

Why Invest in NIH?

By ensuring steady and sustainable annual increases to the budget for the **National Institutes of Health**, Congress can save and improve lives, advance innovation and fuel the economy. Here are some other reasons why Congress must act to **#keepNIHstrong**.



Featured

- James Lair
- Chris Borland
- Cindi Dodd
- Jenelle Stephenson
- A'ndrea Elyse Messer

Every day, research funded by the NIH has a direct impact on patient lives — from enabling people to make better-informed decisions about their health, to enhancing quality of life and saving lives. Patients — today's and tomorrow's — are the reason behind the research.

James Lair

When James Lair was born six weeks early weighing 8 pounds, everything seemed fine. But as months passed, his growth slowed. He was three before he walked. And while his parents knew something wasn't right, test after test came back normal with doctors concluding James was 'just a slow grower.'

A Google search led them to the **Undiagnosed Diseases Network** (UDN), a multi-disciplinary research study funded by the NIH and focused on diagnosing rare and unknown diseases. Researchers at the network's 12 clinical sites act like detectives — pursuing clues gathered from a patient's genetics, imaging, biochemistry and clinical exams and working collaboratively to try to discover what is wrong.

At the UDN clinical site at Washington University in St. Louis, the team investigating James' condition discovered that he has an exceptionally rare genetic variant in a gene, MAP2K1, that makes an enzyme that is important in cell signaling. Disruption of this gene can cause problems in cellular growth and development. Their analysis also uncovered two other patients with the same gene variant and developmental symptoms similar to James'. The similarities in these cases led the team to recommend that James receive growth hormones, which have helped to accelerate his growth rate.

[Learn more here.](#)



Image credit | Huy Mach

“It was just a relief — instant relief. To get that news that you've been waiting seven years to hear — that someone has actually found something that they think is wrong with your child.”

Amy Lair
Mother of James Lair

Chris Borland

Chris Borland retired from the San Francisco 49ers in 2014 after just one season in the NFL citing concerns about chronic traumatic encephalopathy (CTE) and the impact of football on the health of his brain. In 2018, he nominated Dr. Ann McKee, neuropathologist and director of Boston University's Chronic Traumatic Encephalopathy (CTE) Center to **TIME'S 100 Most Influential People** list, explaining "I had dedicated my life to the game of football and realized a dream by competing in the NFL. But after just one season, I quit because I was worried about brain damage. Dr. McKee's groundbreaking work on CTE was central to my decision, and she may have saved my life. At the very least, her work has likely spared me much of the suffering we see today among former NFL players."

CTE is a devastating and progressive degenerative brain disease associated with dementia, mood changes and aggression and afflicts many athletes and soldiers. Dr. McKee's work shifted scientific thought regarding repetitive head trauma by demonstrating that repetitive "mild" head trauma could trigger CTE. Much of Dr. McKee's work has been supported by the NIH.

[Learn more here.](#)

“She may have saved my life. At the very least, her work has likely spared me much of the suffering we see today among former NFL players.”

Chris Borland
Former San Francisco 49ers linebacker



Image credit | Getty Image

Cindi Dodd

Cindi Dodd woke up early one morning in 2017 having had a massive stroke at some point during the night. By the time she was rushed to the hospital, too much time had passed according to medical guidelines for her to be a candidate for the most effective acute stroke treatments. However, doctors where she had been taken for treatment were aware of a study being done at nearby Stanford University in which they were using brain imaging software to identify patients who still might benefit from a thrombectomy, a clot-removal procedure, even after the six-hour "golden" window had passed. Dodd proved to be such a candidate and fully recovered from her stroke following a thrombectomy.

That study was a 38-center clinical trial sponsored by the NIH and led by researchers at Stanford University School of Medicine. The **research** was critical to the decision by the American Heart Association and the American Stroke Association in early 2018 to amend their guidelines for stroke treatment to increase the treatment window for clot removal from six hours to 24 hours in certain patients.

[Learn more here.](#)

“I am literally standing on this Earth as a wife and a mother because of that procedure.”

Cindi Dodd
Ischemic stroke survivor



Image credit | Leslie Williamson

Jenelle Stephenson

In December 2017, Jenelle Stephenson, 27 at the time, began a **novel treatment** for sickle cell disease (SCD) as part of an NIH clinical trial. She was one of the very first people to receive an experimental gene therapy that uses gene editing to modify the patient's bone marrow to make the red blood cells resistant to the bending that causes them to be sickle-shaped in patients with SCD.

SCD affects approximately 100,000 people in the United States. It is caused by a specific gene mutation that affects the shape of red blood cells. Instead of being donut-shaped, they are sickle-shaped, which causes the cells to clump together in the blood vessels, resulting in severe pain, blood cell destruction, anemia, stroke, pulmonary hypertension, organ failure, and often, early death.

Prior to beginning the gene therapy trial, Stephenson said, "Just the idea of being able to potentially live a life that is pain free keeps me smiling and keeps me fighting for another day." A little more than a year later she was able to say, "I am feeling amazing after the treatment; but it has been a year of adjustment, for sure. But I can confidently say that I feel healthy. I never knew the body could feel this good."

[Learn more here.](#)



Image credit | National Heart, Lung, and Blood Institute

“I never knew the body could feel this good.”

Jenelle Stephenson
Sickle cell disease patient and NIH clinical trial participant

A'ndrea Elyse Messer

A'ndrea Elyse Messer, PhD, was one of eight participants in a clinical study at Johns Hopkins University in which researchers tested an implantable technology to alleviate the effects of bilateral vestibular hypofunction (BVH), which is the loss of the inner ear's sense of balance. People with BVH have difficulty walking without falling, experience dizziness and cannot participate in many daily activities that those without BVH take for granted.

Researchers at Johns Hopkins Medicine used basic research and engineering technology to modify a cochlear implant so that instead of stimulating the inner ear's cochlear nerve, it activates the nearby vestibular nerve in response to signals from a motion sensor on the patient's head. In a study of eight patients with BVH, they showed that by electronically bypassing the malfunctioning areas of the inner ear, the implant partially restores the sensation of balance and improves quality of life in patients.

The study results were reported in the **New England Journal of Medicine** in February 2021. The study was conducted with funding from the National Institute on Deafness and Other Communications Disorders, part of the NIH.

[Learn more here.](#)

“Before receiving it, I couldn't walk in the dark, on uneven ground or without a cane. Now, I can do all of those things and am living a fairly normal life.”

A'ndrea Elyse Messer
BVH patient



Image credit | A'ndrea Elyse Messer

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