International OCD Foundation

OCD Newsletter

Vol. 40 • Issue 2 Summer 2026

Digital Reassurance Seeking

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You Belong Here—Find Your Place in the OCD Community

Whether you live with OCD, support someone who does, or work to advance understanding and treatment, you're part of a powerful community. At the International OCD Foundation, we're working to ensure that everyone affected by OCD and related disorders has access to the resources, treatment, and support they need to thrive. Here are a few ways you can get involved.

- **Sign up for emails:** Receive the latest resources, updates, and ways to connect straight to your inbox. iocdf.org/sign-up
- **Attend an event:** Connect, learn, and find hope with others who understand. Upcoming events include:
  - **July 9-12, 2026 | Seattle, WA and Virtual:** 31st Annual OCD Conference iocdf.org/ocdcon
  - **Throughout 2026:** Find or start a One Million Steps for OCD Walk near you! iocdf.org/walk
  - **View all upcoming events:** iocdf.org/events
- **Raise Awareness:**
  - **Sept. 3, 2026 | BDD Awareness Day:** Join us to celebrate the first annual Body Dysmorphic Disorder (BDD) Awareness Day, in partnership with the BDD Foundation! bdd.iocdf.org
  - **Oct. 11-17, 2026 | OCD Awareness Week**
- **Become a grassroots advocate:** Being an IOCDF Grassroots Advocate means joining a community of people who want to raise awareness and educate the public about OCD and related disorders. iocdf.org/advocate
- **Join a special interest group:** Take part in discussions, networking, education, resource development, and research around OCD and related disorders. iocdf.org/special-interest-groups
- **Donate!:** As a donor-supported organization, your support allows us to expand our resources and grow, empowering us to take on bold initiatives and turn the goals in this plan into reality. Together, we can bring this vision to life and provide life-changing support to millions of individuals and families affected by OCD and related disorders worldwide. iocdf.org/donate

Annual OCD Conference July 9-12, 2026

Join us in Seattle or online — most sessions available virtually

The Annual OCD Conference is a unique, immersive event filled with educational programming for the OCD and related disorders community — including clinicians, individuals with OCD and related disorders, family members and supporters, youth, students, and researchers. Attendees come together to connect, learn, and share experiences with others impacted by OCD and related disorders, as well as with expert clinicians and researchers.

Registration now open: iocdf.org/ocdcon

"Thank you for being part of this important work and for all you do to move our mission forward."

President's Letter

Dear Friends,

I am truly honored and energized to connect with you as we look ahead to this year's OCDCon. This is an especially exciting time for our community. OCDCon is more than an event on the calendar. It is a powerful reminder of what we can achieve when we come together with a shared purpose: to learn, to connect, and to move forward with strength and hope.

Each year, OCDCon brings our community to life in a uniquely meaningful way. It is where cutting-edge research meets real-world courage. Clinicians, researchers, families and those with lived experience all learn from each other, while finding understanding, connection, and renewed optimism. The energy, compassion, and commitment that define this gathering extend far beyond the conference itself and continue to shape the work we do all year long.

We are especially proud to celebrate this year's OCDCon Award Winners. Their dedication, innovation, and compassion continue to move the field forward and inspire all of us. They embody what is possible when passion is paired with purpose, and their contributions are helping to create a better future for the OCD and related disorders community.

In this issue, you will also find the powerful story of Noemi Tsai, featured in our spring campaign. Noemi's courage in sharing her journey highlights the importance of visibility and advocacy. Stories like hers not only reduce stigma but also encourage others to take that first step toward seeking help and finding hope.

Our cover story on digital reassurance seeking explores how OCD continues to evolve in today's increasingly connected world. As technology becomes more integrated into our daily lives, understanding these patterns is essential for both individuals and clinicians working toward effective treatment.

We also highlight the importance of self-advocacy in OCD treatment. Empowering individuals to actively participate in their care is critical. When people feel heard, informed, and engaged, treatment becomes more effective and recovery more attainable.

Finally, we are excited to share updates from the Jenike Award work, including promising research on TMS for OCD sensory urges. Advances like these are a testament to the progress being made and offer real hope for expanding treatment options.

As we look ahead to OCDCon, I hope you feel the sense of momentum and possibility that defines this community. Thank you for being part of this important work and for all you do to move our mission forward.

With gratitude,

David Calusdian
President, IOCDF

Introducing the 2026 Annual OCD Conference Award Winners

The mission of the International OCD Foundation— to ensure that no one affected by OCD or related disorders suffers alone—requires the collaboration and dedication of countless individuals and professionals around the world. Each year, the IOCDF is honored to recognize a few of these contributors who have gone above and beyond to inspire hope, build community, and move us closer to a world where everyone has access to effective support and care.

These awards will be presented at the 31st Annual OCD Conference, sponsored by OCD Institute Texas, on Saturday, July 11, 2026.

2026 Career Achievement Award Winner: Sabine Wilhelm, PhD

Highlighting the significant and notable contributions of a professional in the field of OCD and related disorders.

Sabine Wilhelm, PhD, is the Donovan-Chien Family Endowed Professor at Harvard Medical School and Chief of Psychology at Mass General Brigham. She directs both the Center for OCD and Related Disorders and the Center for Digital Mental Health at Massachusetts General Hospital. Dr. Wilhelm's work leverages AI and technology to improve mental health care globally, focusing on developing personalized, scalable digital treatments. She has authored 375 publications and nine books. She has received major awards, including the NAMI Scientific Research Award and the Peter Ranney Innovation Award from the World Medical Innovation Forum.

Dr. Wilhelm is the outgoing Chair of the IOCDF Scientific & Clinical Advisory Council after serving since 2023, and she has served on numerous committees to support the Foundation's work to advance research and resources for OCD and related disorders.

2026 Patricia Perkins Service Award Winner: Aureen Wagner, PhD

Honors any professional or IOCDF member who has stood out as a long-time (10+ years) and active contributor to the IOCDF in multiple ways. This award is named after Patricia Perkins, IOCDF co-founder, past president of the Board of Directors, and previous executive director.

Aureen Pinto Wagner, PhD, has been involved with the International OCD Foundation since 1992 and a frequent presenter at its conferences and programs for families, clinicians, and youth. She serves on the IOCDF's Scientific and Clinical Advisory Board and has been faculty with the Behavior Therapy Training Institute since 2001.

Dedicated to expanding access to evidence-based OCD treatment, Dr. Wagner provides clinician training, workshops, and consultation nationwide. She is the author of the professional treatment manual *Treatment of OCD in Children and Adolescents: A Professional's Kit* and several award-winning books for families, including "Up and Down the Worry Hill: A Children's Book about Obsessive-Compulsive Disorder and its Treatment," "What to do when your Child has Obsessive-Compulsive Disorder: Strategies and Solutions" and "Worried No More: Help and Hope for Anxious Children."

At The Anxiety Wellness Center in Cary, North Carolina. Dr. Wagner provides in-person and telehealth treatment for children, adolescents, and adults with OCD, anxiety, and related conditions, along with parenting support for families.

2026 Hero Award Winner: Stephen Smith

Recognizes any individual that has stood out as a particularly effective advocate for OCD and related disorders or who helped raise awareness of these disorders.

Stephen Smith is the Co-founder and Chief Executive Officer of NOCD, the world's largest OCD-specialty treatment provider for both adults and children. After emerging from a personal struggle with undiagnosed OCD and experiencing the success of Exposure & Response Prevention (ERP) therapy first-hand, Stephen made it his mission to transform the behavioral health treatment system for people with OCD and related conditions. Under his leadership, NOCD has done that. NOCD drives OCD awareness campaigns that reach millions of people each year, cares for hundreds of thousands of people with OCD, and is contracted to serve more than 140 million commercial lives nationally.

2026 Youth Hero Award Winner: Gabriella Lee

Recognizes any youth (under 18) that has stood out as a particularly effective advocate for OCD and related disorders or who helped raise awareness of these disorders. This award is presented by UNSTUCK: an OCD kids movie.

Gabriella Chaeyoon Lee is a junior at Great Oak High School in California who is dedicated to promoting mental health awareness, particularly surrounding OCD. Inspired by her personal connection to OCD through her mother's diagnosis, she actively works to reduce stigma and support others through her school club and independent initiatives. She is passionate about creating safe and inclusive spaces where individuals feel understood and supported. She hopes to continue her advocacy and contribute to meaningful change in mental health communities.

2026 Illumination Award Winner: Tiffany Jenkins

Honors media personalities who have represented OCD or related disorders in a respectful, accurate, and appropriate way, or who have challenged stereotypes and helped to fight stigma around mental health issues.

Tiffany Jenkins is a comedian, *New York Times* bestselling author, speaker, and podcast host with a combined social media following of over 9 million and more than one billion video views worldwide.

While widely recognized for her relatable and candid comedy, Tiffany is deeply committed to raising awareness around mental health and addiction. Drawing from her own lived experience in recovery, she travels across the United States speaking at high schools, correctional facilities, treatment centers, and conferences, where she delivers impactful, honest conversations that resonate with diverse audiences.

Above all, Tiffany is a devoted mother, bringing authenticity, resilience, and humor into both her work and her everyday life.

Sitting With a Cat But You Have OCD - An OCD Short Story

By Victoria Anne Kapassakis

I never really liked cats, but the way she rested her head on my leg made me feel more loved than most people make me feel. I sat with her at every chance, stroking her fur and listening to the birds and the cars driving by. My breath was long and steady. I didn't have a care in the world other than making sure she could feel how much I love her through my touch. I learned that if you don't wash your hands with soap for at least twenty seconds after touching a stray cat you can unknowingly ingest worms that migrate throughout your body until they cause vision loss in one eye. I wondered if I'd washed for long enough, I wondered whether I had a colony of worms living in my stomach by now, traveling to my lungs and up. "How quickly do symptoms of roundworm show?" "Do roundworm eggs stick to any surface they touch?" When I touched her fur, I could almost see the microscopic worm eggs on my hands, spreading, they're on my clothes now, too. Did I touch my face? Did I wash my hands for long enough? Did the eggs transfer from my infected hands, sticking to every surface I carelessly touched? The door handle, the soap dispenser, the faucet. The worms are going to travel to my eyes and I'll never see again and it's my fault.

A Message From Noemi Tsai

My name is Noemi Tsai, and I've lived with OCD for as long as I can remember. In fact, **my first memories were about OCD.**

In preschool, I had an intense fear of getting sick from the gum on the sidewalks. In elementary school, I developed a fear of making mistakes, especially on homework and tests. But in eighth-grade health class, something finally clicked. We each chose a topic to research about mental health, and I chose to research OCD. The first website that popped up was the International OCD Foundation (IOCDF), so I clicked on their website and read about OCD. I thought, "Wow, this describes what I'm going through." However, because of the stigma surrounding OCD, I was afraid to tell my parents.

My symptoms progressed more over that year, and OCD became the center of my life. A few months later, I got the diagnosis. My parents ultimately made the decision to enroll me in OCD treatment. During that time, I learned about Exposure and Response Prevention (ERP), which helped me get my life back.

A year later, I relapsed. My OCD symptoms were bigger than ever. The thing about OCD is that it's never a linear journey. But I wouldn't have met our amazing OCD community without the struggles that I've gone through.

At the Boston OCD Walk, I instantly found the connection and hope that I was so desperately needing. I saw that recovery was possible, and I will never forget that. I knew I wanted to give back to the community that saved my life through OCD Walks, the Annual OCD Conference, and the Online OCD Camp. So in 2023, I co-chaired my first OCD Walk. It was a full-circle moment. **The IOCDF gave me the opportunity to show others that recovery is possible.**

Now, I'm asking you to support the organization that is instrumental to my recovery journey by making a donation to the IOCDF. Your support will expand programs for kids and families like mine, add more resources to the IOCDF's website, and grow our amazing OCD community. **When you donate to the IOCDF, YOU are helping to save lives like mine.** Every dollar makes a difference in bringing us closer to a world where no child or family has to face OCD alone.

Thank you,
Noemi

"...I've lived with OCD for as long as I can remember. In fact, my first memories were about OCD. "

Your Donation Makes a Difference

Your gift helps support kids like Noemi and their families to:

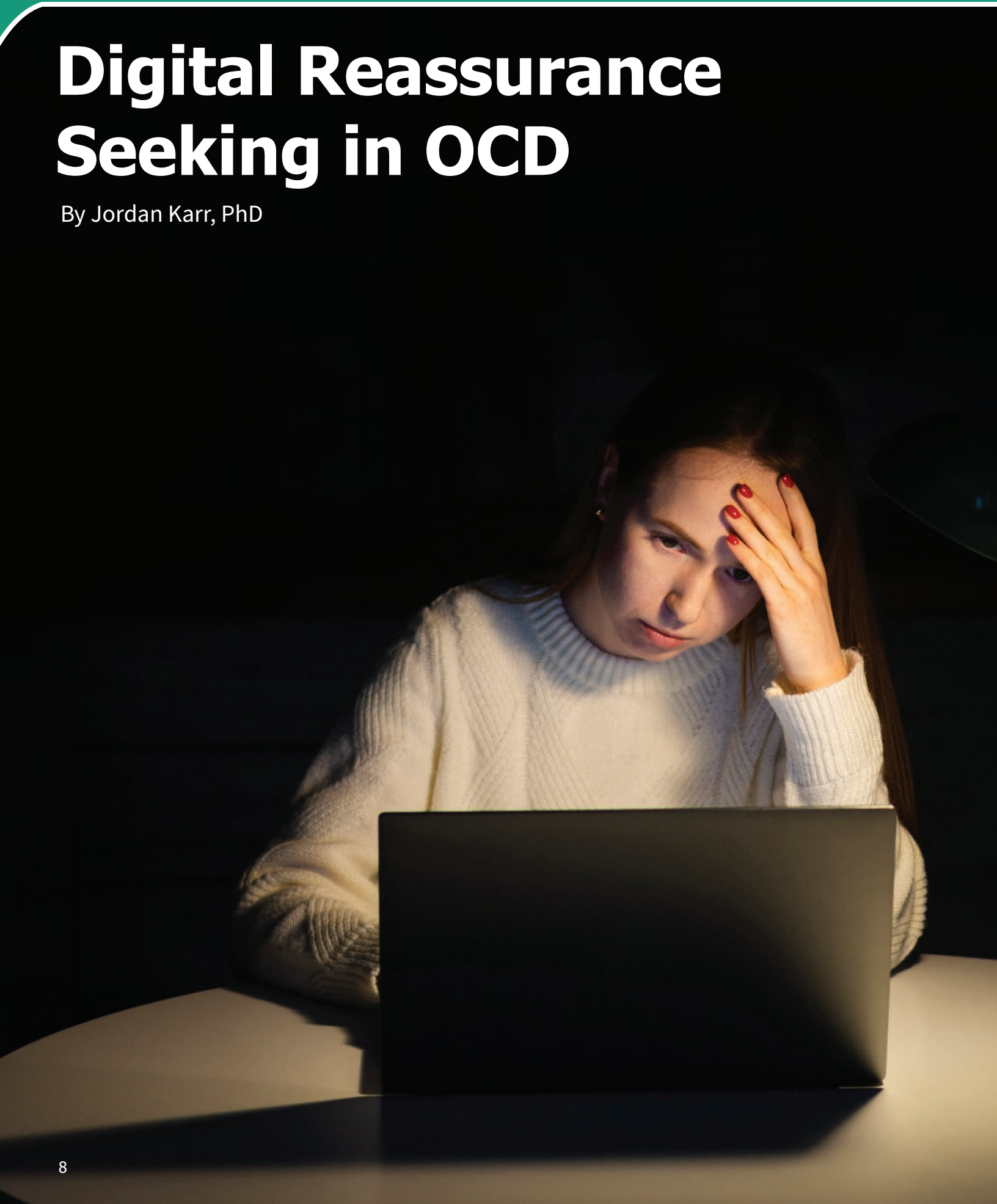
- ***Find accurate information*** when they are first learning about OCD and related disorders at iocdf.org and anxietyintheclassroom.org.
- ***Access evidence-based treatment*** through specialized training for professionals treating children with OCD through the IOCDF Training Institute.
- ***Build community and hope*** at events like the OCD Walks, the Annual OCD Conference, and the Online OCD Camp.

Donate today at iocdf.org/helpkids to bring help, healing, and hope to families impacted by OCD.

This is the last chance to support our spring campaign that benefits kids and families. Will you join us?

Digital Reassurance Seeking in OCD

By Jordan Karr, PhD



We all need reassurance once in a while. Receiving reassurance from a friend, loved one, or expert can reduce short-term distress, foster a sense of connection, and help us move forward in a productive way. On the other hand, excessive reassurance seeking can lead to a painful cycle of stress and doubt. For individuals with obsessive-compulsive disorder (OCD), reassurance is fleeting and is quickly followed by a resurgence of perceived threat and a compelling drive to seek additional reassurance.

As an OCD and anxiety specialist, I am no stranger to reassurance traps. I see them in the patient who repeatedly consults doctors but never fully trusts their answers; the partner who keeps asking, "Do you still love me?" while scrutinizing every response; and the teenager who needs her homework checked repeatedly but does not learn to tolerate uncertainty. While the content of excessive reassurance seeking may vary, its function remains the same—relieving anxiety momentarily while allowing obsessions to rebound more strongly in the long run. In each example, we see an individual desperately trying to protect something they hold dear while being misled by one of OCD's most convincing lines: "What if this time the reassurance sticks?"

Psychologists have long argued that excessive reassurance seeking helps maintain OCD, anxiety, and depression (Abramowitz et al., 2002; Burns et al., 2006). What is new is the landscape. Today, reassurance is available instantly and endlessly through search engines, medical websites, social media, and artificial intelligence tools. Emerging research suggests that online reassurance seeking may be as prevalent as interpersonal reassurance seeking (Parsons & Alden, 2022). These digital reassurance traps present in a variety of forms, including:

- Excessive symptom-checking on WebMD
- Checking a loved one's location on Find My Friends to make sure they are still alive or where they promised they would be
- Asking Google Gemini whether an intrusive thought makes you a monster, a pedophile, or a bad Christian, Muslim, or Jew
- Analyzing the contents of a partner's Instagram to see whether their feelings have changed
- Endlessly searching Reddit for answers to existential questions
- Obsessively checking likes and read receipts to monitor the durability of a relationship
- Finding creative ways to ask ChatGPT whether you might be responsible for spreading a virus or causing someone harm
- Compulsively checking the news to confirm whether a feared event has taken place

Why do some individuals seek reassurance primarily from others in face-to-face contexts while others turn to the internet? Findings from one study suggest that individuals may be more likely to seek interpersonal reassurance when they desire emotional support, whereas online reassurance seeking is more likely when individuals feel ashamed or fear judgment from others (Parsons et al., 2025). In the same study, shame was reported more frequently among individuals with OCD. The perceived anonymity of the internet creates a compelling environment for seeking reassurance about our most distressing fears and the fears we feel ashamed to have.

Wait, hold on... shouldn't having access to all the information on the internet be empowering? After all, there's that famous saying, "Knowledge is Power." Well I'm not sure what Francis Bacon would say if he could scroll on TikTok, but in the age of the internet, more information does not always mean more power or knowledge. In fact, information overload seems to trigger excessive reassurance seeking online (Yang & Luo, 2024). Once digital algorithms detect health-related concerns, users may be exposed to increasingly frequent and targeted content, further amplifying health anxiety and driving additional reassurance seeking online (Zhang et al., 2024).

Despite these challenges, evidence-based treatments offer hope. Exposure and response prevention (ERP), the gold-standard treatment for OCD, helps individuals tolerate uncertainty

Digital Reassurance Seeking in OCD

and break free from compulsive behaviors. ERP therapists are prepared to respond to clients who compulsively seek reassurance while taking care to avoid reinforcing a client's anxiety and setting boundaries when appropriate. On the other hand, AI chatbots are available 24/7 and will continue to reassure users when it would be clear to a skilled therapist that more reassurance is harmful. Some helpful activities I have encouraged clients to try include:

- Going for a walk and leaving your phone behind
- When you have the urge to seek reassurance, use a timer to delay. Start with 5 minutes and gradually increase the time as you go.
- Imaginal exposure: Writing out OCD's worst case scenario while refraining from seeking reassurance.
- Embracing the uncertainty: When you have the urge to seek reassurance, lean into the uncertainty by responding "maybe that will happen, maybe not."
- Watch a movie that triggers obsessions but leave your phone in the other room
- Try a fast from social media. Start with a short fast and increase the length of each fast as you gain confidence.
- Agreeing with the obsessions: Whatever your OCD throws at you, respond by saying "Sure, that is true!"

Clinicians working with youth should also attend to parental accommodations that inadvertently facilitate online reassurance seeking. Supportive Parenting for Anxious Childhood Emotions (SPACE) is an evidence-based, parent-focused intervention that emphasizes increasing supportive statements while reducing unhelpful accommodations. Setting reasonable limits on smartphone use while responding with empathy and confidence can help youth build resilience and independence (i.e. "I know it's tough to be away from your phone and I know you got this!").

Finally, because shame plays a central role in digital reassurance traps, incorporating self-compassion practices may be beneficial. Compassion-focused exercises help individuals respond to their struggles with kindness rather than self-criticism, complementing ERP by fostering emotional resilience. I sometimes ask clients to imagine that a close friend or loved one is feeling ashamed because they are experiencing obsessions and are stuck in an OCD loop. Then, I invite them to write down how they would support this friend while paying special attention to how compassion feels in their body. By practicing compassion for others, we strengthen the same muscles in our brains that help us turn compassion inward.

If you are getting stuck in digital reassurance traps, you are not alone! Many of these technologies are brand new and we are learning how to integrate them into our lives in a healthy way. If you need help managing compulsive online habits, finding a therapist trained in ERP could be a useful step!

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Finding Your Voice: Self-Advocacy as a Critical Tool in OCD Treatment

By Jonathan A. Teller, M.A.; Department of Psychology, Northern Illinois University

Why Self-Advocacy is Difficult with OCD

Self-advocacy means showing up as a partner in your own care—asking questions, naming what is not working, pushing for the treatment that actually fits. Every patient benefits from this. But for people with OCD, it is complicated by an uncomfortable fact: the disorder targets the same processes self-advocacy depends on. Pathological doubt makes one with OCD second-guess what they just noticed. Perfectionism makes asking a "wrong" question feel unbearable. Anxiety makes the whole conversation feel like something to avoid.(Pinciotti et al., 2022).

The case for self-advocacy in OCD is straightforward: patients who engage actively in treatment do better. Adherence to exposure exercises predicts symptom improvement across multiple studies (Simpson et al., 2011; Ojalehto et al., 2020; Tjelle et al., 2021). But engagement is not passive—it requires speaking up in real time. Flagging when an exposure feels off. Asking why a particular exposure was chosen. Communicating with your therapist that yesterday's homework did not go as planned. These are small acts, but they are the difference between treatment that's done to you and treatment you are actually steering. The dysfunctional belief domains that define OCD make every one of them harder than it should be (OCCWG, 2005).

Beyond the disorder itself, several practical barriers get in the way. Many patients with OCD worry about being seen as difficult, demanding, or "too much" by their providers — and that worry alone is enough to keep important questions unasked (Glazier et al., 2015). There is also a problem unique to OCD: how do you tell the difference between a legitimate clinical question and a compulsion? Reassurance-seeking is a well-documented OCD behavior, and patients who know this often err on the side of silence rather than risk feeding the disorder (Kobori & Salkovskis, 2013). Add in unfamiliar medical terminology and a healthcare system most people find confusing on a good day, and the deck is stacked against speaking up.

Pre-Session Preparation

Most of self-advocacy happens before you walk into the appointment. Track your symptoms between sessions with specific examples—what triggered the obsession, what compulsion followed, what you tried instead. Vague reports ("this week was bad") give your therapist less to work with than concrete ones ("I spent forty minutes checking the stove on Tuesday before I could leave for work"). Come in with a working understanding of your treatment, too. If you are doing ERP, know what exposure and response prevention actually are and why they work — that knowledge is what lets you ask real questions instead of just nodding along (Abramowitz et al., 2019). Write your questions down before the session. Anxiety in the room will erase them otherwise. And if it helps, bring someone you trust to take notes so you can actually listen.

In-Session Communication

Once you're in the therapy room, the goal is to be specific. "I" statements help here—not because they're a magic formula but because they keep you describing your own experience instead of speculating about what your therapist thinks. "I notice my anxiety spikes during exposures involving contamination" gives your provider something to work with; "this isn't working" doesn't. The same goes for asking for clarification. If your therapist explains something and you don't follow it, say so — "Can you walk me through how this exposure is supposed to address the harm obsession?" is a fair question, not a challenge. And if you need time to think through a decision, ask for it. Wanting a session to sit with something before you commit isn't avoidance; it's deliberate.

Disagreement is harder. If you think your concerns aren't being heard, naming that directly works better than hinting at it—something like "I hear what you're saying about exposures, and I'm also

Finding Your Voice: Self-Advocacy as a Critical Tool in OCD Treatment (Cont'd.)

noticing that the harm obsessions haven't shifted the way we expected. Can we talk about what to try next?" The both/and framing keeps the conversation collaborative without pretending you don't have a concern. Keep notes after these conversations—date, what was discussed, what was decided. If you're getting dismissed repeatedly, a second opinion is reasonable; OCD is a specialty area, and not every provider who treats anxiety has deep ERP experience. Pushing back on a treatment plan isn't being a difficult patient. It's doing your part of the work.

Family Accommodation

Self-advocacy doesn't stop with your provider. Most families of people with OCD end up accommodating the disorder in some form—answering reassurance questions, helping with avoidance, modifying routines around rituals—and the more accommodation happens, the harder treatment gets (Lebowitz et al., 2012). The fix isn't to cut your family out; it's to bring them in on what treatment actually requires. That conversation is hard, partly because you're asking people who love you to stop doing the thing that visibly reduces your distress. A version that tends to land: "I know it's hard to watch me sit with this. But the treatment works by not avoiding triggers, and what helps me right now is you not stepping in to fix it." Families who understand response prevention—even at a basic level—support treatment more effectively (Thompson-Hollands et al., 2015).

Virtual Treatment

Telehealth opens up real options. Virtual ERP works—outcomes are comparable to in-person treatment when sessions are structured well (Feusner et al., 2022)—and for many patients, doing exposures in the actual environment where the obsession lives (your kitchen, your bathroom, your front door) makes the work more transferable. Advocacy in this format means asking practical questions upfront. What happens if the connection drops mid-exposure? Who calls whom? Is there a plan if a crisis comes up between sessions? It also means setting up your end thoughtfully—a private space where you won't be interrupted, a backup phone number, a clear sense of when you'll be alone in the house. None of this is glamorous, but it's the difference between a session that works and a session that wastes both of your time.

Working with Insurance

Insurance is its own animal. Document everything—every call, every representative's name, every reference number—because the burden of proof in any dispute will be on you. Two phrases worth knowing: "I'd like to appeal this decision" and "Can you arrange a peer-to-peer review?" Both are standard requests, but most patients never make them. That's not an accident. Initial denials are common, and insurers count on the fact that appeals are exhausting and that most people won't follow through. Following through often works.

The Long Game: Relapse and Transitions

Recovery isn't a finish line. Relapse risk is real—partial remission and certain symptom dimensions predict it more strongly than others, which is part of why ongoing self-monitoring matters (Eisen et al., 2013). Build a relapse prevention plan with your therapist before you need one: what early warning signs look like for you specifically, what you'll do if you notice them, who you'll tell. And when you move between providers or levels of care, don't assume the handoff happens cleanly. Ask for a written treatment summary, make sure your new provider has it, and flag what's worked and what hasn't. Continuity of care isn't automatic in the U.S. mental health system (Senter et al., 2021); it's something you have to actively protect.

Community and Peer Support

You don't have to figure this out alone. The IOCDF runs support groups and online communities where people with OCD compare notes on what's worked with their providers, how they've handled accommodation conversations at home, what they've learned about appealing insurance denials. Some of the most useful self-advocacy strategies don't come from clinicians at all—they come from other patients who've already had the conversation you're about to have. Peer connection isn't a substitute for treatment, but it's a context where you can practice naming what you need before you have to name it in a higher-stakes setting.

Becoming an effective self-advocate isn't a switch you flip. It's a practice, and like any practice, it gets easier the more you do it. Start small—one additional question this week, one concern named that you'd normally hold back. Pay attention to what works and what doesn't. And try to remember, especially when it feels uncomfortable, that advocating for yourself in OCD treatment isn't difficulty or noncompliance. It's the work.

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Training Opportunities from the International OCD Foundation

The International OCD Foundation (IOCDF) Training Institute continues to expand access to high-quality education for clinicians seeking to improve care for individuals with OCD and related disorders. This fall, several specialized programs offer unique opportunities for professional growth and culturally responsive training.

The Behavior Therapy Training Institute (BTTI) for Treating OCD in Communities of Color, taking place September 23–25 in Detroit, MI, is designed to address disparities in mental health care by offering BIPOC clinicians a safe and welcoming space to gain practical skills for treating OCD while exploring the impact of culture, identity, and systemic factors on diagnosis and care. Registration is now open!

In addition, the BTTI Virtual en Español, scheduled for November 5–9, provides comprehensive OCD training entirely in Spanish. This program supports Spanish-speaking clinicians worldwide in building competency in exposure and response prevention (ERP), helping expand access to evidence-based care across diverse communities. Registration is now open!

Beyond these intensive trainings, the IOCDF Webinar Series offers ongoing learning opportunities throughout the year. These sessions cover a wide range of topics—from foundational treatment approaches to emerging research—making it easy for professionals to earn CEs and stay current and engaged.

Looking ahead, the IOCDF Advanced Forum on Comorbidities will take place October 22-24 at Baylor College of Medicine in Houston, TX. This event will bring together advanced clinicians and experts to explore the complexities of co-occurring conditions and their impact on OCD treatment.

Together, these offerings reflect IOCDF's continued commitment to education, equity, and excellence in OCD care.

Understanding Sensory Phenomena in OCD

By Goi Khia Eng, PhD

This article describes the results of a 2022 Michael Jenike Young Investigator Award, an IOCDF-funded research project.

Obsessive compulsive disorder (OCD) is a chronic condition with diverse symptom presentations. OCD is often thought of as driven by fears, such as fear of germs leading to washing, or worries about safety driving checking. However, many people with OCD also experience sensory phenomena, which are uncomfortable and aversive sensory experiences, including sensory-based physical urges. Consider someone who experiences a compelling need to tap both sides of the body the same number of times until it feels "even", not out of fear that something bad might happen if they do not, but because of an intense urge like a persistent itch demanding relief. Sensory phenomena affect as many as 60% of individuals with OCD (Miguel et al., 2000; Shavitt et al., 2014) and can drive compulsive behaviors such as touching, tapping, repeating, evening-up or arranging objects that are performed until they feel "just right" (Ferrão et al., 2012; Katz et al., 2022).

The Science Behind Sensory Urges

Sensory-based urges in OCD (and the urges before tics in Tourette disorder) are similar to everyday urges-for-action, such as the urge to blink or scratch an itch, both in how they feel and in the brain processes involved. Like everyday urges, sensory urges are internally generated and tend to intensify when they are suppressed or delayed (Berman et al., 2012; Neuner et al., 2014). Brain imaging studies in people without mental health diagnoses show that everyday urges-for-action activate a network of brain areas involved in movement preparation,

as well as physical sensations and sensations arising from within the body. This brain network involves the insula and sensorimotor regions (including the postcentral gyrus, precentral gyrus, supplementary motor area, and cingulate cortex) (Jackson et al., 2011; Zouki et al., 2024). Most work examining brain regions related to pathological urges has been conducted in Tourette disorder, where studies found increased activation in a similar network of brain regions a few seconds prior to the onset of tics (Bohlhalter et al., 2006; Neuner et al., 2014). Our previous work examining the urge to blink in people with OCD also found activation in similar regions when participants were told to suppress blinking (Stern et al., 2020).

Current Treatments for Sensory Phenomena Are Lacking

Although they are common and distressing, sensory phenomena are not well addressed by first-line OCD treatments, behavioral therapies like cognitive behavioral therapy (CBT) and exposure and response prevention (ERP), and serotonin reuptake inhibitor (SRI) medication (Abramowitz et al., 2003; Stein et al., 2007). Although these treatments help many people with OCD, symptoms like sensory phenomena without a fear component may be more challenging to treat, as behavioral therapies may not be as readily applicable and medications may be less effective (Foa et al., 1999; Stein et al., 2007). Even when sensory phenomena do respond to these treatments, only about half of patients achieve full recovery, underscoring the need to develop new approaches to targeting sensory symptoms in OCD.

Transcranial Magnetic Stimulation (TMS)

TMS is a non-invasive neuromodulation technique that involves placing a specialized coil against the scalp, which generates a magnetic field that induces small electrical currents in the brain (Hallett, 2007). Depending on the stimulation parameters, TMS can either increase or reduce brain activity in the targeted region.

TMS offers several research and clinical advantages. It requires no surgical intervention, no needles, and no substances entering the body beyond the magnetic field itself. Individuals remain seated while the coil is positioned against the scalp using anatomical landmarks or a neuronavigation system. Aside from clicking sounds and mild scalp sensations, TMS is generally well-tolerated with minimal side effects. TMS received FDA approval for treatment-resistant depression in 2008 and for OCD in 2018; it is typically delivered in multiple sessions over several days or weeks, and has an established safety profile across multiple psychiatric applications (Cotovio et al., 2023; Rossi et al., 2021).

From Eyeblinks to Clinically Relevant Sensory Urges

Our research began by studying eyeblink suppression as a model for investigating sensory-based urges (Bragdon et al., 2023; Eng et al., 2024; Stern et al., 2020). People with OCD failed to suppress eyeblinks more than control participants when instructed to do so (Stern et al., 2020). These failures were associated with more severe sensory phenomena (Eng et al., 2024), measured using the gold-standard University of São Paulo-Sensory Phenomena Scale (USP-SPS) (Rosario et al., 2009). Importantly, greater activation in several brain regions, including the postcentral gyrus (involved in processing sensory information), was associated with both eyeblink suppression failures and more severe sensory phenomena in OCD (Eng et al., 2025).

Building on these findings, we tested whether reducing activity in the postcentral gyrus could modulate sensory urges and brain activation. In an initial pilot sample of four participants with OCD, we delivered single-session inhibitory TMS to an individualized target in the postcentral gyrus on one day (*active* TMS) and *sham* (inactive) TMS on another (Eng et al., 2025). *Active* TMS, compared to *sham*, was generally associated with reduced activity in this brain region during eyeblink suppression and lower self-reported urge to perform compulsions.

Through funding from the Michael Jenike Young Investigator Award, we expanded data collection to include 12 additional participants, for a total sample of 16. Each participant completed i) one baseline brain-imaging session, during which they performed the eyeblink suppression task while their

Understanding Sensory Phenomena in OCD (Cont'd.)

brains were scanned using magnetic resonance imaging (MRI), and ii) two single-session TMS visits on different days, at least 5 days apart. Of these two TMS visits, one visit delivered active inhibitory TMS to an individualized target in the postcentral gyrus, and the other delivered sham TMS, which followed the same procedures but without actual brain stimulation. Participants were not told which condition they received. Immediately before and after each TMS session, participants rated the strength of their urge to perform compulsions using visual analogue scales (VAS). Changes in this rating served as the primary outcome, reflecting acute changes of clinically relevant OCD urges. Immediately after TMS and completing the VAS ratings, participants performed the eyeblink suppression task in the MRI scanner.

The Innovation

To our knowledge, this is the first study to use neuromodulation to specifically target sensory-based urges and the postcentral gyrus in individuals with OCD. Our selection of the postcentral gyrus as a target region is novel and supported by evidence linking higher activation there to more eyeblink suppression failures and more severe sensory phenomena. To tailor stimulation for each participant, we did not target the exact same brain location in everyone. Instead, we used each participant's own brain scan to identify the specific "hotspot" within the postcentral gyrus that was most active during eyeblink suppression. To lessen discomfort, we delivered TMS in quick bursts rather than using traditional repetitive protocols, so that stimulation can be completed in under a minute. Neuronavigation technology, which is essentially a GPS system for the brain, was used throughout the session to track the TMS coil's position in real time relative to the participant's brain to ensure precise and consistent targeting. These approaches acknowledge individual differences in brain anatomy and apply principles of personalized medicine to neuromodulation.

Study Findings

Our study results, while preliminary given the small sample size, showed encouraging patterns across multiple measures. Most importantly from a clinical perspective, participants reported greater reductions in the strength of their urge to perform OCD-related compulsions following *active* TMS compared to *sham*, suggesting that modulating activity in the postcentral gyrus may have clinical relevance. In terms of brain activation, regions of the urge network including the postcentral gyrus, precentral gyrus, and insula showed less activation during eyeblink suppression following *active* TMS compared to *sham*.

Notably, there was individual variability in response. Some participants showed substantial decreases in the strength of their urge to perform compulsions following *active* TMS compared to *sham*, while others showed smaller decreases or minimal change. We found that participants who reported greater reduction in their urge to perform compulsions after *active* TMS (compared to *sham*) showed greater decreases in brain activity in regions associated with urges-for-action (including the postcentral gyrus, precentral gyrus, supplementary motor area, and insula), as well as regions involved in cognition and emotional processing, and reduced connectivity between the postcentral gyrus TMS target and these regions.

Conclusion and Study Implications

This proof-of-concept investigation represents an important step toward addressing a significant unmet clinical need. By demonstrating that modulating activity in the postcentral gyrus was associated with changes in both the urge to perform compulsions and underlying brain circuitry (with notable individual variability), we established a foundation for developing targeted neuromodulation approaches for sensory-based urges in OCD. These findings are promising and worthy of replication in a larger sample.

Although this study examined only short-term effects, these mechanistic findings will inform future clinical trials employing repeated (multi-week) sessions of individualized TMS to achieve longer-term modulation of sensory phenomena in OCD.

Beyond TMS, the insights gained from this work are also guiding our exploration of other cutting-edge non-invasive brain stimulation techniques, such as low-intensity focused ultrasound, which can reach deeper brain structures and may ultimately expand treatment options for individuals with sensory phenomena.

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Summer 2026 Research Participants Sought

Do You Care for Someone With OCD?

OCD treatment is hard to access for many reasons, and we want to help change that.

The Lab for Expanding Access for Families (LEAF) is developing a free online program designed to reduce caregiver stress and help break the cycle of OCD as part of a research study.

- Access to a digital program for OCD
- No cost to you, up to $45 in compensation
- Follow-up surveys (2 & 4 weeks)
- Voluntary + Asynchronous + From your own home
- Who are we? Researchers at Boston University and the Center for OCD and Related Disorder at MGH/Harvard Medical School

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www.leafbyleaf.org/empowerocd

Share with your caregivers if you'd like them to learn more about how to best support you!

Interested?
Scan the QR code to participate.

Do You Have a Child Who Pulls Their Hair?

Help Us Learn More About How They Feel.

The **Pediatric Anxiety and Related Disorders Center (PARC)** at Kent State University is conducting a research study to better understand how children and teens who pull their hair (a condition known as *trichotillomania*) feel about themselves and their behavior. We are currently seeking **parent-child pairs** to participate. While we strongly encourage participation from both you and your child, we also welcome responses from parents who are participating on their own.

You may be eligible if:

- You are a parent of a child between **12 and 18 years old**
- Your child **currently pulls their hair**
- You live with your child at least **50% of the time**
- English is your and your child's primary language

Eligible participants will complete a set of online questionnaires.

- The parent portion takes about **15-20 minutes**
- The **child portion** (if applicable) also takes about **15-20 minutes**

Your participation is completely **voluntary**, and responses are **confidential**.

To participate or learn more scan the QR code or visit: https://kent.qualtrics.com/jfe/form/SV_74LEr3jWEyNRPj8

Principle Investigator: Christopher Flessner

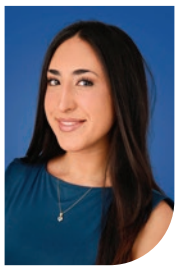
Contact us at: anxiety@kent.edu or 330 672-2200

This study has been approved by the **Kent State University Institutional Review Board (IRB).**

Authors in This Issue

Victoria Kapassakis

Sitting With a Cat (Pg. 6)



Victoria Kapassakis is passionate about researching OCD and has completed an Honors Thesis proposing an intervention for OCD stigma in her undergraduate studies. She is considering specializing in OCD treatment in her future career as a clinical psychologist. She is grateful for this experience to share her story and connect with like-minded people.

Noemi Tsai

A Message From Noemi Tsai (Pg. 7)

Noemi Tsai won the IOCDF Youth Hero Award in 2024. She works to raise awareness of OCD through sharing her recovery journey and advocating for others to gain access to treatment. Tsai has participated in One Million Steps for OCD Walks in three cities, served as co-chair of the Dallas One Million Steps for OCD Walk, and presented at the IOCDF's Online OCD Camp.

Jordan Karr PhD

Digital Reassurance Seeking (Pg. 8)

Jordan Karr, PhD, is the owner of River Falls Therapy in Portland, OR. He is a licensed psychologist in Oregon and Virginia, and specializes in evidence-based therapies for OCD and anxiety disorders. Dr. Karr has experience working in outpatient, community-based, and school-based settings.

Jonathan Teller

Self-Advocacy in OCD Treatment (Pg. 11)

Jonathan Teller is a fifth-year clinical psychology Ph.D. candidate at Northern Illinois University. His research focuses on mental health literacy and treatment-seeking in OCD and anxiety. He is most passionate about deconstructing the stigma around mental health and expanding access to evidence-based care.

Goi Khia Eng, PhD

Understanding Sensory Phenomena in OCD (Pg. 14)

Goi Khia Eng, PhD, is a Research Scientist at Nathan Kline Institute for Psychiatric Research. Her current research involves understanding the neural underpinnings of sensory phenomena in OCD and she aims to utilize non-invasive stimulation methods to elucidate the pathophysiology of these processes.

International OCD Foundation

The International OCD Foundation is the leading authority on obsessive compulsive disorder (OCD) and related disorders. The largest 501(c)3 nonprofit organization in this space, we are dedicated to serving a broad community of individuals around the world along with their family members, loved ones, mental health professionals, and researchers. The mission of the IOCDF is to ensure that no one affected by OCD and related disorders suffers alone. Our community provides help, healing, and hope. Visit iocdf.org.

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