The
Catatonia
Foundation

No one's life should be lost to catatonia

The Catatonia Foundation: Insights and Impact

Advancing understanding, changing outcomes.

Ava's Art: A Courageous Woman's Window Into the Experience of Catatonia

Families, caregivers, and medical professionals often wonder what the internal experience is like for someone living with catatonia. Ava Cardwell bravely shares her experience through her paintings. These paintings need no description—what she experienced clearly comes through in her art.

> ***"Through her artwork, Ava offers a rare glimpse into the lived experience of catatonia."***

Ava painted this during a period of catatonia

Ava painted this after effective treatment

Ava began experiencing strange, frightening symptoms in her teens—symptoms that came and went without explanation. It took four years before she was finally given a diagnosis of periodic catatonia. Her parents sought out experts to help them navigate the best treatment for her, and Ava is doing well today.

Ava created the first painting during a period of catatonia and the second after effective treatment. By sharing them, she offers a rare glimpse into her lived experience—something many individuals with catatonia are unable to express in words.

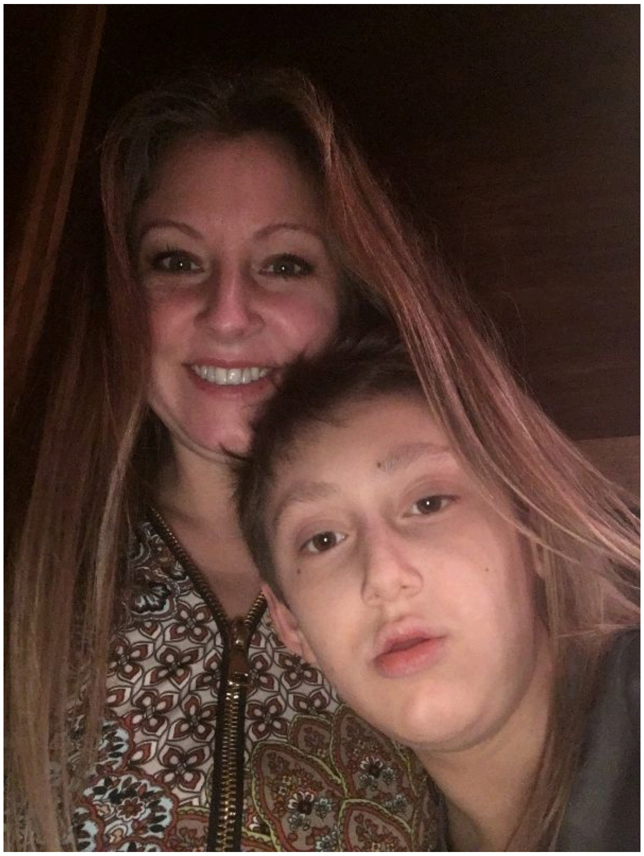
Today, Ava is in college, and she shares her artwork in the hope that it will help others better understand this often-misunderstood condition.

Ava's father, a physician, had never heard of periodic catatonia when her symptoms began. Today, he adamantly says, ***"Once you see catatonia, you can't unsee it."*** He has become a fierce advocate for better diagnosis and treatment for catatonia, and now serves on the Board of Directors of The Catatonia Foundation.

Why Families Face Years of Misdiagnosis

Catatonia is devastating. It can cause children and adults to lose their personalities, independence, and joy, and in its most severe form, they could die. Families are left exhausted, traumatized, and searching for answers—often for years.

Because catatonia is not covered adequately in most medical schools or residency programs, too many doctors miss the signs. Families like Mo's are told symptoms are "just autism behaviors," while precious time is lost.



When Mo was 10, he experienced a traumatic bullying incident at summer camp. Shortly thereafter, he began exhibiting delusional and disorganized thinking, uncontrollable crying, and obsessive looping thoughts. Because Mo has autism, his worsening symptoms were attributed to the autism. At the time, he was misdiagnosed with a mood disorder. It took eight long years before he was correctly diagnosed with the excited form of catatonia. At that point, his condition was severe and he was hospitalized for months.

The Catatonia Foundation helped Mo and his family by providing up-to-date information and connecting them with experts in catatonia. Mo's mom says, ***"The Catatonia Foundation is the lighthouse directing families to find help when they feel lost at sea."***

Mo's story of misdiagnoses and delayed treatment is not unique. Each one of the founders of The Catatonia Foundation had similar experiences, which is what brought them together to create The Catatonia Foundation. We are unwaveringly committed to changing this by:

- Providing families with educational and advocacy resources, and connecting them with providers who have experience with catatonia when possible.
- Connecting local doctors with national experts and educational materials on our comprehensive website, along with links to current professional resources.

- Working hard to fill in the gaps in education about catatonia for clinicians, residents, and medical school students.

We can't do this alone. We receive emails and calls daily from people in desperate need of help. There is so much to do and our resources are limited. Together, we can change the course of care for individuals suffering from catatonia.

Please consider a gift today to bring light to families who feel lost at sea.

Make a Gift to The Catatonia Foundation Today

The Education Gap That Leaves Families in the Dark

The Catatonia Foundation is committed to being a lighthouse for families in need. Over and over, we hear the same painful story: catatonia is rarely the first diagnosis clinicians consider when symptoms begin to appear. As a result, families endure delayed or ineffective treatment—and in some cases, interventions that actually worsen symptoms. Every one of our founders lived this reality themselves.

From the beginning, it was clear that there was a serious lack of awareness and knowledge about catatonia among both clinicians and families. In response, The Catatonia Foundation created a comprehensive, freely accessible website for families, clinicians, and trainees. This became our first step toward addressing the gap in education and resources.

As we began working with the Education Committee of our Medical Advisory Board to develop more formal educational materials, we realized we needed a clearer picture of the current landscape. Were clinicians actually being taught about catatonia? What training opportunities already existed?

To answer these questions, we undertook an enormous effort: surveying psychiatry residency programs and medical schools across the country. We directly contacted 200 psychiatry residency programs, and with the support of the Association of Directors of Medical Student Education in Psychiatry (ADMSEP), surveys were also distributed to all of their members.

The picture that emerged from our surveys was both consistent and troubling. Based on the responses, what we found is that the full spectrum of catatonia—across different presentations, ages, populations, and clinical contexts—is rarely covered in depth. Even in programs where diagnosis and treatment are included, the instruction is typically brief—often less than an hour in total.

We identified a small number of residency programs and medical schools that teach catatonia thoroughly and thoughtfully. In these programs, trainees learn to recognize the full range of presentations and understand appropriate approaches to treatment. In those settings, patients receive timely, effective care.

Unfortunately, these strong programs are the exception—not the norm—which means that most clinicians enter practice without the knowledge needed to recognize this highly treatable condition.

This lack of comprehensive education contributes directly to delayed recognition and barriers to effective treatment. Catatonia is relatively common, well described in the medical literature, and highly treatable when identified early—yet many clinicians simply have not been given the tools to recognize it.

Building on the foundation of our website and informed by these survey findings, our next step—in collaboration with the Education Committee of our Medical Advisory Board—is to develop and disseminate clear, current educational materials about catatonia. This will include written resources, didactic modules, and courses designed for medical students, residents, and practicing clinicians.

Our goal is to ensure that no family faces the darkness of catatonia alone—and to keep shining a light that leads to understanding, recognition, and the care every person deserves.

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.

Donate

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**.

Learn More