The
Catatonia
Foundation

Insights and Impact

Advancing understanding
changing outcomes

Bringing Family Stories to the Physicians Whose Recognition of Catatonia is Critical

For families affected by catatonia, suffering goes beyond the disorder itself. There is the unbearable amount of time spent in the dark and being constantly dismissed, all while watching a loved one decline as answers remain out of reach.

Catatonia can be frightening, confusing, and devastating. It can often be treated effectively when recognized and addressed appropriately. A systemic gap exists between patients who are suffering profoundly and access to appropriate treatment from clinicians who understand catatonia. Addressing this gap is at the heart of why The Catatonia Foundation continues to educate healthcare providers and bring patient and family experiences into clinical and professional spaces.

In May, The Catatonia Foundation exhibited at two important annual professional meetings: the American Psychiatric Association (APA) and the International Society for ECT and Neurostimulation (ISEN). The Catatonia Foundation had the opportunity to distribute educational brochures, share patient and family stories, and speak directly with clinicians, trainees, researchers, advocates, and others whose work can shape how catatonia is recognized, understood, and treated.

At APA, the focus was on awareness and education. Too many families struggle to get a catatonia diagnosis, and even if they do, it's often following an agonizing delay — after symptoms have been misunderstood, misdiagnosed, or dismissed.

We used real stories of delayed recognition and remarkable recoveries to inform direct conversations with psychiatrists, trainees, and other mental health professionals. Through those conversations, we helped illuminate the realities families face when catatonia goes unrecognized — and the profound difference timely diagnosis and treatment can make.

We helped inform psychiatric professionals that catatonia is not uncommon while raising awareness of its impact on the lives of patients and families who are actually living through catatonia. It is urgent. It is serious. And it needs to be considered as a diagnosis whenever the signs are present.

The Catatonia Foundation Medical Advisory Board member Dr. Lee Wachtel with The Catatonia Foundation Board member Jon Fink and Administrator Sam Zell-Breier

At ISEN, the conversation centered more closely on access to electroconvulsive therapy (ECT), one of the gold-standard treatments for catatonia.

For families who have watched a loved one benefit from ECT, it is a real and viable treatment option. It can represent a significant turning point after a period of profound fear and uncertainty: the return of speech, movement, eating, communication, and connection. In severe cases of catatonia, timely treatment can be lifesaving.

Yet the stigma surrounding public perception of ECT is often a barrier for families. Having firsthand experience, ISEN members understand how effective ECT can be as a treatment for catatonia and recognize the urgent need for better access.

These conversations matter because awareness and education do not change care overnight. It starts person by person, conversation by conversation, clinician by clinician. A physician who better recognizes catatonia may think of it sooner. A trainee who hears a family's story may carry it with them into a future emergency department, hospital unit, or clinic. A researcher or advocate may better understand the human urgency behind the work.

We were grateful to connect with members of The Catatonia Foundation's Medical Advisory Board at both APA and ISEN, including Dr. Lee Wachtel and Dr. Andrew Francis, who both spent time with us at the booth. We also appreciated the opportunity to connect with professionals who share our commitment to improving recognition, reducing stigma, and expanding access to effective care.

The Catatonia Foundation Medical Advisory Board member Dr. Andrew Francis with The Catatonia Foundation Board member Jon Fink at APA

For families who have lived through catatonia, the need is not theoretical. It is personal. It is immediate. And it is why The Catatonia Foundation will continue working to ensure that more people understand what catatonia can look like, how serious it is, and how much can change with appropriate treatment.

Continuing the Work: Reaching More Front-Line and Pediatric Providers

The Catatonia Foundation will continue this outreach at the American Academy of Child and Adolescent Psychiatry (AACAP) 2026 Annual Meeting in Atlanta and the American College of Emergency Physicians (ACEP) 2026 Scientific Assembly in Chicago.

AACAP 2026 | OCT 26–31 ATLANTA

Raising awareness and educating child and adolescent psychiatrists at AACAP is important because pediatric catatonia remains under-recognized despite growing evidence that it is not uncommon in child and adolescent psychiatric settings. Children and adolescents may present with signs that are misunderstood or attributed solely to other psychiatric, developmental, neurologic, or behavioral conditions, including autism and other neurodevelopmental disorders. This delays recognition of catatonia itself, forcing families to watch a child deteriorate while they search for clinicians who are familiar with pediatric catatonia, know how to assess for it, and understand that timely treatment matters.

The barriers are even greater when ECT is needed. Fear from parents, stigma in clinical contexts, limited availability, and additional restrictions around pediatric treatment can delay or prohibit access to care, even when a child's condition is severe. By attending AACAP, The Catatonia Foundation aims to help bring pediatric catatonia into more conversations with the clinicians who are most likely to evaluate and treat young people in crisis.

acep Scientific Assembly CHICAGO 26

Educating emergency physicians at ACEP is critical because, for many patients experiencing signs of catatonia, the emergency room may be the only place they can receive immediate care. In those moments, treating physicians need to be familiar with catatonia's signs and varied presentations. Families may arrive in crisis, unsure how to explain what is happening while patients may be unable to respond to questions about their experience.

When emergency clinicians are more familiar with catatonia, they may be better equipped to consider it earlier, avoid misinterpretation, and help connect patients to appropriate evaluation and treatment. For families who are frightened and desperate for help, that first point of contact can make an enormous difference.

The Importance of Showing Up

Every conference gives The Catatonia Foundation another opportunity to bring family experiences forward, build understanding, and help more clinicians recognize that catatonia is serious, treatable, and too often missed. When even one clinician leaves with a clearer understanding of catatonia — and carries that knowledge into a future hospital room, emergency department, clinic, or treatment decision — the impact can be profound.

Conference outreach is The Catatonia Foundation's largest investment and one of our most important commitments. For a small organization, exhibiting at national medical conferences requires significant planning, financial resources, and volunteer support. Yet these conferences provide an unparalleled opportunity to reach the clinicians whose knowledge can change—and even save—the lives of people with catatonia.

To continue showing up in these critical spaces, and to expand our reach to even more healthcare professionals, we need your support. Every contribution helps make it possible for TCF to continue educating clinicians, raising awareness, and improving the recognition and treatment of catatonia.

Donate

Ways to Support The Catatonia Foundation

- **Share your story** — your experience brings hope and spreads awareness
- **Spread the word** — tell others about catatonia and our resources
- **Volunteer your skills** — outreach, design, peer support, fundraising, nonprofit
- **Donate or fundraise** — your support sustains education, advocacy, and research. Click the button below to donate.

How You Can Help Spread Awareness (It Really Matters)

Awareness grows person by person, share by share. You can make a meaningful difference by helping amplify our mission:

- Share this email
- Follow us on Instagram, Facebook, LinkedIn, and X
- Like and comment on our posts (this dramatically increases reach)
- Share our posts and/or add them to your Stories
- Invite friends, family, and colleagues to follow and engage as well

Every interaction helps extend accurate information to someone who may desperately need it—today or in the future.

If there's something you'd like us to cover in our next newsletter, please let us know. You can email us at **info@thecatatoniafoundation.org**.

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