The Catatonia Foundation

No one's life should be lost to catatonia

The Catatonia Foundation: Insights and Impact

Advancing understanding, changing outcomes.

Patient Impact

We hear from families, patients, and clinicians every week—often at critical moments. Here's what that looked like recently (details anonymized):

- ***When "it's just autism" wasn't the answer:*** A mother was told repeatedly that her daughter's sudden aggression and regression were *"just autism."* We connected her with an expert in catatonia*. "Thank you for the opportunity for my daughter to be evaluated when I had lost all hope."*
- ***When someone needed an advocate:*** A patient who felt alone was connected to a clinician experienced in catatonia and to private advocacy services she didn't know existed. *"OMG didn't know these services existed. Thank you thank you thank you. Can I let you know how it goes?"*
- ***When a patient needed a care team in another state:*** For a patient moving to another state, we provided several referral options from our provider resource list for a smooth transition of continued care.
- ***When a neurologist needed resources for patients with catatonia:*** We connected the physician with psychiatrists and ECT programs in the area to coordinate evaluation and treatment.

Time after time, we hear: *“Talking to TCF was the first time I felt like someone truly understood what we’re dealing with.”*

1–2 new subscribers/day

4–5 direct help requests/week

100 clinicians currently in our provider directory

Our Presence at AACAP in Chicago

We exhibited at the **American Academy of Child and Adolescent Psychiatry** (AACAP) Annual Meeting in Chicago (October 23-25, 2025). Our booth was staffed by **Eileen Donovan, M.D.** - pediatric physiatrist, TCF co-founder, and mother of David (23), who has catatonia and autism, and **Lezley Pisone** - principal of Ripple Effect Studios, TCF development consultant, and mother of Mo (18), who has catatonia and autism.

Eileen Donovan, M.D. at The Catatonia Foundation booth at AACAP in Chicago

Many psychiatrists visited the booth, having learned about TCF in expert-led sessions at the meeting. A total of 21 sessions and posters addressed catatonia. The sessions were well attended, and pre/post treatment videos were especially impactful.

Key takeaways from the meeting:

- Access to effective treatment with ECT for children remains inconsistent. There are too few clinics, administrative hurdles are challenging, and in some states, there is no pediatric access to ECT, causing ECT to be delayed or inaccessible.
- More pediatric catatonia diagnoses are being made, but consensus varies on diagnosis and treatment pathways.
- There's a growing recognition of the need for interdisciplinary care, with neurology and psychiatry collaborating.
- Attendees expressed a strong interest in education modules tailored to different types of clinicians (PAs, nurses, physicians).
- Appreciation was expressed for TCF's website having centralized, accurate information.

Updated Provider Resource Page

The most common question we're asked is: ***"Where can I find a provider with expertise in catatonia?"***

We've been diligently searching for clinicians with relevant experience, and our updated provider resource—now listing **100 providers**—is our best effort to make that information easier to find. We'll continue to add names as we hear from families, clinicians, and community partners.

One of the biggest obstacles is **outpatient access**. Many clinicians with catatonia expertise work in hospital settings as consultation-liaison psychiatrists (supporting inpatient medical teams) or in ECT clinics, which can make routine outpatient appointments hard to secure. We're actively working to identify outpatient options where possible.

This list is a community resource. Names are submitted by patients, families, or professionals who report positive experiences. Inclusion does not imply endorsement or verification by The Catatonia Foundation; we have not independently evaluated these providers or their expertise. It's important for patients and families to perform their own due diligence.

Help us expand this list—recommend a provider:
Email info@thecatatoniafoundation.org with as much of the following as you can:

- Provider name, city, state
- Specialty/role
- Inpatient or outpatient
- Pediatric and/or adult
- Link to current bio

Find providers here: **https://www.thecatatoniafoundation.org/physicians-with-expertise-in-catatonia**

Featured Article: Evidence-based consensus guidelines for the management of catatonia: Recommendations from the British Association for Psychopharmacology (BAP, 2023)

An evidence-informed, consensus guideline that synthesizes recognition, assessment, treatment, and management of catatonia, with graded recommendations and dedicated sections for children/adolescents, older adults, perinatal patients, and individuals with neurodevelopmental disorders. It underscores benzodiazepines (lorazepam) and ECT as first-line treatments, offers cautions around antipsychotic use in active catatonia, and details recommended medical work-ups.

Read (open access): **https://pmc.ncbi.nlm.nih.gov/articles/PMC10101189/**

Forum Status

Our website's forum is currently unavailable. The platform we use no longer supports forums, and the previous format wasn't user-friendly. We're actively evaluating alternative solutions. In the meantime, please contact **info@thecatatoniafoundation.org** for support and questions.

What's in the Works

- **Site-wide content update** to ensure it is current and comprehensive.

- **Surveying experts, residency programs, and medical schools** to understand the current status of catatonia education. The results will identify gaps and, with our Medical Advisory Board, guide development of targeted educational materials.
- **Collaborating with leading international experts** on proposed research projects and funding options.
- **TCF's annual fundraising campaign** is launching soon. TCF is volunteer-run with a part-time virtual assistant and we can only continue this work through the generous support of our community.

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.

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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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