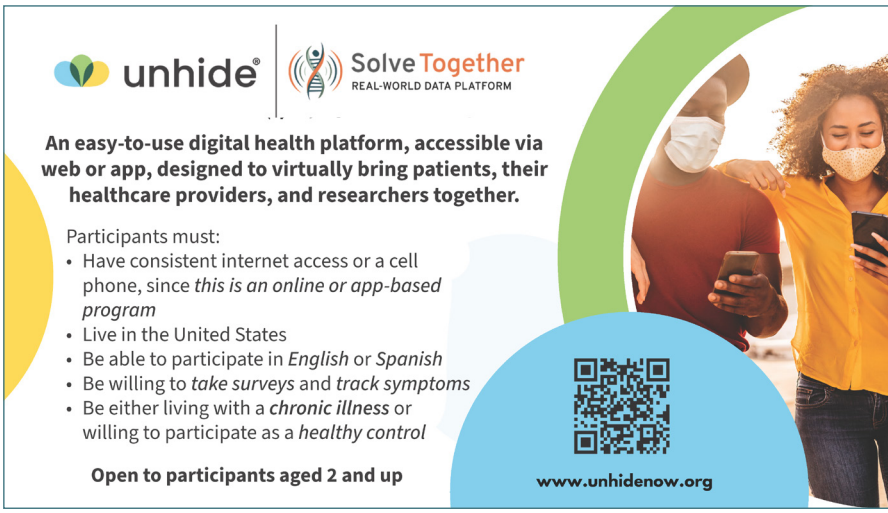
The Solve CHRONICLE

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DECEMBER 2025

Solve M.E. and The Brain Inflammation Collaborative Launch the Unified Platform to Advance Research Across 30+ Chronic Conditions

Solve M.E., in partnership with The Brain Inflammation Collaborative (BIC), recently launched the unhide® Solve Together Unified Platform, a digital health tool designed to uncover hidden connections between inflammation, chronic illness, and overall health.



Building upon Solve M.E.'s original Solve Together platform and incorporating the unhide project's innovative focus on brain inflammation-related symptoms and conditions, the Unified Platform is an exciting resource for patients and researchers alike. The easy-to-use, secure platform allows patients to contribute data through symptom surveys, validated assessments, wearable devices, and health history to support research across 30+ related conditions.

Parents and guardians can now enroll their young children (ages 2-6) and participate on their behalf. School-age children (ages 7–12) can complete surveys and track symptoms side-by-side with their parents/guardians. Teens (ages 13+) can enroll themselves with parental consent, and will also be able to link data from wearable devices, such as an Apple Watch. This milestone expands the reach of The Unified Platform, making it one of few large-scale digital health research initiatives actively collecting real-world data from pediatric participants.

"For too long, children and teenagers have not been able to narrate the lived experience of their illnesses themselves, and their voices have been missing from clinical research. Allowing teens and school-age children to participate directly in unhide® changes that. In addition, enrolling pediatric participants will allow researchers to better understand the effects of chronic illness on critical periods of brain development across the

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Solve M.E. and The Brain Inflammation Collaborative Launch the Unified Platform to Advance Research Across 30+ Chronic Conditions (cont'd)

lifespan", said Dr. Megan Fitzgerald, the platform Principal Investigator.

Solve M.E. CEO Emily Taylor noted, "By joining forces through the Unified Platform, we're not just combining data—we're combining hope, purpose, and possibility. This collaboration streamlines research efforts, lowers the cost of research, and opens new doors for scientists who are urgently seeking answers. For the patients and families who've waited too long, it brings us one step closer to the breakthroughs they deserve."

The Unified Platform enables patients and caregivers to:

- Track symptoms and visualize health patterns over time
- Connect wearable data for more complete insights
- Download and print customized reports to have better conversations with healthcare providers
- Contribute to cross-disease research initiatives
- Optionally receive invitations to participate in clinical trials and studies
- Identify ways to determine relationships between brain inflammation and mental health symptoms such as brain fog, difficulty concentrating, memory issues, sleep problems, mood changes, anxiety, and depression

This patient-centered, cross-condition approach complements traditional single-disease advocacy groups by providing data to support their work and enabling findings for one condition to inform and impact many more. By facilitating partnerships between advocacy groups, patients, caregivers, researchers, and healthcare providers, the Unified Platform will serve as a catalyst for better health among all who are impacted by neuroinflammation.

Adult participants can register at unhidenow.org.

Existing Solve Together participants will automatically gain access to the enhanced features—no re-enrollment is necessary. All data remains private and securely stored.

Solve recently hosted a webinar exploring the Unified Platform. CEO Emily Taylor was joined by Brain Inflammation Collaborative (BIC) co-founder and CEO Christy Jagdfeld, BIC Principal Investigator and lived experience expert Megan L. Fitzgerald, PhD, and Chris Nowak (CareEvolution), the platform architect and caregiver to a person with ME/CFS. You can watch a recording of the webinar here.



From AI Insights to Treatment Trials: Highlights from Q3 2025 Research

For the third quarter of 2025, we highlight these dozen research papers about Long Covid, ME/CFS, and other infection-associated chronic conditions. These include several large-scale artificial intelligence studies to find disease drivers, risks, and subtypes, and several studies (both large and small) on treatments.

Reading Through Colored Plastic Can Help People With Long Covid Read Faster and More Comfortably

Dr. Jan Johansson is a neuroscientist at the Karolinska Institute (Sweden) who recently tested whether using colored overlays (tinted plastic sheets placed over pages of text) helps people with Long Covid–associated visual problems to read quicker and more comfortably. Many people with Long Covid have trouble reading. Among the 29 people with Long Covid participating in this study, 6 in 10 reported strain when reading under fluorescent lights; half reported needing more time to read than before; and 4 in 10 reported strain even when reading clear text. For reasons not fully understood, using colored plastic overlays or colored lenses can reduce eye strain and increase reading speed for people with other neurological conditions affecting vision (like migraine or stroke). Indeed, almost 9 in 10 people taking part in Dr. Johansson's study said the overlays helped, for example by making them more comfortable or calm while reading or by making the text clearer. Participants read significantly faster with the colored overlays, especially participants with the greatest visual discomfort, the greatest mental fatigue, and the longest-lasting disease. Comparing a dozen options (11 colored, one gray), participants overwhelmingly favored the colored overlays over the gray one—half picked lilac, aqua, or purple, and none picked gray. Although people may have just liked the colors, some research suggests certain colors help certain people in ways beyond dimming light. This study appeared in the journal *Vision Research*.

Pyridostigmine Quickly Improves Muscle Strength and Reduces Heart Rate for People With ME/CFS

Researchers at the Charité–Universitätsmedizin Berlin (Germany)—Ms. Ella Schlömer, Dr. Laura Kim, and two-time Solve Ramsay Research Grant awardee Dr. Carmen Scheibenbogen—recently studied whether the drug pyridostigmine improves muscle strength and lowers orthostatic intolerance for people with ME/CFS. Pyridostigmine helps nerves to stimulate muscles. It is approved for strengthening muscles in people with myasthenia gravis and can strengthen heart muscles and reduce symptoms in people with POTS. For this study, participants with ME/CFS visited the clinic twice, once to measure symptoms without pyridostigmine treatment, and again to measure with treatment. During each visit, researchers measured symptoms at two points (60 minutes apart). Muscle strength was measured with a hand dynamometer, and orthostatic intolerance was measured with the 10-Minute Lean Test. Comparing measurements from different visits and time points showed that pyridostigmine treatment significantly reduced symptoms. Without treatment (during the first visits), participants' grips got progressively weaker. For the 10-grip sets, the last grips were significantly weaker than the first ones; and grips at the second time point were significantly weaker than at the first time point. Also, participants' heart rates during the second lean test were faster than during the first test, reflecting orthostatic intolerance. But with pyridostigmine treatment (administered right after the first set of measurements during return visits), participants had significantly stronger grips that remained firm and significantly steadier heart rates. Overall, these results show that pyridostigmine treatment swiftly improves muscle strength and reduces orthostatic intolerance–related changes in heart rate for people with ME/CFS. This is important because for these people, hand grip strength predicts severity of other symptoms (e.g., cognitive impairment, fatigue, and muscle pain) and overall prognoses. This study was published in the journal *Frontiers in Neuroscience*.

Successful Treatment for a Woman With Long-Standing, Severe ME/CFS by Using Oral 5-Aminolevulinic Acid, Sodium Ferrous Citrate, and Ubiquinone

A team led by Dr. Tomohiro Koga, professor of immunology and rheumatology at Nagasaki University (Japan), published a case report about a 35-year-old woman with ME/CFS for whom treatment with oral 5-aminolevulinic acid, sodium ferrous citrate, and ubiquinone substantially improved vigor and wakefulness. This woman had experienced persistent exhaustion since she was 11 years old, and drugs for treat-

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From AI Insights to Treatment Trials: Highlights from Q3 2025 Research (cont'd)

ing psychiatric or sleep disorders did not help. Critically, the researchers found that this woman had an uncommon mutation in the gene ADCK1, which encodes a protein important for muscle mitochondria to function properly and for reducing reactive oxygen species (a normal but potentially dangerous product of mitochondrial metabolism). 5-aminolevulinic acid boosts mitochondrial function in general and improves vigor and mood for people with mitochondrial diabetes. And ubiquinone (critical for mitochondria to make ATP) reduces fatigue for people with mitochondrial dysfunction–associated diseases. At the time this study was published, the woman had been taking 5-aminolevulinic acid for four years with no adverse effects and with considerable benefits—better mental functions, improved mobility and physical functions, and more sociability. Overall, this study shows how mitochondrial problems can drive ME/CFS symptoms; how genetic mutations can promote ME/CFS; and how mitochondria-targeting drugs can profoundly reverse symptoms for some people with ME/CFS. This study was published in *Immunological Medicine*.

Carefully Designed Cardiovascular Reconditioning Exercise Can Substantially Help People With Long Covid

The American Heart Association just published a statement advocating exercise training programs that reverse cardiovascular deconditioning (poor heart function caused by physical inactivity) to reduce Long Covid symptoms. Indeed, athletes recovering from COVID-19 by doing cardiovascular reconditioning exercises have lower Long Covid rates (0.02%) than do other people recovering from COVID (>25%). And cardiovascular reconditioning can improve mitochondrial function, mood, vigor, and quality of life for people with Long Covid. But not all exercises are helpful. To avoid adverse effects, exercises must be carefully selected and exercise intensity must be limited. For example, reclined exercises (like rowing or semi-recumbent cycling) can reverse cardiovascular deconditioning without provoking orthostatic intolerance. And limiting exercise intensity and duration can reduce post-exertional malaise. Unfortunately, accessing professional cardiovascular reconditioning programs may be substantially harder for people with low incomes, people without insurance, and marginalized/underrepresented people. Thus, the Association highlighted the need to help disadvantaged people with Long Covid to better access these programs. This article appears in the journal *Circulation*.

Significant Associations Between Functional Diseases (Fibromyalgia, ME/CFS) and Internalizing Disorders (Anxiety, Depression)—Details From a Large Population Study

Dr. Nathan Gillespie, professor at the Virginia Institute for Psychiatry and Behavioral Genetics, led a study of how fibromyalgia and ME/CFS (functional diseases) associate with generalized anxiety disorder and major depressive disorder (internalizing disorders). Studying almost 200,000 people from the Netherlands, his research team found that people who have either of these functional diseases are significantly more likely to develop one of these internalizing disorders. Similarly, people who have either internalizing disorder are significantly more likely to develop one of these functional diseases. These results are consistent with the fact that fibromyalgia and ME/CFS often increase anxiety and depression; that fibromyalgia and ME/CFS are often comorbid with generalized anxiety and major depressive disorders; and that certain genetic factors can simultaneously increase risk for each of these functional diseases and internalizing disorders. The team uncovered interesting details. Symptoms of fibromyalgia and ME/CFS usually remained constant, while symptoms of anxiety or depression waxed and waned. Also, having a functional disease predicted developing an internalizing disorder more strongly than having an internalizing disorder predicted developing a functional disease. For example, having fibromyalgia associated with developing either generalized anxiety or major depressive disorder, but having major depressive disorder associated only with developing ME/CFS (not fibromyalgia). This shows how despite having many of the same comorbidities and symptoms, fibromyalgia and ME/CFS differ in important ways regarding anxiety and depression. This study appeared in the journal *Psychological Medicine*.

Comparing How Long Covid Affects Lean and Obese Monkeys Clarifies How It Affects Humans

Drs. Charles Roberts, Jonah Sacha, and Paul Kievit, professors at the Oregon National Primate Research Center, specialize in metabolic diseases, obesity, and viral pathogens. Their research team recently compared long-term responses to SARS-CoV-2 infections for lean male macaque monkeys with those for obese ones. In some ways, the lean monkeys responded to infections like the obese monkeys. For example, SARS-CoV-2 levels and

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many antibody and cytokine profiles in lean monkeys were like those in obese ones. But there were important differences. Over the long term, SARS-CoV-2 infections damaged the lungs of obese monkeys significantly more than they damaged the lungs of lean monkeys. In contrast, SARS-CoV-2 infection preferentially lowered the lean monkeys' adiponectin/leptin ratios, which signaled greater chronic cardiometabolic risk and inflammation. Over time, the adiponectin/leptin ratio of the infected lean monkeys became like the ratio of uninfected obese monkeys (even before infection); and by the end of the study, the lean monkeys weighted significantly more than they did at the start of the study, while the obese monkeys weighed the same. Over the long term, lean monkeys also had significantly more disturbed sleep. Another key finding was that the SARS-CoV-2 infections caused significant, chronic physiological changes for most animals—both lean and obese. Some changes were very serious but unnoticeable to a casual observer. For example, only by directly sampling monkey lung tissues could researchers appreciate how significantly viral infections had damaged lungs. Since macaques are closely related to humans, these results suggest that routine examinations and self-report surveys greatly underestimate how many people have chronic physiological damage caused by SARS-CoV-2. They also suggest that a person's body weight will significantly affect how they experience Long Covid. This study was published in *PLoS Pathogens*.



Comparing How Diverse Treatments Affect People with Long Covid to How They Affect People with ME/CFS

Dr. Ronald Davis is professor of biochemistry and genetics at Stanford University, and Dr. Wenzhong Xiao is director of the Immuno-Metabolic Computational Center at Harvard University. These eminent researchers published an important paper in the *Proceedings of the National Academy of Sciences USA* comparing how treatments affect people with Long Covid with how they affect people with ME/CFS. The researchers surveyed 4,000 people (half with Long Covid, half with ME/CFS) to catalog the perceived efficacies for over 150 interventions, medicines, and supplements. They also cataloged and compared disease symptoms. Symptoms of Long Covid were much like those of ME/CFS. People in both groups had the same top five symptoms (brain fog, fatigue, poor memory, poor sleep, and post-exertional malaise) and the same comorbidities. Furthermore, treatment responses for people with Long Covid significantly correlated with those for people with ME/CFS. Considering comorbidities, symptoms, and responses, the researchers segregated people into four subgroups. Different treatments worked best for people in different subgroups, regardless of disease. Overall, this work showed how Long Covid and ME/CFS are extremely related in terms of symptoms and treatment effects; identified promising treatments to test in clinical trials for both diseases; and described which subgroups of people are most likely to respond to distinct treatments. Dr. Jonas Bergquist, Solve Ramsay Awardee, was a coauthor on this study.

Influenza Infection Significantly Increases Risk of Chronic Fatigue Syndrome, but Vaccines Help

Dr. Shin-Yi Tsai is a professor at the Johns Hopkins Bloomberg School of Public Health and doctor at the MacKay Memorial Hospital (Taiwan). Her team just published a study to understand whether influenza infection increases risk of chronic fatigue syndrome. Using the Taiwanese national dataset (containing high-quality data from nearly everyone in the country), the researchers compared over 300,000 adults who had been diagnosed with influenza between 2000 and 2019 with over 300,000 participants who had not. Following participants for a dozen years after diagnoses (on average), the researchers found that the risk of chronic fatigue syndrome for people infected by influenza was significantly greater than it was for uninfected people (about 50% greater). The risk of chronic fatigue syndrome for older adults infected by the virus was about twice as much as for infected younger adults. And the risk of chronic fatigue syndrome for infected adults with pre-existing anxiety, sleep problems, or certain other comorbidities was greater than it was for infected adults with none of these pre-existing issues. Importantly, influenza vaccines lowered risk of chronic fatigue syndrome for nearly all groups, regardless of whether people were vaccinated before infection or after. Overall, these results strongly support older adults and people with certain pre-existing conditions getting vaccinated against influenza to reduce risk of chronic fatigue syndrome. This study appeared in the *Journal of Translational Medicine*.

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Strong Support for Specific Long Covid Subtypes and Subtype Biomarkers

Dr. Stephanie Richard is a lead epidemiologist in the Infectious Disease Clinical Research Program at the Uniformed Services University of the Health Sciences, specializing in SARS-CoV-2 respiratory infections. Using artificial intelligence to analyze data from 2,000 adults with moderate or severe Long Covid, her team recently identified three subgroups of the disease. People in the first subgroup usually had sensory symptoms, like problems with smell or taste. These people were less likely to be vaccinated than people in the other subgroups. People in the second subgroup usually had more fatigue and cognitive difficulties. These people were more likely to be obese than people in the first subgroup. And people in the third subgroup usually had problems with breathing and exercise. These people were also more likely to be obese and to have been hospitalized for COVID-19. The researchers found specific inflammatory molecule biomarkers that, when measured in samples early on, predicted which of the three Long Covid subtypes would develop. Importantly, other recent studies (including a large NIH RECOVER study) found similar subgroups and biomarkers. Overall, these results support classifying people with Long Covid into disease subgroups that are associated with unique biomarkers, early inflammatory responses, and risk factors. This study appears in the *Journal of Infectious Diseases*.

Artificial Intelligence–Based Method to Diagnose People With ME/CFS Shows Key Physiological Problems Associated With the Disease

Dr. Maureen Hanson (professor of molecular biology and genetics) and Dr. Iwijin De Vlaminck (biomedical engineering), both at Cornell University, recently used artificial intelligence to accurately diagnose people with ME/CFS and to understand how this disease disrupts physiological processes in the body. The researchers analyzed cell-free RNA (RNA molecules released from cells, which show how cells and tissues are functioning) in blood from people with ME/CFS (n = 93) or from healthy people (n = 75). The participants with ME/CFS had a wide range of disease severity (from "good health" to "very poor health") and duration (a few months to several decades). Despite this variation, the researchers could accurately tell who had ME/CFS and who did not by considering levels of fewer than two dozen cell-free RNAs. These key RNAs gave important clues about the physiological problems associated with ME/CFS. For example, the identified RNAs suggest ME/CFS disease is strongly associated with aberrantly activated platelets; abnormal cell signaling; chronic inflammation; dysfunctional mitochondria and metabolism; and a hyperactive immune system. Interestingly, levels of some cell free–RNAs changed only in women; and the functions of these RNAs suggest that women with this disease have more problems with chronic inflammation and immune hyperactivation than do men with the disease. Overall, this study present a simple, blood-based assay to accurately diagnose people with ME/CFS. It also suggest that drugs that reduce inflammation, that control cell signaling, or that boost mitochondria and metabolism may be especially valuable for reducing key ME/CFS symptoms. Finally, the study shows how ME/CFS affects women differs from how it affects men. This article appears in the journal *Proceedings of the National Academy of Sciences USA*.

A Better Algorithm for Analyzing Electronic Health Records to Identify People With Long Covid

Dr. Emily Pfaff, professor of medicine at the University of North Carolina School of Medicine, recently led an effort by the NIH RECOVER Initiative to update the artificial intelligence algorithm her team developed four years ago to identify adults with Long Covid by analyzing electronic health records. Algorithms like this are critical for creating Long Covid computable phenotypes—Long Covid definitions based on computer data. Computable phenotypes are extremely helpful for studying underdiagnosed and poorly documented diseases, like Long Covid and ME/CFS. Most people with Long Covid are not diagnosed as such, so most electronic health records don't explicitly say who has the disease and who does not. As a result, using these records to recruit the right people for Long Covid clinical trials can be challenging. But with Long Covid computable phenotypes, researchers can use other information in the records to tell who has the disease. Dr. Pfaff's team updated their algorithm by "training" it on many more records than they had used before. By learning from so many more records, the algorithm could better figure out which other pieces of recorded information to use. The team also designed the algorithm to work with records lacking dates of SARS-CoV-2 infection (as is true in most cases) and to leave out SARS-CoV-2–reinfection data (which complicate analyses). Because of these adjustments, the new algorithm "describes" Long Covid much better than the old one—the features considered by the new algorithm are more relevant to Long Covid than were features considered by the old algorithm. And the new algorithm is highly sensitive and specific. From electronic health record data, the updated algorithm estimates that about one in ten adults with COVID-19 develop Long Covid. This study appeared in *The Lancet Digital Health*.

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Having Alternative Versions of Key Protein Affecting Lung Functions Increases Risk of Long Covid

Dr. Hanna Ollila, group leader of genetics at the University of Helsinki (Finland), and Dr. Hugo Zeberg, assistant professor of physiology at the Karolinska Institute (Sweden), recently searched for genetic factors associated with developing Long Covid. Analyzing the genomes of almost two million healthy people and over 22,000 people with Long Covid from countries around the world, the team found that people with variants of the gene FOXP4 have greater risk of developing Long Covid than people without these variants. FOXP4 is a transcription factor—a protein that controls expression of genes. It is expressed in almost all tissues and in diverse cell types but is especially important for lung tissues—in lung endothelial cells (which line blood vessels), lung immune cells, and type 2 alveolar cells (which keep lungs expanded and help repair lung tissues). FOXP4 variants can build up too much in tissues and are associated with greater risk of severe acute COVID-19. Since people with FOXP4 variants have higher risk of severe acute COVID-19 and since having severe acute COVID-19 increases Long Covid risk, it makes sense that people with FOXP4 variants have greater Long Covid risk. But the researchers found that these variants significantly increased Long Covid risk in other ways too, independently of acute disease severity. Exactly how the variants independently increase Long Covid risk is still unclear, but this work is important by showing that genetic factors directly influencing lung functions can significantly increase Long Covid risk. This study appears in the journal *Nature Genetics*.

Watch! "What's New in ME/CFS?"



In our new interview series "What's New in ME/CFS?" Solve Director of Advocacy Monique Wike talks to scientists on the front lines of ME/CFS research.

First up is Dr. Chris Ponting of the University of Edinburgh, lead researcher of DecodeME — the largest ever genetic study of ME/CFS. Dr. Ponting weighs in on recent notable discoveries, how a major increase in ME/CFS research funding could make a difference, and what he tells patients who are struggling to stay hopeful. Watch the full interview on our YouTube channel.

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Solve Research Programs Yield Impressive 43-Fold Return on Investment

One of Solve's core missions is to facilitate research on ME/CFS, Long Covid, and associated conditions. In fact, Solve is one of the largest private funders in the US for peer-reviewed research focused on ME/CFS. Through Solve's Ramsay Research Grant Program and Catalyst Awards, our donors have funded over 40 scientists working to understand ME/CFS and Long Covid work to develop new treatments for people with these diseases. Importantly, Solve-affiliated researchers have won substantial follow-up funds from other institutions (**Table**). So far, our researchers have received ~$1.6 million from Solve and gone on to win another $68 million from other groups—a 43-fold return on investment for our donors (**Figure**). Here, we describe how we calculated this return on investment and highlight some notable successes.

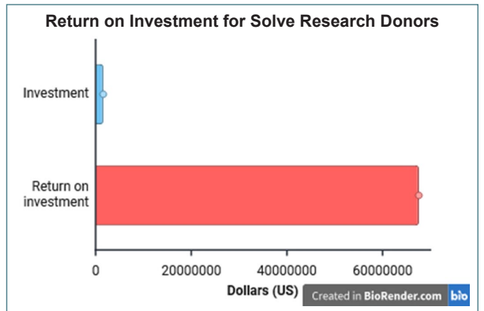


Figure. Return is actually higher than shown due to undisclosed grant amounts.

CALCULATING THE RETURN ON INVESTMENT

To find follow-up grants won by Solve-affiliated researchers (winners of a Catalyst Award, a Ramsay Grant, or Solve funds equivalent to a Ramsay Grant), these databases were searched: Grantome, a database of NIH- and NSF-funded grants; #MEpedia, a crowd-sourced online encyclopedia focused on ME/CFS; NIH Research Portfolio Online Reporting Tools (RePORTER), which summarizes NIH-sponsored research projects; Open Researcher and Contributor ID (ORCID), an open-source, nonprofit record of researcher profiles; Pivot and Research Professional (Pivot-RP), a private, curated database of funded grants and grant opportunities; and Scopus, an abstract and citation database. Researchers' academic or professional websites (if any) were also reviewed. Finally, the Google search engine was queried by using researchers' first and last names and "grants."

Table. Follow-up funds won by Solve-affiliated researchers

Researcher	Follow-up funds[a]	Funders
Carmen Scheibenbogen	$11,850,000	Deutsche Forschungsgemeinschaft
Elizabeth Worthey	$10,198,000[b]	Cystic Fibrosis Foundation; NIH
Eran Segal	$7,411,000	European Research Council; Israel Science Foundation; NIH
Aaron Ring	$6,235,000	Mark Foundation; NIH
Jonas Bergquist	$5,878,000	Open research Foundation Canada; Patient Led Research Collaborative; Swedish Research Council
Bindu Paul	$3,821,000	NIH
Jarred Younger	$3,486,000	ME Research UK; NIH; DOD
Shad Roundy	$3,132,000	NSF; USDA
Michael Van Elzakker	$2,845,000	NIH
Nikos Kyrpides	$2,781,000	NIH
Liisa Selin	$2,447,000	NIH
Dawei Li	$1,399,109	DOD; NIH; Patient Led Research Collaborative
Lubov Nathanson	$1,398,000	DOD
Alon Friedman	$915,000	Canadian Institutes of Health Research; NSF
Bhupesh Prusty	$865,000	Amar Foundation; German-based foundations[c]; Helmholz Center for RNA-based Infection Research; ME Research UK
Rob Wust	$592,000	Zon Mw
Heather Edgell	$535,000	Catalyzing Interdisciplinary Research Clusters; Heart and Stroke Foundation of Canada; York University
Jennifer Stone	$449,531	National Health and Medical Research Council
Vincent Lombardi	$401,000	NIH
Francisco Westermeier	$347,702	FWF Austrian Science Fund
Avik Roy	$225,000	NIH
Amy Proal	$206,000	ME Research UK
Dana Yelin	$85,000	Israel Science Foundation
Geraldine Cambridge	$81,000	ME Research UK

[a] In US dollars.

[b] Including NIH cooperative agreement (Pilot Center for Precision Animal Modeling, U54OD030167); Worthey, lead investigator for bioinformatics unit.

[c] *Bundesministerium für Bildung, Wissenschaft, Forschung und Technologie*; *Deutsche Forschungsgemeinschaft*; *Deutsche Gesellschaft für* ME/CFS; *Gemeinnützige Stiftung zur Unterstützung Der Betroffenen und zur Erforschung von Undiagnostizierten Krankenheiten*

Abbreviations: DOD, Department of Defense; FWF, *Fonds zur Förderung der wissenschaftlichen Forschung*; NIH, National Institutes of Health; NSF, National Science Foundation; USDA, United States Department of Agriculture

For funds awarded in non-US currencies, amounts were converted to US dollars by using Google Finance on September 17, 2025. Solve donors' initial investment (~$1.6 million) included awards through the Ramsay Research Grant Program ($30,000–$50,000/award) and the Catalyst Award Program ($100,000/award).

RAMSAY RESEARCH GRANT PROGRAM | NOTABLE SUCCESSES



Dr. Carmen Scheibenbogen (Charité—Universitätsmedizin Berlin) won a $12 million grant (€10 million) from the German Federal Ministry of Education and Research for clinical trials to treat people with ME/CFS or Long Covid.



Dr. Aaron Ring (Fred Hutchinson Cancer Center) won $5.5 million in follow-up funds, including a large NIH grant to study how SARS-CoV-2 affects the central nervous system. (Dr. Ring is a co-investigator on this grant; and Solve Catalyst Award winner Dr. Akiko Iwasaki, at Yale University, is head investigator.)



Dr. Jared Younger (University of Alabama at Birmingham) won $3.5 million in follow-up funds, including grants from the National Institutes of Health, the Department of Defense, and ME Research UK, to study neuroinflammation in chronic fatigue syndrome and Gulf War illness.

Importantly, these returns on investment do not belong to Solve, but to the people who donated money to fund these projects. So on behalf of our patient and research communities, Solve congratulates you—our generous donors—on this amazing success. More to come!

SOLVE M.E.
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Each board member has a personal connection to post-infection diseases. They either themselves live with these diseases, have a loved one who suffers, or care for people who are impacted.

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Building the Future Now: How Solve M.E. Advocacy Held the Line and Pushed Forward in 2025

By Monique Wike, Director of Advocacy

In a year marked by political gridlock and institutional uncertainty, Solve M.E. didn't wait for the federal government to move—we took action. With appropriations stalled, key agency roles unfilled, and chronic illness programs at risk of falling through the cracks, we chose to lead where we could. We strengthened coalitions, mentored grassroots leaders, preserved vulnerable research channels, and laid the groundwork for the next wave of change.

Solve M.E. has long played a critical connective role in this field. We track the federal landscape closely, help researchers stay in motion when systems stall, and make sure patients are informed when decisions affecting their health happen behind closed doors. This year, that work expanded in meaningful ways thanks to your support.

Advancing Research Through Cross-System Advocacy

A top priority in 2025 was protecting ME/CFS's inclusion in the **Congressionally Directed Medical Research Programs (CDMRP)**, a unique and vital funding stream housed in the Department of Defense. CDMRP funds high-risk, high-reward biomedical research through its Peer-Reviewed Medical Research Program (PRMRP), where ME/CFS has been an eligible topic in recent years. But when a long-term continuing resolution slashed the program's budget by 57%, ME/CFS research faced real danger.

That's where our Advocacy Week 2025 efforts paid off. In dozens of meetings with members of Congress, our advocates elevated the importance of CDMRP, and since then, Solve M.E. has worked behind the scenes through coalitions like the **Defense Health Research Consortium** to fight for funding restoration and topic area protection.

That advocacy appears to be working. ME/CFS remained an eligible topic in the current CDMRP cycle, and signs point toward a broader restoration of funding in FY2026. The program's track record speaks for itself: one of its recent projects, the i-STAT TBI Test (a 15-minute blood test for brain injuries) was just named to *TIME Magazine's Best Inventions of 2025*. These are the types of breakthroughs that become possible when we fight to protect research infrastructure.

Solve M.E. ADVOCACY WEEK June 23-27, 2025

187 Congressional Meetings	8 member-level meetings
226 Attendees	67 Senate meetings
36 States & D.C. Represented	120 House meetings
98% Meetings Confirmed	116 Democrat offices
	69 Republican offices
	2 Independent office

We've continued to champion patient-informed research at NIH, from tracking RECOVER-TLC clinical trials to co-developing public-private pilot projects like the **Solve ME/CFS Catalyst Awards**. We're helping bridge the gap between early-stage ME/CFS investigators and federal grant systems, ensuring that promising scientists aren't lost due to unstable funding cycles. Through our **Ramsay Research Grant Program**, early-career ME/CFS researchers are now seeing a 49x return on investment via follow-on federal grants.

Solve ME/CFS CATALYST AWARDS

Protecting Institutional Memory and Uniting the Field

One of our other consistent areas of advocacy is in supporting and protecting ME/CFS research in government agencies around the country. This year has been hard for our government partners, with some federal programs, like the CDC's ME/CFS program, experiencing significant strain. Layoffs and hiring freezes threaten to erase years of progress. Where our government partners are having to pull back, Solve is working to stand in the gap, to support and preserve institutional knowledge and connections between researchers and the community, and keep the pressure on Congress to fund the program fully.

The Power of Alliances

We continue to coordinate with other advocates and ME/CFS organizations around the country through the **U.S. Action Working Group (USAWG)**, with monthly strategy meetings in which grassroots advocates across the field stay informed and aligned, allowing us to support each other's work. At an international level, Solve co-founded and continues to work with **World ME Alliance**, composed of 21 national ME/CFS organizations from all over the world who work together to advance progress and raise the overall level of care and guidance people with ME/CFS receive across the globe. The Alliance is working to advance international standards of care for ME/CFS, helping to identify areas of opportunity in individual countries, while also spotlighting those regions whose actions are replicable and exciting.

World ME Alliance

Solve also coordinates with various national cross-disease alliances such as the **National Health Council** and **Research!America**, bringing ME/CFS into the broader policy conversation and ensuring our needs are captured when advocating on broader healthcare issue, such as telehealth accessibility and medicare policies, that impact us all.

Solve M.E. ADVOCACY WEEK 2026

SAVE THE DATE: ADVOCACY WEEK 2026

This past year has demanded creativity, persistence, and courage. Through it all, Solve M.E. has remained a steady force, ensuring that ME/CFS remains visible, prioritized, and protected. But there is more work to do.

Mark your calendars: Advocacy Week 2026 will be back from March 23–27, 2026.

More details to come! Registration opens in January!

Whether you're a veteran advocate or joining for the first time, we invite you to add your voice to this movement.

Solve and Partner Organizations are #UnitedForME

Solve regularly joins forces with our fellow ME organizations Bateman Horne Center, #MEAction, and the Open Medicine Foundation in order to collectively boost the signal on important issues that touch our community. We use the hashtag #UnitedForMe when promoting all of our posts on social media and reposting our messaging across all of our social channels.

In August, we rallied together to help raise awareness for Severe ME Day (August 8th), spreading the word about our combined resources and webinars dedicated to the estimated 25% of people with ME/CFS who are severely ill.

In November, we teamed up again to highlight National Family Caregivers Month. We combined all of our tools and event information in a shared Caregiving Resource & Events Hub.

Our community knows all too well that we are stronger together, and we're proud to be part of the #UnitedForME Coalition!





Q&A with Solve M.E.'s New Director of Advocacy Monique Wike

Monique Wike is the Director of Advocacy at Solve M.E. She brings experience in political strategy, volunteer coordination, and community organizing, along with lived experience as a Long COVID survivor. Her work centers people, prioritizes sustainability, and keeps a clear eye on the long game.

In this interview, Monique shares how her lived experience, organizing background, and belief in community-centered power are shaping her approach to the work ahead.

What have you learned about what keeps people engaged in advocacy long-term?

People stay engaged when they have clarity, a clear purpose, a vision, and a way forward. When those elements are in place, advocacy stops feeling abstract. It becomes real, and personal, and urgent.

At Solve, we listen carefully to both researchers and the patient community to figure out where our efforts can have the most impact. One example: right now, our advocates are responding to a proposed Medicare policy that could block access to procedures like peripheral nerve blocks that early research results show are helping patients with ME/CFS and Long COVID. The effort is spearheaded by Deborah Duricka, PhD, a Solve Ramsay Grant Research winner and vital community member, so it's very driven from the grassroots level. We know this is worth fighting for because people have told us directly what it means to them.

But what sustains people over time isn't just caring about the issue. It's the connection. The feeling of not being alone. I wouldn't be here if the ME/CFS and Long COVID communities hadn't carried me through my illness. They shared what they'd learned. They offered support without asking for anything in return. I promised myself that if I ever had enough of an energy envelope to work again, I would give back. And now I'm here.

Many advocates are looking for new pathways to make meaningful change. Where do you see the most promising opportunities for progress right now?

As we track the ebb and flow of momentum at the national level, we stay realistic and responsive. We pivot our strategy based on where levers are most accessible and where we can gain traction. Right now, that means focusing on relationship building, coalition work, and strengthening alignment with others across the ME/CFS space and beyond.

We're collaborating more closely with other ME/CFS organizations, both nationally and globally, and we're deepening our participation in cross-disease coalitions that share our goals on things like medicaid eligibility policies, telemedicine access, and sustaining government-funded medical research funding.

These are not fights the ME/CFS community can take on alone, but they are winnable when we act as part of a broader coalition. Our stories highlight specific gaps in healthcare that resonate widely. Many energy-limiting illnesses share our needs, so we consistently look for opportunities to highlight for our community the ways they can be part of these broader efforts with us.

With so many in our community managing limited energy, how are you approaching strategy to make sure it's sustainable?

We take that question seriously. Many in our community live with post-exertional malaise, and many are also managing burnout from years of advocacy that haven't always led to visible change. We don't have spoons to waste.

Right now, with Congress focused on short-term funding bills and continuing resolutions, we're not pushing energy-intensive campaigns on long-term appropriations that can't move yet. Instead, we're focusing on how our advocacy can best stand in the gap for researchers, clinicians, and scientists. That includes using more immediately accessible levers like partnering with universities, advocating with state and local systems, and supporting regulatory and private-sector change.

These aren't placeholder tactics. They build capacity and relationships that will matter even more when Congress is ready to move forward again. Every step we take now strengthens our position later.

What gives you confidence that progress is possible for people with ME/CFS and Long COVID?

It's personal for me. I've lived through something that felt insurmountable and came out the other side. That changes your relationship to what's possible.

There may not be one single cure developed tomorrow, as this illness has so many causes, subsets, and triggers. But there are dozens of tools being developed across multiple disciplines that are getting closer to becoming real options. Our job is to make sure that those tools are funded, studied, and eventually accessible for all patients to find what works for them.

What grounds you when the work feels overwhelming?

I try to stay pragmatic. Even when things look impossible, I ask, "What lever can we pull here? Who's not in the room yet? What is still possible today?"

That mindset keeps me steady. So do my family and the small routines that bring comfort. My cats, Spider Gwen and Cassian, definitely help with perspective. My husband is the one who reminds me to pace and gives me pep talks. And my two-year-old daughter is my constant reminder of why this work matters.

What would you want the community to hear from you in this moment?

I know things feel chaotic. The shutdown. The policy setbacks. The long wait for better treatments. But chaos can be the beginning of something. It can be the thing that brings people into the fight. It creates openings for new alliances across illnesses, industries, and movements.

And I believe we are building something together. I see it in the way researchers are inviting patients into study design. I see it in how universities are taking Long COVID research seriously and incorporating post-exertional malaise into their study design. I see it in how some doctors are shifting their practices after hearing directly from patients.

We're building a world where clinicians are trained to understand infection-associated chronic conditions and illnesses, where businesses adopt flexibility because it helps everyone, and where the knowledge and resilience of this community are seen as assets, not as liabilities.

We may be in a planning phase right now. But implementation is coming. Healing is coming. And we'll get there together.

What role can private donors play in keeping this work moving?

Public funding has slowed. In some cases, it's disappeared altogether. That leaves gaps, especially in research, and we don't want to lose momentum. *We have to move the science forward!*



Solve CEO Emily Taylor and Director of Advocacy Monique Wike in Washington, DC.

Solve funds researchers who are either right at the beginning of their careers and just need that initial grant to get them started as a specialist in our field, or right on the edge of making breakthroughs. Some of them are just one grant away from results that could change lives. Donor support helps us close that gap. It allows us to move quickly, fund promising science, and support advocacy efforts grounded in real patient needs.

We can't afford to wait for the system to catch up. We have to keep pushing forward now.

Is there a quote or idea that's shaping how you show up in this work?

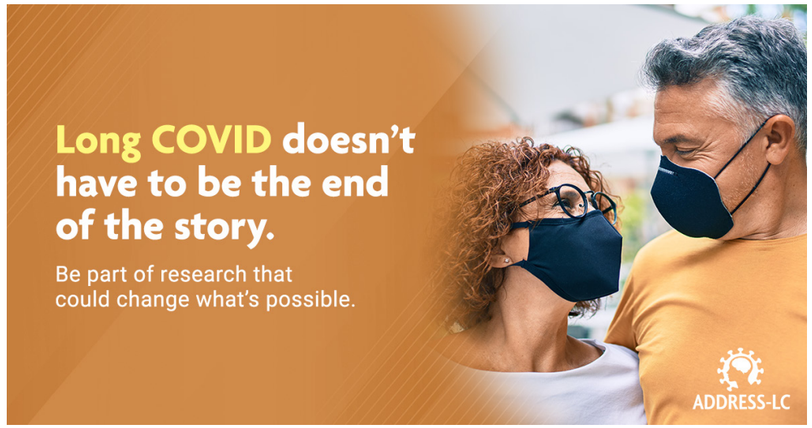
I've been rereading *Hope in the Dark* by Rebecca Solnit. There's a passage that stays with me:

"Hope is not the belief that everything was, is, or will be fine… Hope locates itself in the premise that we don't know what will happen and that in the spaciousness of uncertainty is room to act…Hope is a gift you don't have to surrender, a power you don't have to throw away."

That spaciousness, where we don't know the outcome, but we keep showing up anyway, is where all real change begins.

Patient Feedback Spurs Expansion of ADDRESS-LC Trial: More Trial Sites, Broader Enrollment

In July, Solve hosted a webinar featuring representatives of the ADDRESS-LC Trial, which was designed to assess the potential impact of the drug bezisterim on cognitive impairment/brain fog and fatigue in people with Long Covid.



Hosted by Solve CEO Emily Taylor, panelists Michael Peluso, MD (Assistant Professor of Medicine, University of California, San Francisco), Penny Markham, PhD (Senior Vice President, BioVie), and Ezra Spier (Creator, LongCovidStudies.net) discussed how the lived experience of patients has informed the development and conduct of the ADDRESS-LC trial, and how patient-researcher collaboration has been a crucial component.

Shortly thereafter, and in response to input from scientific and patient communities, BioVie opened the trial up to all qualified individuals, including those who have been suffering from Long Covid since 2020.

Now, enrollment has broadened even further.

You may now **qualify to participate** if any of these apply to you:

- ☑ You take **low dose naltrexone (4.5 mg or less per day)**
- ☑ You have **ADHD but aren't taking stimulant medications**
- ☑ You're **under 70 years old**

New sites have begun enrolling, with 15 of 19 planned sites currently enrolling across the U.S.

Visit the trial website for more information on site locations and other trial requirements.

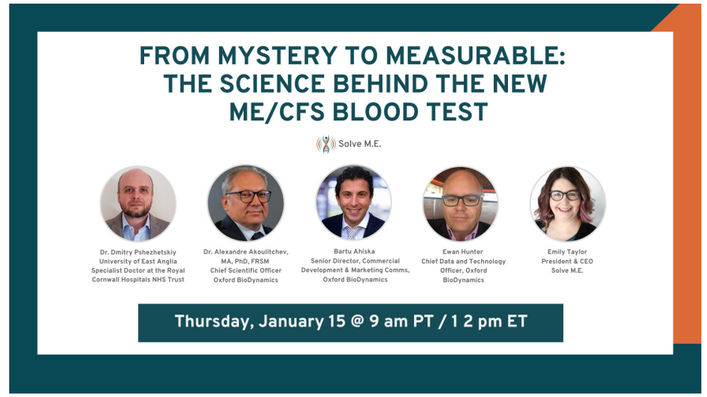
Patient representative Ezra Spier noted, "I've been sick with Long Covid for three years. When I joined the ADDRESS-LC trial team as a patient representative, study participation was limited to those with Long Covid for two years or less. It was disappointing to learn I didn't qualify for this important trial, but I understood the reason for the two-year restriction based upon what was known about Long Covid when the trial was being designed. I'm thrilled that Biovie continued to track new research findings for Long Covid, and now more of us can join the ADDRESS-LC Trial and help find a treatment for the brain fog, cognitive impairment, and fatigue that affect us every day."

Learn more about the trial at www.addresslc.com and watch Solve's ADDRESS-LC Trial webinar here. View the deck for the webinar here.

Register Today for Solve's 2026 Webinar Series!

January 15, 2026 @ 9 am PT / 12 pm PT

In **"From Mystery to Measurable: The Science Behind the New ME/CFS Blood Test,"** Solve CEO Emily Taylor will talk to the research team responsible for the landmark discovery of a new blood test to identify ME/CFS. Register here.



February 11, 2026 @ 1 pm PT / 4 pm ET

In **"Protecting the Ones You Love: Legal & Insurance Tools for ME/CFS Caregiver,"** Solve Director of Advocacy Monique Wike will talk to Andrew Kantor, Esq. (Senior Partner at Kantor & Kantor, LLP) about essential legal and insurance strategies to support a loved one living with ME/CFS. Register here.

In honor of National Family Caregivers Month, Solve teamed up with Kantor & Kantor, LLP to create a series of practical tools for caregiving in complex illness, including our one-pager **Supporting a Loved One Through a Disability Insurance Claim: ERISA 101 for ME/CFS Caregivers.**

Co-authored by Solve M.E. and Kantor & Kantor, this document breaks down what caregivers need to know about the Employee Retirement Income Security Act (ERISA), disability insurance, and how to meaningfully support a claim. Download it here.

Also, be sure to check out our Caregivers Resources Hub, which includes new tools, articles, and upcoming sessions for caregivers compiled by the #UnitedForME Coalition (Solve M.E., Bateman Horne Center, #MEAction, and the Open Medicine Foundation).





Rebecca Groble: From Caregiver to Powerhouse Advocate

Across the country, Solve M.E. invests in people-powered advocacy—and one of the clearest examples of that vision in action is unfolding in Cook County, Illinois. There, Rebecca Groble has emerged as a dynamic force for ME/CFS awareness and systems change: meeting with local legislators, engaging with public health officials, and opening doors at every level of government.

Rebecca's journey began, as so many do in this community, with a caregiving crisis. Her son Gabe, who developed ME after a bout of mononucleosis in 2018, has been completely bedbound for years. Unable to find local clinical support or meaningful answers, Rebecca started reaching out to others—and then speaking up. Over time, her role evolved from that of a caregiver working largely in isolation (like so many of us on a day-to-day basis) to a powerful connector, bringing lived experience, data, and strategic thinking to policy conversations across her county and state.

This fall, her advocacy reached a milestone when Cook County Commissioner Josina Morita read a public resolution recognizing ME/CFS and acknowledging Gabe's story. It was more than symbolic. It was the result of sustained relationship-building, community engagement, and behind-the-scenes coordination, and a sign of what is possible.

Rebecca had already briefed the Commissioner's office and met with Cook County's Director of Public Health Policy, laying the groundwork for potential medical education sessions, public awareness work, and future private-public partnerships between the ME/CFS community and local leadership. Solve is now partnering with Rebecca to map out next steps, including the formation of a regional advocacy team.

At every stage, the work of Rebecca and her family mirrors Solve's three-pronged mission: advocacy, research, and education. Whether she's staffing a table at her local farmer's market and handing out awareness stickers made by her husband (and Gabe's caretaker), David Hull, briefing members of Congress, or urging state legislators to support ME/CFS resolutions, she's helping shift the conversation and make the disease visible where it matters most.

She's also taken on another critical role: fundraiser. In honor of Severe ME Day on August 8th and in honor of her son Gabe, Rebecca and her family hosted an online fundraiser for Solve. With a campaign designed and overseen by Gabe, they raised nearly $5,000 to support community resources, advocacy work, and research into treatments and cures. Their effort was personal, heartfelt, and impactful—an example of how families touched by ME/CFS can transform their story into power.

Rebecca, David, and Gabe are not waiting for a path to appear—they are building one. From legislative offices to local health departments to online donation platforms, they are demonstrating what patient-centered advocacy can look like: strategic, collaborative, and deeply human.

If you're inspired by their story and want to host your own fundraiser for Solve, we can help. Our team handles the details so you can focus on what matters: honoring your loved ones and advancing change.

Contact our Development Department at development@solvecfs.org to get started.



Left to right Cook County Commissioner, 13th District Josina Morita, Rebecca Groble, Mary Ann Borys, County Commissioner, 11th District John Daley



Rebecca addressed her local Cook County Board members and met with the Cook County director of health policy.



Gabe Hull

Letter from Solve President and CEO Emily Taylor

Dear Solve Community,



When my mother was first diagnosed with ME/CFS, one of the most important things I did for her was build a care team. It wasn't easy and we had to navigate it one piece at a time. We had to form a partnership and become a team, tackling challenges together. But over time, her doctors, caregivers, family, and providers created something none of us could have done alone: a network of support that made her life better and gave her hope.

At Solve M.E., we're doing the same thing at a different scale by building a care team for the entire ME/CFS and Long Covid research community. Together, we are creating a connected ecosystem of researchers, advocates, clinicians, and patients who share one goal: to move science forward and improve lives in tangible ways.

You'll read in this issue's cover story about our partnership with the **Brain Inflammation Collaborative (BIC)** and the future of the **Solve Together** platform. This collaboration expands Solve's research network across more than thirty chronic conditions, creating a single, powerful hub for discovery. By sharing data and breaking down silos, we're helping scientists see connections that were invisible before.

This same spirit of working together fuels our **Catalyst Awards**, which support innovative new research that might not otherwise be funded. Every study we launch represents a partnership between patients who share their data, scientists who dedicate their expertise, and supporters like you who make it all possible.

Right now, that partnership is being put into action through our **$321,000 year-end matching gift campaign**. If we meet this goal, we'll be able to double the number of Catalyst Awards next year by providing funding for up to four groundbreaking studies that could lead to new diagnostics, treatments, and a better understanding of post-infection illnesses. It's a tangible example of how your generosity directly multiplies scientific impact.

Collaboration is at the heart of everything we do. It means listening to patients and centering their voices in research. It means convening scientists across disciplines and connecting advocacy to evidence. And it means remembering that every donation, every shared story, every act of engagement is part of a much larger community.

Together, we are building a powerful research ecosystem, an advocacy engine, and a compassionate community all working in harmony. Just like my mother's care team, it takes every one of us.

Thank you for being part of this team. Thank you for believing that through collaboration, we can and will solve ME/CFS, Long Covid, and other infection-associated chronic conditions.

All the best,

Emily Taylor
Solve President & CEO

Solve M.E.

Patrick Buchanan
Organizational Support Coordinator

Elissa Regan
Director of Advancement

Erin Gary
Director of Operations

Emily Taylor
President and CEO

Karman Kregloe
Director of Communications

Monique Wike
Director of Advocacy

Join Our $321,000 Matching Challenge!

Solve is moving science forward—pushing bold, translational research across the finish line and bringing us closer to real diagnostics, treatments, and cures.

Now, we have an extraordinary opportunity to go even further. Thanks to generous friends of Solve, every gift you make through **December 31st** will be matched—up to **$321,000**!

That means your support for cutting-edge science and tireless advocacy will go twice as far. Every dollar invested in Solve generates, on average, a **43× return** in follow-on research funding. With this match, your impact will multiply even more.

Scan to Donate

Please make a gift today by clicking HERE or by scanning this QR code.

Together, we'll turn research into reality!



STAY IN TOUCH!

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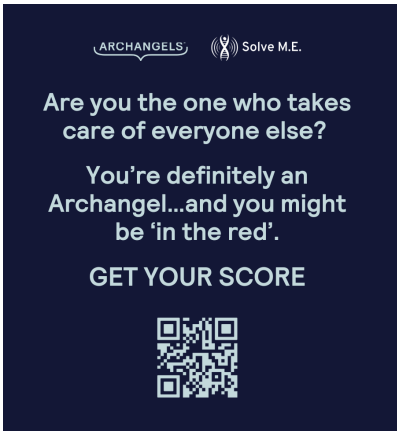
Solve M.E. Chronicle archive: SolveME.org/news-and-insights

Humans of Chronic Illness: HumansofChronicIllness.org

The unhide® Solve Together Unified Platform: unhidenow.org

Solve Partners with ARCHANGELS to Help the 40%+ of Adults Serving as Unpaid Caregivers

Whether you're living with ME/CFS or supporting someone who does, caring in any way can be intense. Your well-being matters to us, so we invite you to take two minutes to get your Caregiver Intensity Score from our friends at ARCHANGELS, an organization working to make change happen for caregivers everywhere.



It's a super quick check-in on yourself to find out whether you are in the "red," "yellow," or "clear" and, if you'd like, get connected to trusted support.

- Find out if you're in the "red," "yellow," or "clear"
- See what's most driving your intensity (and what's helping bring it down)
- Access free tools that can help—now or whenever you have the time

Click here or use the QR code above to get your score.

CHARITY NAVIGATOR
★★★★
Four Star Charity

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