



SOLVE M.E.

RESEARCH 1st

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You + ME Survey Finds Health of People with ME/CFS More Likely to Worsen Compared to Controls After Vaccination

19% of people with ME/CFS said health worsened after vaccination compared to 4% reported by controls.

A recent survey by our You + ME Registry found that the health of people with ME/CFS is significantly more likely to worsen after Covid-19 vaccination compared to controls.

About five months after receiving their first or only shot of Covid-19 vaccine, 19% of survey participants with ME/CFS indicated their health had worsened, 9% reported that it had improved and 73% responded that it had not changed.

This compares to 4% of controls (people who did not have ME/CFS) who said their health had worsened, 7% who indicated it had improved and 89% who reported it had not changed. (See Table 1.)

“The ME/CFS community has raised concerns about how Covid-19 vaccination might affect people with ME/CFS. Our survey suggests that people with ME/CFS are much more likely to report that their health had worsened after vaccination compared to controls,” said Oved Amitay, CEO and president of Solve M.E., which founded the You + ME Registry.

“Yet, vaccination may still be a better option for people with ME/CFS than risking Covid-19 infection and spreading the virus. Individuals and their healthcare providers should work together to make these decisions,” Amitay continued. “Also, these results do not tell us if the reported health changes were caused by vaccination, and more research is needed.”

Our survey suggests that people with ME/CFS are much more likely to report that their health had worsened after vaccination compared to controls. Yet, vaccination may still be a better option than risking Covid-19 infection and spreading the virus. These results do not tell us if the reported health changes were caused by vaccination, and more research is needed.

Table 1. Health Status 22 Weeks* After First/Only Covid-19 Vaccine Shot**

Cohort	Health Did Not Change***	Health Improved	Health Worsened***
ME/CFS	73%	9%	19%
Controls	89%	7%	4%

*22 weeks is the median amount of time after vaccination that health status was reported by participants.

**Analysis based on 457 total respondents

***ME/CFS and control differences are statistically significant at $\alpha=0.05$.

Controls: What You Need to Know

What are they and why are they so important?

A control is a person who does not have the disorder or disease being studied—ME/CFS and Long Covid in our case—who has agreed to participate in a study. To understand what’s happening in someone with a disease we need to compare it to what’s happening in someone without a disease.

#WomenInSTEM

We can thank a woman—a pioneer in so many ways—for introducing controls to medical research. In 1912, Dr. Janet Lane-Claypon (below) published her study of two groups of babies: one was fed breast milk and the other cow’s milk. She found that breast milk correlated with higher weight gain, a key indicator of healthy development.

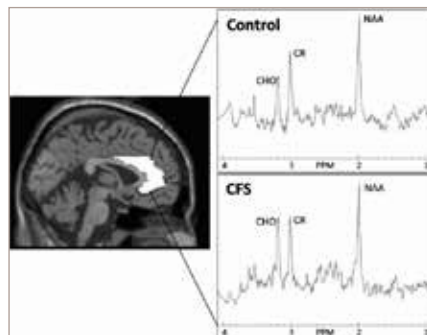


In 1926, her research on breast cancer risks (which identified most of the same risks recognized today) cemented the efficacy of the new methodology, changing medicine forever. Controls became widely used in medical research.

Building on Dr. Lane-Claypon’s efforts, researchers developed further ways to reduce bias. Randomized clinical trials (RCT) decrease bias by randomly assigning participants to groups. To reduce bias further, the double-blind study, in which neither the participants nor the investigators know who is receiving the treatment, was developed next. It’s the gold standard of medical research.

Controls and ME/CFS Research

Jarred Younger’s neuroimaging research (supported by Solve ME’s Ramsay Grant Program) found increased levels of choline and lactate and elevated temperature in the brains of people with ME/CFS compared to controls [see image below.] Younger concluded that ME/CFS may be caused by chronic, low-level neuroinflammation.



Thanks to studies like Dr. Younger’s, recent clinical trials on drugs that reduce neuroinflammation in people with ME/CFS include:

- **Rintatolimod:** A phase 3 clinical trial showed a positive effect on exercise tolerance and quality of life for some ME/CFS patients and testing on Long Covid is underway. It is not yet approved by the FDA.
- **Solriamfetol:** A phase 4 clinical trial is underway.
- **CT38:** A phase 2 clinical trial showed sustained symptom improvement and additional trials are planned.
- **Why Are Controls Important to You + ME?**

To identify treatments, we’re gathering information about the experience of

living with ME/CFS and Long Covid, the most common symptoms found in both and the activities and/or medicines that affect them. We need that same information from people who do *not* have ME/CFS or Long Covid so that we can compare the two and identify patterns seen only in people with the illness.

What Does it Mean to Be a Control in the You + ME Registry?

It means that you’re actively participating in ending these diseases.

The process is easy. Simply sign up [youandmeregistry.com] and answer questions about your health and complete surveys on how you’re feeling. That’s it! We take your privacy very seriously and the information you provide is completely secure.

Conclusion

With a grateful nod to trailblazer Dr. Lane-Claypon, we encourage controls to join the You + ME Registry along with people with ME/CFS and Long Covid.

We know much more about ME/CFS and Long Covid than even a year ago but what really matters—treatments and a cure—remain elusive. Their complex, multi-system nature and life-altering symptoms and global impact demands that we all—patients, controls and researchers—work together to end the suffering of millions.

Please ask your family, friends and co-workers to sign up for the You + ME Patient Registry.

Prepping for Your Medical Appointment

ME/CFS and Long Covid are complex, multi-system conditions that can be challenging to understand and manage, especially within a typical medical appointment.

So here are 6 tips to help you prep for your appointment.

1

Focus on the symptoms that most impact your quality of life. Write them down, along with your questions, and use them to guide the conversation.

4

Take notes. You may forget information or advice, especially if you're feeling unwell.

2

Track your symptoms. Providing specific examples and recognizing patterns may help manage your symptoms. Join the Registry to download our free Symptom Tracking App.

5

Have someone with you. They can help by taking notes, asking questions, advocating, or providing support, especially when you're not feeling well.

3

Ask questions. Be sure you understand the purpose and side effects of suggested prescriptions or supplements.

6

Remember you are your own best advocate. If your concerns are not being addressed or if your provider is dismissive, try to find a new one.

Help Us Welcome Leslie Phillips, PhD!



We recently welcomed Leslie Phillips, an epidemiologist, as consulting director of product management and operations for the You + ME Registry. Leslie has a PhD from the University of Washington, an MS from the Harvard School of Public Health and a BA from the University of Texas at Austin.

Using Data Analysis to Study ME/CFS + Long Covid

This two-part series features winners of our 2021 Stupski Awards, which support research using data from the You + ME Registry.



Jennifer Stone, PhD,
Australian National University
February 15, 3pm PT

You + ME 

Via Zoom

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