more targeted and effective treatments.

- Studies are examining the use of cognitive behavioral therapy and transcutaneous electrical nerve stimulation (TENS) in people with fibromyalgia, which researchers hope will result in better management of the disorder.

Find Out More

- ✓ **National Institute of Arthritis and Musculoskeletal and Skin Diseases:** www.niams.nih.gov/health_info/fibromyalgia
- ✓ **National Center for Complementary and Integrative Health:** www.nccih.nih.gov/health/fibromyalgia
- ✓ **Fibromyalgia:** www.nlm.nih.gov/medlineplus/fibromyalgia.html

10 New NIH Research Highlights

With NIH support, scientists across the United States and the world conduct wide-ranging research to improve the health of our nation. Here's a small sample of recent research accomplishments made by NIH-supported scientists.

Breast Cancer Tumor Test May Help Women Avoid Chemotherapy

A new test may help some women diagnosed with early-stage breast cancer avoid unnecessary chemotherapy treatment. The National Cancer Institute sponsored a large clinical study to determine the types of tumors that would benefit from chemotherapy.

Participants included more than 10,000 women who had recently been diagnosed with hormone-receptor positive, human epidermal growth factor receptor type 2 (HER2) negative breast cancer that had not spread to the lymph nodes. Scientists used a diagnostic gene test called the 21-gene recurrence score (Oncotype DX® Recurrence Score, Genomic Health, Inc.) to help predict the usefulness of chemotherapy and the likelihood of breast cancer recurrence.

The results: 16 percent of women had a test result indicating a very low risk for recurrence. These women did not receive chemotherapy, but did receive standard hormone therapy. Researchers followed up five years later and found that the risk for any breast cancer recurrence for these women was less than 2 percent, and the risk for a recurrence at a distant site was less than 1 percent. The overall survival rate was 98 percent. However, while the study was in 10,000 patients, these results only refer to the 16 percent with the lowest score. Researchers are still waiting for results for the randomized portion of the study. But these findings suggest that gene testing may help guide treatment choices in the future.



A Comparison of Blood Pressure Control Targets

High blood pressure has no noticeable symptoms, but if left untreated can cause serious health problems.

Currently, the standard treatment for patients with hypertension is a systolic target of 140 mmHg. But in 2015, the National Heart, Lung, and Blood Institute, along with other NIH components, sponsored a large clinical study to determine if a more intensive treatment—a target goal of less than 120 mmHg—would be more beneficial for patients with high blood pressure.

More than 9,300 patients ages 50 and older with increased cardiovascular risk were enrolled in the study. Researchers concluded that, compared with the 140 mmHg target, a target systolic pressure of 120 mmHg reduced cardiovascular events, such as stroke, heart attack, and heart failure, by 25 percent. Risk for death was also reduced by 27 percent. Adverse events occurred in both groups, but results suggest that the benefits outweigh these risks.



Photos: iStock

NIH-Supported Researchers Earn Prestigious Awards

Groundbreaking NIH-funded research often receives top scientific honors. In 2015, these honors included three NIH-supported Nobel Prize winners:

- **Paul Modrich, PhD**, of Howard Hughes Medical Institute and Duke University School of Medicine, and **Aziz Sanchar, MD, PhD**, of the University of North Carolina at Chapel Hill, shared the chemistry prize. It honored the mapping at a molecular level of how cells repair damaged DNA and safeguard genetic information.
- **Angus Deaton, PhD**, of Princeton University, was awarded the economics prize. His recent work examined the impact of the financial crisis on well-being in the United States. It also examined how subjective measures of well-being vary across people in different societal groups and in different countries.

Two NIH-funded researchers received top awards from the Lasker Foundation in 2015:

- **Stephen J. Elledge, PhD**, of Harvard Medical School and Brigham and Women's Hospital, shared the Albert Lasker Basic Medical Research Award. It honors discoveries concerning the DNA-damage response, a fundamental mechanism that protects the genomes of all living organisms.
- **James P. Allison, PhD**, of University of Texas MD Anderson Cancer Center, received the Lasker-DeBakey Clinical Medical Research Award. It recognized the discovery and development of a monoclonal antibody therapy that unleashes the immune system to combat cancer.



Researchers ID Genes to Help Predict Heart Disease Risk and Statin Benefits

Healthy lifestyle choices can often help prevent or treat heart disease. If lifestyle changes aren't enough, medicines such as statins can help. But genetics also play a role in heart disease risk, particularly genetic variations known as single-nucleotide polymorphisms (SNPs).

Funded in part by the National Heart, Lung, and Blood Institute, researchers asked if a composite of SNPs could predict heart disease risk and determine who might benefit most from statin therapy. Researchers analyzed data from five studies that included more than 48,000 people who experienced nearly 3,500 heart-disease related events. They then calculated a genetic risk score based on 27 heart disease-associated SNPs, and divided each participant into a low, intermediate, and high genetic risk category. Compared with the other groups, people with the highest genetic risk had an increased risk for coronary heart disease, and a 70 percent greater risk for a heart attack. Genetic risk score also predicted the ability of statin therapy to reduce the risk for heart attack or other heart disease-related events.

These findings suggest that people with the highest genetic risk may benefit the most from statin therapy. This may lead to targeted therapies for patients at risk for heart disease.

Non-surgical Treatment Helps Paralyzed Men Get Moving

In 2015, researchers reported that a surgically stimulating device allowed paralyzed men to regain leg movement. In a follow-up study, scientists tested a nonsurgical strategy for stimulating the spinal cord, known as transcutaneous stimulation. This method sends an electrical current to the spinal cord through electrodes placed on the skin over the spine. The follow-up study included five men who were each paralyzed for more than two years. Each participant received 18 weekly sessions of spinal stimulations for 45 minutes. The men also received muscle conditioning by a therapist, and twice-daily doses of buspirone during the last four weeks of the study.



At first, spinal stimulation only allowed for involuntary step-like movements. But after four weeks, their range of motion was doubled. By the end of the study, the men's legs could move with no stimulation at all, and their range of movement equaled that during spinal stimulation, on average. Electrical signals in the participants' calf muscles also increased over time—suggesting a re-establishment of communication between the brain and spinal cord.

The researchers are assessing if these men can be trained to fully bear their weight. The work was funded in part by the National Institute of Biomedical Imaging and Bioengineering, National Center for Advancing Translational Sciences, and other NIH components.

New NIH Research Highlights

Researchers Identify Energy-Burning Fat Cells

Humans have both white and brown fat cells. Brown fat burns energy and helps maintain body temperature, while white fat stores excess calories. Too much white fat can cause obesity and metabolic disorders.

But researchers recently discovered another type of fat cell: beige. These fat cells appear in white fat cells, but can burn calories like brown fat cells. How beige cells form, however, is uncertain, and brown fat can be difficult to find in humans.

In a study funded in part by NIH's National Institute of Diabetes and Digestive and Kidney Diseases, researchers aimed to better characterize brown and beige fats on a cellular level in adults. After obtaining human fat cells, researchers discovered that genes active in the human cells were similar to those active in mouse beige fat cells, but not in mouse brown fat cells. Analysis of two of the genes in mice revealed that the genes were required for beige fat cells to become brown fat cells, as well as to burn energy to create heat. In the future, these findings may help scientists engineer fat cells to address obesity.



Multiple Sclerosis Patients May Benefit From Immune System Reboot

According to the three-year results of an ongoing clinical trial funded by the National Institute of Allergy and Infectious Diseases, high-dose immunosuppressive therapy with autologous hematopoietic cell transplant (HDIT/HCT) is a promising treatment for early-stage multiple sclerosis (MS).

HDIT/HCT allows doctors to reset a patient's immune system. This is done by collecting hematopoietic stem cells (HSCs), which are cells that eventually develop into blood cells. Then, high-dose chemotherapy and other drugs deplete the patient's immune system. Finally, the patient is infused with his or her own HSCs, which produce red and white blood cells that re-establish the patient's immune system.

The results of the clinical trial so far show that nearly 80 percent of those treated with HDIT/HCT survived without an increase in disability, relapse of MS symptoms, or new brain lesions. Currently, researchers believe this is most applicable to those with early-stage relapsing-remitting MS, the most common form of MS. Research is ongoing to further evaluate the benefits and risks of HDIT/HCT for those with MS.



Eating Peanut-containing Foods in Early Childhood Reduces Peanut Allergy

A recent *New England Journal of Medicine* study suggests that infants who begin consuming peanut-containing foods early and continued through age 5 are less likely to develop a peanut allergy than those who avoid these foods. Researchers followed more than 600 infants at high risk for peanut allergy for about five years. The infants were randomly assigned to either avoid peanut entirely or to regularly eat at least 6 grams of peanut protein, such as smooth peanut butter, every week.

The results showed that eating peanut-containing foods caused an 80 percent reduction in the development of peanut allergy for those who ate them regularly beginning at an early age. While this research shows promise for preventing peanut allergy, the researchers cautioned parents of children with increased risk—such as those with eczema or egg allergies—to consult an allergist or pediatrician before giving their kids peanut products. The study was funded primarily by NIH's National Institute of Allergy and Infectious Diseases.

End-of-Life Care for Dementia Greatly Outpaces Other Diseases

Those living with dementia face far higher health care costs than for those living with other diseases like cancer or heart disease. That's according to a recent study in *Annals of Internal Medicine*. Researchers reviewed data on more than 1,700 Medicare beneficiaries age 70 and older who died between 2005 and 2010. While Medicare covers most medical costs for those over age 65, expenses like home care and medical equipment aren't always included.

For those with dementia, the average total health care cost was greater than \$287,000 in the last five years of life. That was significantly higher than the average health care cost for those who died of heart disease (\$175,000), cancer (\$173,000), and other causes (\$197,000). The average out-of-pocket costs associated with treating dementia was more than \$61,522, which was 81 percent higher than those without the disease (\$34,068).

The study, which is supported by the National Institute on Aging, provides a critical look at the cost of treating dementia and the financial burden many families face.



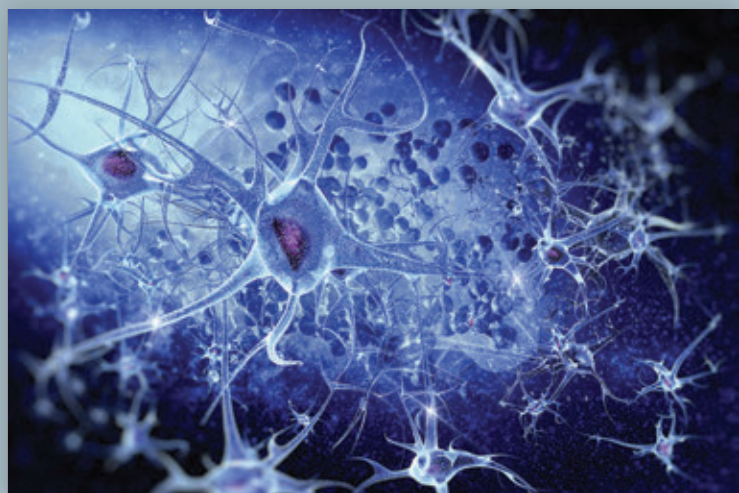
New NIH Research Highlights

Cataloging Human Genetic Variation Around the World

A team of international scientists has collected the world's largest assortment of human genetic differences in various populations around the globe. These data provide researchers with a powerful tool to study how genetic variation affects disease risk and drug response for treatment.

The 1000 Genomes Project Consortium, partially funded and directed by the National Human Genome Research Institute, a part of NIH, published the results in two studies in the journal *Nature*. The researchers sequenced the genomes of more than 2,500 people from 26 populations across Africa, East and South Asia, Europe, and the Americas. In the main paper, researchers identified about 88 million sites in the human genome that vary among people. The majority of these—about 84.7 million—were differences in a single DNA building block called single nucleotide polymorphisms (SNPs).

In the companion article, researchers found 69,000 rarer structural variants in the genome. While less common than SNPs, these variants were much more likely to be associated with traits such as disease risk. Researchers hope these data increase the understanding of variations in genomes and provide a foundation for better insights into human disease genomics.



3-D Printing Holds Promise for Nerve Regeneration

Treatment for peripheral nerve damage varies depending on the type of injury, and current treatment options typically rely on grafting a portion of healthy nerve to help replace the damaged section. This type of treatment is limiting, however, and can have negative health outcomes for patients.

As a result, researchers have been investigating other techniques to guide nerve regeneration, one of which includes using a 3-D printer to mimic naturally branching nerves. To create a customized, 3-D printed nerve scaffold, a section of the nerve is removed and a cast is prepared. A 3-D light scan is conducted at various angles, and a 3-D model of the nerve pathway can then be printed.

So far, this method has been used on damaged sciatic nerves in rats, improving the animals' ability to walk within three months. As this technique develops, scientists hope this technique may be used to create a range of customized nerve scaffolds to aid in cell regeneration. Research was funded in part by NIH's National Institute of Neurological Disorders and Stroke and National Heart, Lung, and Blood Institute.

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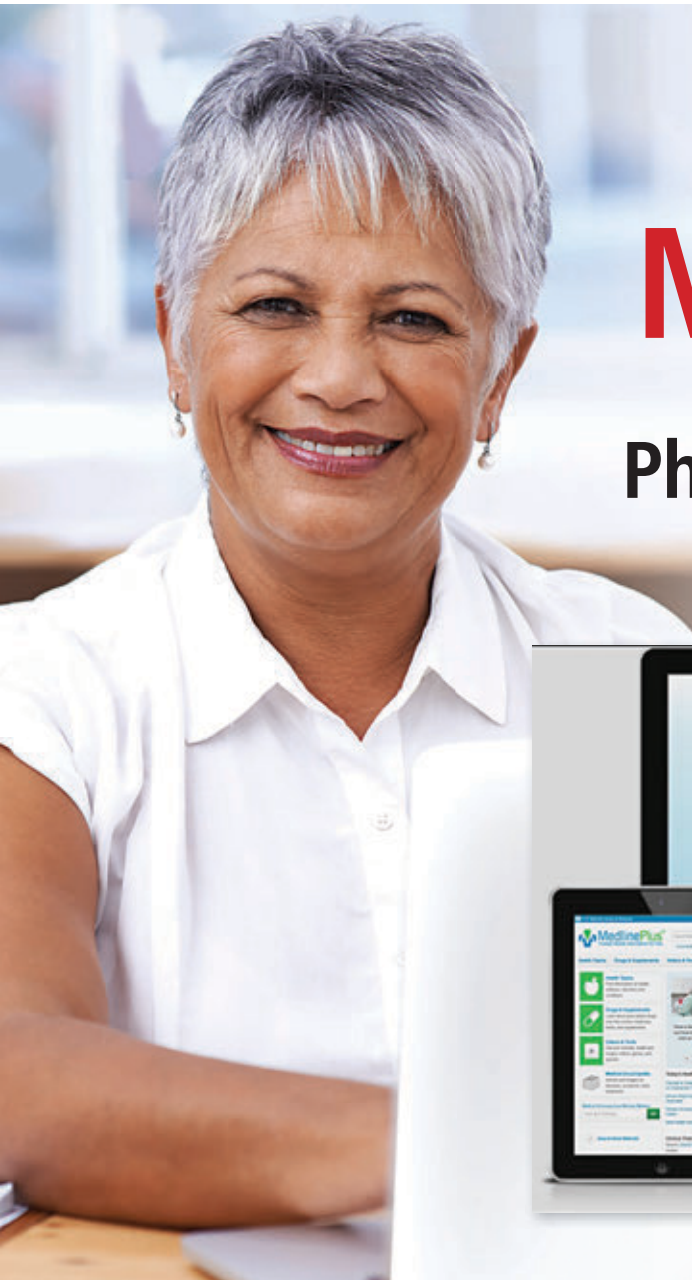
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