TuSalud

What RFK Jr. Isn’t Talking About: How To Make Vaccines Safer

The NIH appears not to have funded studies of postvaccine syndrome, which can have symptoms that mimic those of long COVID.

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Within an hour of receiving a COVID vaccination in November 2020, Utah preschool teacher Brianne Dressen felt pins and needles through her arms and legs. In the medical odyssey that followed, she suffered double vision, chronic nausea, brain fog, and profound weakness. Once a rock climber, she became a couch potato.

Although Dressen’s symptoms were rare in that season of hundreds of millions of COVID vaccinations, they were common enough to draw the attention of a National Institutes of Health neuroscientist named Avindra Nath, who examined Dressen and more than 30 other people with a similar syndrome in 2021. He recommended Dressen take steroids and antibodies — treatments that saved her life, she said.

And then, according to emails reviewed by KFF Health News, Nath said he couldn’t help anymore. His clinical study was ending. He directed the patients to seek local help. But, Dressen said, there wasn’t any.

Nath declined to speak to KFF Health News for this article. The FDA searched international vaccine safety databases for small-fiber neuropathy, one of the most common symptoms he mentioned in a write-up of the patients, and found it was less prevalent in vaccinated than in unvaccinated patients, said Peter Marks, who led the FDA division responsible for vaccines until Health and Human Services Secretary Robert F. Kennedy Jr. forced him out in May.

While it’s possible that Nath’s patients suffered COVID vaccine injuries, Marks said, their symptoms were so varied it was hard to characterize a possible syndrome.

But for Dressen and others convinced the vaccines injured them, their experiences were symptomatic of a well-intentioned but flawed U.S. system for monitoring the rare ill effects of vaccines. The system isn’t well-funded enough to answer questions that people urgently want answered, and that can feed vaccine hesitancy, safety experts say.

Its shortcomings were on particular display during the mass vaccination campaigns of the

pandemic, when even rare serious side effects could affect thousands of people.

Now some leading vaccine scientists are calling for more resources to research vaccine safety and support people with claims of injury — and asking Kennedy, who has a history as an anti-vaccine activist, to step up.

“Spending money on vaccine safety is not saying vaccines aren’t safe; it’s showing a commitment to continued improvement,” said Y. Tony Yang, a professor of health policy at George Washington University’s Milken Institute School of Public Health.

So far, they’ve been disappointed. While Kennedy gives the public the impression that vaccines are harmful, he hasn’t talked about ways to make them safer. And he’s made the problem worse by cutting programs and dismissing scientists who are most knowledgeable about the problems, according to numerous vaccine experts.

“The reduction in emphasis on the unbiased ascertainment of vaccine safety signals, and redirection toward certain specific issues like autism in vaccines, which we know is not true — that is what’s dangerous,” Marks said.

In March, the Trump administration abruptly canceled a contract with researchers just as they began a massive COVID vaccine study aimed at discovering the genetic traits that make certain people vulnerable to vaccine-triggered myocarditis. That condition struck about 1 in 13,000 teenage boys and young men who received two doses of the Pfizer or Moderna mRNA vaccine in 2020 and 2021.

Then, on June 9, Kennedy sacked the entire 17-member Advisory Committee on Immunization Practices, or ACIP, which during the pandemic impaneled a group of experts that reviewed safety data from nearly 700 million COVID vaccinations.

The new ACIP contains members who have said most vaccines are dangerous and improperly tested. Sen. Bill Cassidy (R-La.), who chairs the Senate committee with oversight of HHS, said on X on June 23 that the ACIP meeting scheduled for June 25-26 should be delayed until ACIP is staffed with less biased, more knowledgeable members.

HHS officials have suggested that Kennedy intends to throw out the whole vaccine safety system and start over. In a statement to KFF Health News, spokesperson Emily Hilliard accused the Centers for Disease Control and Prevention of “suppressing information about vaccine injuries” and said the Vaccine Adverse Event Reporting System, or VAERS, and the Vaccine Safety Datalink, monitoring systems in place since the early 1990s, were “designed to fail” and “templates of regulatory malpractice.”

She said HHS was “building surveillance systems that will accurately measure vaccine risks as well as benefits.” Asked for details, Hilliard did not respond. The HHS budget proposal for fiscal year 2026 makes no mention of vaccine safety programs.

The current U.S. vaccine safety system began with passage of the 1986 National Childhood Vaccine Injury Act, which aimed at stabilizing the vaccine supply by stopping lawsuits against drug companies. At the time they were getting out of the vaccine business, finding it less risky and more profitable to produce drugs for chronic diseases. The act set up the National Vaccine Injury Compensation Program and VAERS.

CDC vaccine safety officer Robert Chen built on VAERS to create the Vaccine Safety Datalink, which looks for evidence of vaccine harms in electronic health records. In 2001, the CDC set up the Clinical Immunization Safety Assessment project, through which a network of eight U.S. centers study rare vaccine reactions.

But the vaccine safety system's budget has been stuck at around $20 million most years. That hasn't been enough to study rare but recurring vaccine injuries in a serious way.

"$20 million to look at all the licensed vaccines in this country is woefully inadequate," Dan Salmon, director of Johns Hopkins University's Institute for Vaccine Safety, said at a recent conference. Without a more serious commitment, he said, "our products won't be as safe as they could be."

As an HHS vaccine safety official during the Clinton, Bush, and Obama administrations, Salmon helped write two plans that called for expanded safety work, including examinations of whether the vaccine schedule might be contributing to an increase in allergic diseases.

A little-publicized CDC-led 2022 study suggested that the aluminum salts added to make some pediatric vaccines more effective might cumulatively be linked to an increased incidence of asthma. Salmon thinks it merits further research — to refute or confirm the results. The issue "should have been studied decades ago," he said.

A Failed Compensation Program

Vaccine advocates and skeptics agree that the government program established to compensate people injured by vaccines or other public health measures during emergencies — the Countermeasures Injury Compensation Program — has miserably failed those with COVID vaccine-related injuries. As of June 1, the program has compensated only 39 of nearly 14,000 people who have filed COVID vaccine injury claims. Only five have gotten awards of more than $10,000.

The program is far less generous and user-friendly than the National Vaccine Injury Compensation Program, funded since 1988 by an excise tax on vaccines. It has paid out about 12,000 awards worth a total of $4.8 billion, mostly to care for vaccine-injured children.

People with COVID vaccine injuries, however, are stuck in a kind of limbo, often without clear medical options. It's unfair and "very bad for public confidence in vaccines," said Amy Pisani, CEO of Vaccinate Your Family, a nonprofit that promotes vaccination, speaking on a panel with Salmon at the April conference.

Kennedy has condemned the injury compensation system for shielding drug companies from lawsuits, but if he wants to help patients he should move COVID vaccines into the program, said Renée Gentry, who runs a law clinic for vaccine injuries at George Washington University Law School.

“The longer you hang these people out to dry, you are creating a perfect storm where nobody’s going to want to get vaccinated,” she said.

A Curtailed Vaccine Injury Investigation

In December 2021, the NIH’s Nath emailed Dressen and the other patients suffering from postvaccine problems that he could no longer help them. He told Science magazine that investigating vaccine side effects was a delicate business when public health leaders were urging everyone to get their shots.

“You have to be very careful. You can make the wrong conclusion,” he said. “The implications are huge.

Nath published an article in 2023 calling for more investigation of vaccine-related neurological conditions. His lab also released preliminary results from its study of Dressen and the other patients, which pointed to helpful treatments. But the paper has not been published in a peer-reviewed journal.

And none of the federal agencies recognized that her condition might be vaccine-related, said Dressen, who received her shot in an AstraZeneca clinical trial. (FDA officials were concerned about the vaccine’s side effect profile, and it was never distributed in the United States.)

Dressen said Nath’s withdrawal left her distraught.

“They reassure everyone there’s a safety net, but every one of those things is a complete failure,” she said. “I didn’t speak out because of my injury. The reason I spoke out is because of what happened after my injury.”

“People are suffering, and we don’t yet understand why or how to help them,” said Harlan Krumholz, a cardiologist who is part of a research project at Yale University led by immunobiologist Akiko Iwasaki that includes hundreds of patients with postvaccine issues. “Worse, many of them have felt ignored or dismissed by the very institutions meant to help and support them.”

The NIH appears not to have funded studies of postvaccine syndrome, whose symptoms mimic those of long COVID. Yet genetic studies could help “to determine who might be more susceptible to this condition,” Iwasaki said in an email.

Such research appears ideal for the Clinical Immunization Safety Assessment, established to examine rare vaccine reactions. But the network has published nothing on COVID vaccines, nor

are any trials related to the issue listed on government websites.

German researchers have studied postvaccine syndrome in more depth. Germany's Paul-Ehrlich-Institut, a sort of FDA for vaccines, reported in December that it had reviewed 919 cases of postvaccine syndrome that were similar to long COVID — a rate of about 1 in 100,000 vaccinations. It said causality was hard to establish because of the diverse symptoms reported.

Can Vaccine Safety Move Out of HHS?

In 1999, Chen, the CDC scientist, published an article suggesting that to speed studies and boost public confidence, vaccine safety should be moved to an independent agency, perhaps modeled on the National Transportation Safety Board, which can subpoena records from industry or other government agencies for its crash investigations.

Although HHS did not respond to a query about the idea, vaccine litigant Aaron Siri, who has been a personal attorney to Kennedy, told KFF Health News that Kennedy supported it.

In the meantime, some vaccinologists hope they can persuade Kennedy to spend more money on good vaccine safety research.

While it is "very painful to watch" what Kennedy is doing to HHS vaccine policy, "it would behoove us to find common ground," Salmon said at the conference. That doesn't mean "funding terrible studies to confirm hypotheses that some people believe," he added.

Though that is what many see Kennedy doing. One of his first moves as secretary was to hire David Geier, whose previous publications are considered junk science by many in the field, to conduct a review of vaccine links to autism. Studies around the world have thoroughly debunked such a connection.

Building on an Existing System

When HHS' Vaccine Safety Datalink was set up in the early 1990s, it was the envy of the world. There are now also good systems in Denmark, England, Israel, and Australia, but the U.S. system has worked pretty well, said Steve Black, who co-directed the Kaiser Permanente Vaccine Study Center from 1985 until 2007.

The Vaccine Safety Datalink was largely responsible for the 1999 removal of a rotavirus vaccine that triggered rare intestinal disorders in babies. And its discovery of a rare but deadly side effect helped keep the AstraZeneca COVID vaccine off the U.S. market and led to the removal of the Johnson & Johnson vaccine, Black said. It also helped pinpoint myocarditis soon after young men began getting mRNA shots in 2021.

Since 2019, Black has co-directed an ambitious, 30-country consortium called the Global Vaccine Data Network, which enables vaccine safety analyses across massive, diverse populations around the world.

The group was just beginning its study of genetic predispositions to myocarditis when the Trump administration withdrew a $2 million CDC payment, halting the work.

An email from the Department of Government Efficiency, or DOGE, “asked a bunch of irrelevant questions like, Had we ever been funded by China? Did we have collaborators in Europe?” It ordered the network to cease and desist with no due process or means of appeal, Black said.

Research funded by the grant had progressed to the point of finding seven genetic variants known to be related to cardiac inflammation in people who got myocarditis postvaccination, said Bruce Carleton, the lead investigator, at the University of British Columbia. Work remains, but the data suggests a $6 test could clear vulnerable patients before they are vaccinated, Carleton said.

“Millions got mRNA vaccines. Very few got myocarditis,” Black said. “The public would like to know, ‘Am I at risk?’ Genetics can answer that.”

The CDC has been an honest broker of vaccine safety information, Black added, but if taking the issue out of HHS would improve public confidence, he’s for it.

Vaccines need to be safer, Dressen said, but the idea of banning them doesn’t sit well with her.

“There’s the crowd that wants mRNA vaccines to be pulled off the market, but that’s not going to fix the problem. Vaccines are not going to go away,” she said.

As of June 5, a patient group she leads had provided $1.2 million to 162 people needing medical care for injuries they attributed to vaccination.

Meanwhile, the federal countermeasures program, which doles out COVID vaccine injury awards through a trust, has committed $2.6 million for one patient and $370,376 for another. As of June 1, it had granted an additional 37 claimants a grand total of $198,809.92.

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