

Issue 1 / February 2026

STORIES, SCIENCE, AND VOICES: THE IACFS/ME NEWSLETTER IS BACK

After a quiet pause, we are happy to share that the IACFS/ME newsletter returns three times a year. We have missed having a space where news, ideas, and perspectives can come together in a more personal way. This newsletter is not meant to be another scientific journal - it will be shorter, more visual, and easier to read. Our aim is to highlight new research in a compact format, add clinical insights, offer glimpses into personal experiences and viewpoints, and occasionally raise questions that invite discussion.

You will find regular features such as “President’s Corner,” with reflections from our leadership, or “Lea’s Corner,” where the editor shares what currently captures her interest. Our board members will likewise share their perspectives on a regular basis.

We are also eager to include contributions from people living with the illness.

Recent studies or developments that resonate within the ME/CFS community will be summarized, and visuals will play a central role - since pictures can often say what words alone cannot.

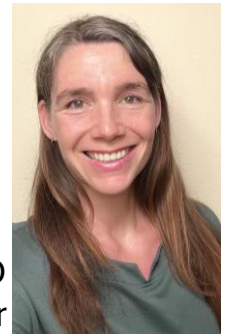
Most importantly, this newsletter is meant to grow with our community. If you have ideas, contributions, or feedback, we kindly invite you to share them.

We look forward to building a lively exchange together.

With warm regards,

Lea

Lea Höfel, PhD
Newsletter editor



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PRESIDENT'S CORNER

Dear IACFS/ME Members and Colleagues,
It's been awhile since I've written a note for the newsletter - about 10 years actually since our last issue. Now, thanks to Dr. Lea Höfel taking on the editor role, we have revived the publication.

Lea brings a refreshing level of visual appeal and content creativity to the newsletter that highlights our mission of scientific advocacy and improved patient care.

We had a successful virtual conference in October, 2025 that was highly rated by attendees.

Our Association journal, *Fatigue: Biomedicine, Health and Behavior* is now in its 13th year of publication with Taylor and Francis. About half of the published articles focus on ME/CFS. We welcome your submissions (<https://www.iacfsme.org/journal>).

Professional membership (\$125/year) in the IACFS/ME includes an online subscription to the journal and conference admission discounts. The board of directors and our recently added board nominees and volunteers are very active in advancing our scientific and clinical mission that now includes the overlapping illness of Long COVID.

The emerging illness of Long COVID initially attracted a younger generation of new researchers, although the federal funding environment has become less clear as program cuts have impacted many Long COVID grants. That said, one wide-ranging NIH program, the \$1.7 billion Researching COVID to Enhance Recovery (RECOVER) was rescued from the chopping block through advocacy from the Long COVID patient community and involved researchers.

Looking ahead, we are considering an in-person international conference for 2026 or 2027. We would prefer an attractive university-based location (given lower costs) that also has high accessibility. Feel free to drop me a note (ffriedberg12@gmail.com) if you have conference venue ideas.

With best regards,
Fred

IACFS/ME 17TH RESEARCH & CLINICAL CONFERENCE: A VIRTUAL SUCCESS!

By Lily Chu, MD, MSHS (IACFS/ME VP)

Our 17th Research and Clinical Conference, held **October 22–25, 2025**, brought together **160+ attendees from 10 countries** for an engaging virtual event featuring **50+ talks/ workshops and 37 posters**.

Conference Highlights

- **Workshops:** Clinical trial design, animal models, ME/CFS pathophysiology, occupational therapy, visual communication, using validated questionnaires, and treatment options.
- **Special Presentations:** Overall pathophysiology of ME/CFS, research case definitions, real-world insights from a participant-centered digital health platform.
- **Keynote:** Dr. Ziyad Al-Aly explored how Long COVID research may unlock answers for infection-associated chronic conditions (IACCs).
- **Plenary:** Dr. David Goldstein proposed central noradrenergic deficiency as a cause of post-exertional malaise.
- **Poster Competition:** In partnership with ME Research UK - congratulations to winners and Ph.D. candidates Jolien Hendrix (Vrije Universiteit, Belgium) and Anne E. Gardella (Cornell University, USA)!

What Attendees Told Us

- 87%** rated the conference as useful or very useful
- 76%** appreciated the availability of continuing education credits
- 80%** would recommend the meeting to their colleagues
- 70%** of clinicians learned something new to improve patient care

TWO SESSIONS IN FOCUS



Keynote Lecture

Long COVID: Illuminating Infection-Associated Chronic Illness

Ziyad Al-Aly, MD

Professor at Washington University in Saint Louis and Chief of Research and Development at the VA Saint Louis Health Care System.

In this keynote, Ziyad Al-Aly provided a clear and compelling synthesis of current knowledge on Long COVID, emphasizing its multi-system clinical impact, shifting epidemiology, and profound economic and societal costs. He positioned Long COVID within the larger group of infection-associated chronic conditions and illnesses (IACCI), drawing important parallels to ME/CFS.

Al-Aly underscored the urgency of coordinated action and concluded with a forward-looking research and policy roadmap designed to accelerate progress in prevention, diagnosis, and treatment across the entire IACCI spectrum. With this approach, Al-Aly helps shape understanding of COVID-19's long-term effects.

Workshop

Animal Models in ME/CFS Research

Dada Pisconti, PhD; Julie Williams, PhD; David M. Raizen, MD/PhD; Jessica Ellis, PhD

SUNY Stony Brook (USA), University of Pennsylvania (USA), Wake Forest University (USA)

This workshop showcased how genetic animal models - including mouse, fruit fly, and roundworm - are advancing our understanding of the cellular and molecular mechanisms underlying ME/CFS, particularly fatigue and post-exertional malaise (PEM). Speakers presented recent mechanistic insights, discussed strengths and limitations of these models, and outlined opportunities for developing more standardized, translational approaches.

This workshop was quite unique as we do not have an established animal model of ME/CFS.






Read more!

Every conference, IACFS/ME provides press passes to a limited number of reporters and content creators in exchange for providing the public free access to their work. Explore [our article collection](#) and [Dr. Emma Slack's recent piece](#) for ME Research UK.



WANT THE CONFERENCE TO COME TO YOUR CITY?

While virtual participation was appreciated, many attendees missed meeting in-person.

	We plan meetings at least a year ahead and look specifically for areas with:
	Individuals, institutions, or groups that can help support us logistically and/or financially.
	Conveniently-located and affordable conference venues and lodging.
	Multiple transportation options to, from, and within the location (e.g., airlines, buses, trains, subways, etc.).
	Nearby tourist attractions - participants often schedule vacations around conferences.

Locations outside the United States are possible:
IACFS/ME meetings have been held in Okinawa, Norway, and Canada before.

Interested?

Email us at iacfsmeorg@gmail.com !



INTERPRETING STUDIES DO'S AND DON'TS

With research on ME/CFS and Long COVID expanding rapidly, it's becoming increasingly important to understand how to read studies critically.

Not all evidence is equal!

Good interpretation helps us separate solid science from preliminary signals.

Make sure to watch out for the next newsletters, we'll share concrete examples to make these and other principles even more practical.

Do	Don't
<u>Check the study design</u> It tells you how robust the findings are (e.g., randomized trials reduce bias; observational studies show associations but not causation).	<u>Rely on single studies</u> Science moves through accumulation, not one-off findings.
<u>Look at sample size</u> Small samples can exaggerate effects or miss important differences.	<u>Confuse correlation with causation</u> Two things occurring together doesn't mean one caused the other.
<u>Check how outcomes were measured</u> Objective measures are more reliable than self-report alone.	<u>Ignore limitations</u> Every study has them; they help you judge how far the conclusions can be generalized.
<u>Seek replication</u> Results are stronger when confirmed by independent research groups.	<u>Overlook bias</u> Conflicts of interest, selection bias, or unblinded procedures can distort results.

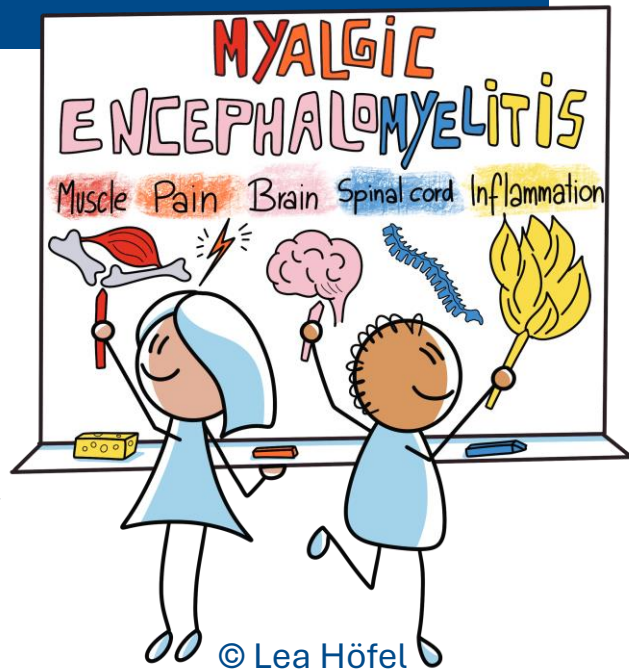
VISUAL OF THE EDITION

Myalgic Encephalomyelitis

Muscle, pain, brain, spinal cord, inflammation - a name that reflects its biology.

ME is more than fatigue.

It is a complex, multisystem neuroimmune disease affecting energy production, pain processing, cognition, and autonomic function. Visual explanations help us show what the name already says: the body is struggling on many levels.



THIS ISSUE'S ESSENTIALS & CALL TO ACTION

Let's build a newsletter community together!

Send topics and ideas for the newsletter!

Mail venue ideas for an in-person conference!

Thanks to all the sponsors, speakers and attendees of the 2025 conference!

Need help recruiting participants to your study? Announce it here!