



How Disease and Medication Shape the Brain in OCD: Learning from Global Collaboration



Background of the ENIGMA-OCD Consortium

Brain imaging is a powerful tool that has greatly contributed to our understanding of mental health disorders, including obsessive compulsive disorder (OCD). Since the 1980s, researchers worldwide have extensively used brain imaging techniques to study the structure and function of the brain in people with OCD compared to people without OCD.

Acknowledgements:

The work has been supported by BD2K grant (NIH grant U54 EBO20403), Amsterdam Neuroscience grant, and an International OCD Foundation Innovator Award.

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The **OCD Newsletter** is published by the International OCD Foundation, Inc.

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The mission of the International OCD Foundation is to help those affected by obsessive compulsive disorder (OCD) and related disorders to live full and productive lives. Our aim is to increase access to effective treatment through research and training, foster a hopeful and supportive community for those affected by OCD and the professionals who treat them, and fight stigma surrounding mental health issues.

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DISCLAIMER: *The IOCDF does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep you informed. We strongly advise that you check any medications, products or treatments mentioned with a licensed treatment provider.*

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OCD WALK!

The One Million Steps for OCD Walk is back! Visit iocdf.org/walk to find an OCD walk near you this June or October.



President's Letter

by Susan Boaz



Dear IOCDF Community,
When I joined the IOCDF Board of Directors, I made it my mission to increase the scale and the impact of our pediatric programming. Watching my young daughter grow up at

the Annual OCD Conferences, I've had opportunities to talk to parents — and kids — about their needs and how IOCDF might meet them. Through my own personal experience and stories shared by others, I came to understand that each age brings unique challenges that require distinct solutions. And so, year after year, we've added programming for families and kids of all ages — from "littles" to young adults.

Building on the idea that each audience had its own needs, in 2011 we launched a companion website focusing on issues specific to youths with OCD and their parents (kids.iocdf.org). In 2013, we developed a mental health training program, the Pediatric Behavior Therapy Training Institute (BTTI), which spent extra time on instructing pediatric therapists how to deliver ERP therapy to young children, understanding that early diagnosis and treatment are critical to helping kids develop long-term skills.

We then turned our attention to an issue that we kept seeing come up over and over again. Where were a lot of kids struggling the most with their OCD symptoms? We heard from both kids and parents that school had become overwhelming and that, more often than not, teachers and schools didn't know what to do. Over the next several years we developed, and then sent out three different "needs assessments." In other words, we asked school personnel, parents, and students what they felt they needed in order to address OCD symptoms in the context of school. More than 3,000 responses later we set out to create Anxiety in the Classroom (AitC), an online resource center for school personnel, students, and their families. Our current goal with this program is to get it into as many classrooms as possible. The potential for this program to change the lives of millions feels palpable. Anxiety and OCD in school-aged youth are widespread and can have devastating impacts on learning and social and emotional development. However, there are few

comprehensive programs available to address the problem. At anxietyintheclassroom.org you will find specific resources for teachers, parents, and youths of all ages. In addition, there is information to help you or your kids present to their classroom (or write a paper) and explain how OCD and anxiety impact you and how the school or teacher can help.

When the COVID-19 pandemic hit, we were initially unsure how to provide programming to our youngest kiddos. We knew the struggles that schools were having in executing online schools, so we set simple goals: building friendships, reducing stigma, and modeling some basic therapeutic skills so that kids could more easily understand how therapy for OCD works. This took the form of our Online OCD Camp. This is a fun and educational experience that provides opportunities for elementary, middle, and high school kids to connect and enjoy themselves. This past January marked the program's third iteration, with more than 300 youths and 500 parents attending. Like our attendees, I found myself continuing to learn from our outstanding presenters and our community as I participated in hours of Q&A from our parents. Listening to their questions was an education in their challenges at all ages.

Though the pandemic certainly presented unique challenges, we found that our virtual programming opened doors for many who could not attend our in-person event. While the Online OCD Camp positively impacted so many, I am struck by how much more we can do. The average time to receive an OCD diagnosis and treatment is still over a decade. This means that many kids can lose their entire childhood to OCD. That is entirely unacceptable. While the conference attendance of 300 children was exciting, it is just a drop in the bucket of the current need! We still have much to do. I'm so excited to see kids, parents, and siblings together again in person in Denver where they can learn so much and making lasting friendships.

Thank you for all you do — and take good care!

Susan Boaz

IOCDF Board President
and mom to a fabulous young adult

FROM THE FOUNDATION

The Annual OCD Conference Returns (to Denver!)



Join the OCD and related disorders community this July in the Mile High City, known for its Rocky Mountains, world-class cultural attractions, innovative craft breweries, chef-driven dining, and new-age music scene. Dozens of attractions will be steps away from the Conference, including:

- **The 16th Street Mall:** a mile-long pedestrian promenade in the heart of downtown
- **Larimer Square:** an iconic, lively, pedestrian-friendly gathering place — and the beating heart and creative soul of downtown Denver
- **LoDo Historic District:** a 29-block section of trendy bars, restaurants, and shops with preserved buildings from the city's original settlement
- **The Denver Art Museum, the Buffalo Bill Museum and Grave, and the Colorado Railroad Museum**

Conference attendees will enjoy hundreds of restaurants offering local and international cuisine with prices to suit everyone. Whatever your tastes or interests, Denver has it all!

GETTING THERE IS EASY

Denver International Airport (DEN) is a major hub with convenient rail service to downtown Denver. Attendees can take the airport rail (the "A Line") from the airport to Denver Union Station and vice versa for \$10.50 each way. From Denver Union Station, hop on the 16th Street MallRide, a free bus that will get you to the Conference hotel in under 10 minutes.

SPECIAL HOTEL RATE FOR ATTENDEES

Conference attendees are eligible for a discounted room rate of \$209/night (plus taxes and fees) at the Hyatt Regency Denver at Colorado Convention Center. Housing will open in late March 2022 along with registration, and rooms will be available on a first-come, first-served basis while space is available. ⓘ

Visit iocdf.org/ocdcon today to register for the Conference and start planning your trip to Denver!

Hyatt Regency Denver at Colorado Convention Center

650 15th Street
Denver, CO 80202

Discounted room rate:
\$209/night (plus taxes and fees)

FROM THE FOUNDATION

Announcing: 2022 IOCDF Conference Series



We're excited to offer a variety of in-person and virtual conferences in 2022! There is truly something for everyone. Join us for one or more events to connect with the community, collaborate, and learn — visit iocdf.org/2022conferences.

FAITH & OCD CONFERENCE | VIRTUAL

Monday, May 9, 2022

iocdf.org/faithconference

For faith leaders, those with lived experience, supporters, and mental health professionals



This unique event began out of recognition that many people living with OCD initially seek assistance from a faith leader. The conference will address the needs of a diverse community that spans all faiths, ethnicities, and backgrounds. We'll provide opportunities to connect and educate about effective treatment and ways to support faith members living with OCD.

27TH ANNUAL OCD CONFERENCE | IN-PERSON

July 8–10, 2022

Denver, CO

iocdf.org/ocdcon

For those with lived experience, supporters, mental health professionals, and researchers



The Annual OCD Conference is the largest national event focused solely on OCD and related disorders. This year's event will take place in Denver, CO, and we have so much great content planned! Join the entire OCD and related disorders community under one roof to meet others like you, learn about the latest treatments and research, and (importantly), have fun!

IOCDF RESEARCH SYMPOSIUM | HYBRID

Thursday, July 7, 2022

Denver, CO & Online

iocdf.org/symposium

For researchers, trainees, and students

An event designed by researchers for researchers, the Symposium brings together scientists to network, learn, and engage in high-level discussion. For the first time ever, it will be conducted adjacent to the Annual OCD Conference in Denver as an in-person/online event. Join fellow researchers from around the world to share data and findings from the latest research in OCD and related disorders.



CONFERENCIA DE TOC ONLINE | VIRTUAL

September 10–11, 2022

iocdf.org/conferencia-toc

For those with lived experience, supporters, and mental health professionals

Now it's third year, the Online Spanish Conference (la Conferencia de TOC Online) will once again bring together Spanish-speaking experts, those with lived experience, and supporters from around the world for a weekend of community and learning. We hope to facilitate networking and awareness around OCD in the Spanish speaking community around the world. Talks will address the many aspects of OCD, its treatment, and specific difficulties faced around the disorder in Latinx communities.



2022 ANNUAL ONLINE OCD CONFERENCE | VIRTUAL

November 4–6, 2022

For those with lived experience, supporters, and mental health professionals

The Online OCD Conference provides an opportunity for the global OCD community to connect, share, and learn from one another. The event program is filled with talks, discussion groups, and networking opportunities via a virtual platform. Chat with new friends and presenters, and enjoy evening activities!



PUBLIC POLICY CORNER

Spring Update



Happy 2022, all! We hope that you entered this new year with renewed energy for advocacy for the OCD and related disorders community — we certainly did! Our 2022 policy advocacy thus far has focused on two priority areas: telehealth and parity. We're excited to let you know about a few recent developments in the public policy sphere.

TELEHEALTH POLICY ADVOCACY

We've joined two advocacy coalition organizations, the Mental Health Liaison Group and the Health Innovation Alliance, in congressional advocacy around telehealth-related provisions. These include asking for the retroactive reenactment of telehealth coverage flexibilities were provided by the CARES Act of 2020 and expired in December 2021, such as waiving certain restrictions around geographic/originating sites and allowing employer-based health plans to provide pre-deductible coverage. Furthermore, we have asked for these flexibilities to be extended through 2024.

PARITY POLICY ADVOCACY

The OCD community in particular had a win with regards to insurance coverage of deep brain stimulation (DBS). Thanks to the advocacy of several IOCDF members, the insurance company Anthem Blue Cross Blue Shield now considers DBS for OCD as a "medically necessary" treatment when appropriate criteria have been met. Thank you to Dr. Rachel Davis in particular for her leadership on this issue!

More generally in the parity sphere, we were excited to see several key federal organizations prioritize parity enforcement. The Department of Health and Human Services, the Department of Labor, and the Department of the Treasury released a joint report that documented an overall failure to deliver parity for mental health and substance use disorder benefits and made a renewed commitment to ensuring that people receive the mental healthcare they need and are entitled to under the law. We'll keep our community apprised of any developments and/or advocacy opportunities!

TAKE ACTION TODAY

We invite you to visit the IOCDF Action Center at iocdf.org/take-action to contact your Congresspeople directly about legislation of great importance to the OCD and related disorders community. Advancements are made possible in large part by your advocacy, so don't hesitate to reach out to your elected representation today!

Also be sure to visit the IOCDF Public Policy Advocacy page to sign up for email notifications about upcoming public policy events, action alerts, and other ways to get involved at iocdf.org/public-policy.



Three Ways I Manage OCD as an Adult

by Kyle Elliott, MPA, CHES



As early as I can remember, I experienced symptoms of OCD. I distinctly recall turning light switches on and off, incessantly straightening the picture frames on my bedroom walls, and ensuring my clothes hangers were perfectly spaced apart as a young child. Now, as an adult, my OCD is characterized primarily by obsessive thoughts and ruminations. While I also experience panic attacks at times, they occur less frequently and are less severe than in previous years.

Over the years, I have built a powerful self-care toolkit to support me when I am feeling anxious. It is important to note these self-care practices are in addition to therapy with a licensed clinician that has dramatically decreased my anxiety and increased my quality of life. Included here are three ways I effectively manage my OCD as an adult.

1. MOVE MY BODY

There are few things I dislike more than sweating. Yet, I find moving my body to be one of the best ways to manage my anxiety. This has been especially true during the COVID-19 pandemic as I've spent more time at home running my career coaching business.

I find great satisfaction and joy in dancing through our apartment, practicing tai chi, or taking walks by the beach with my partner, J.V. (we recently moved to Santa Barbara, California for his new job in healthcare). Regardless of the exact activity, my mental health appreciates the movement — if I'm not sweating, of course.

2. JOURNAL MY THOUGHTS

Next, I frequently write about my mental health and feelings. I keep a journal and use this space to write out all my thoughts and weigh my options when I am feeling stuck. I find it particularly helpful to practice freewriting, where I write without self-editing or attempting to select the perfect words.

If you find solace through writing down your feelings, consider the following prompts that I personally use to tackle my anxious thoughts:

- How am I feeling right now, at this moment? (Get specific.)
- What action can I take right now? (Stay grounded in the present.)
- What do I need to let go of to feel better? (Focus solely on what is in your control.)

3. TALK TO MY ANXIETY

Beyond writing about my mental health journey, I also talk to my anxiety — a powerful technique I learned from my current therapist, Stephanie. I regularly speak to my anxiety, appropriately named “Mr. Peanut,” about the impacts — both positive and negative — he has on my career, my business, and my life.

Although regularly speaking to Mr. Peanut reduces my anxiety, I importantly decided to retire him last year and requested that he no longer bother me. (J.V. and I even went out to dinner to celebrate his early retirement.) Of course, Mr. Peanut occasionally comes out of retirement to pester me; however, when this happens, I remind him I've got everything under control. These talks keep me grounded and help fend off my anxiety.

Self-care is an iterative and ongoing process. In addition to participating in therapy, take the time to find which self-care techniques work for you and your unique situation. Recovery is possible. You've got this! 🧠

Kyle Elliott, MPA, CHES is the founder and career coach behind [CaffeinatedKyle.com](https://www.caffeinatedkyle.com). His goal is simple: to help people find jobs they LOVE (or at least tolerate). As a queer person, male sexual assault survivor, and someone living with mental health conditions, Kyle is proud to get to use his voice and platform to help others share their stories, get help, and achieve recovery.

FROM THE FRONT LINES

Notwithstanding

by Dennis Rhodes

My poor long-suffering therapist
 has listened to a mountain of woe
 for many years. How can he stand it
 week after week, with my litany
 of suicide attempts, OCD,
 depression, exhilaration and
 various fears real or imagined--
 I have loaded all my demons on
 to his plate. He knows them better than
 I do. My therapist's name is Scott:
 no less than an angel in my book.
 It would come as no surprise at all
 to him, that amidst my pain and strife
 it truly is a wonderful life. ☺

Dennis Rhodes is the author of The OCD Poems (Indolent Books, 2021), in which some proceeds are donated back to the IOCDF. His poems and essays have appeared in BLOOM, Chelsea Station, Lambda Literary Review, The Cape Cod Times, New York Newsday, and other journals. Rhodes served as literary editor of Body Positive magazine and later as poetry editor of Provincetown Magazine. He co-founded the Provincetown Poetry Festival in 1999. For a number of years, Rhodes hosted a weekly radio show on WOMR in Provincetown, featuring interviews with local poets. He currently lives in Florida.



International
 OCD
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peace
 of mind
 virtual community

IOCDF Live Stream Schedule. Watch all at iocdf.org/live

	Tuesday @ 7pm ET	Wednesday at Noon ET
1st Week	Town Hall	Ask the Experts
2nd Week	Community Conversations	Research Roundtable
3rd Week	Diversity Roundtable (6pm ET) or Faith & OCD Roundtable (<i>alternating</i>)	Ask the Experts
4th Week	Community Conversations	Lunch & Learn
5th Week (if exists)	Community Conversations*	Ask the Experts

Raising Resilience: 25 Tips for Parenting Your Child with Anxiety or OCD

by Josh Spitalnick, PhD, ABPP, and Marti Munford, LPC



If you are a parent or guardian of a child that is struggling with anxiety or OCD, we are speaking directly to you. Keep these tips in a spot where you will remember to look and be ready to share them with other caregivers in your child's life.

1. **Parents, please remember: You are not the problem... but you're a big part of the solution.** Watching your child suffer from anxiety can be painful, frustrating, and confusing. Every parent has wondered at one time or another if they are the cause of their child's struggles. Recognizing how influential and positive you can be in your child's recovery is the first step towards getting them proper care and support.
2. **You are not alone.** Whether through a support group, social media, or your local and state resources, there is strength in numbers. Finding other caregivers who have children with anxiety and OCD can help you connect with resources, build a sense of community, and recognize that you are not alone — and neither is your child.
3. **It's OK to not be OK.** It's one of the hardest lessons for us to learn, and it's something anxiety specialists truly believe. Sending the message to children that their meltdowns or terrifying moments signify that something is wrong keeps them stuck in the loop of false alarms. You have the opportunity to model acceptance by letting them know that it's okay to not be okay. The same applies to you: it's ok to not be ok as a parent.
4. **Be aware of how your own stress impacts your parenting style and expectations.** While there will be amazing moments to witness, parenting a child with anxiety or OCD can be exhausting. If you find yourself feeling frustrated, take a break. Explain to your child you want to be helpful and do not think that you can do that without taking a break. This does not make you a bad parent, it makes you a more capable one and gives you the chance to model healthy distress tolerance.
5. **Confidence is something you show AND tell.** Research is clear: communicating confidence in your belief that your child can effectively cope and use their skills is crucial. Additionally, your reactions and behaviors are often heard louder than your words. Anxious children pay extra attention to non-verbals as they are constantly assessing threats and uncertainty. By validating their feelings and their ability to cope with them, rather than the feared outcome, you emphasize resilience and independence.
6. **Teach your child to live with fear, not in fear.** Everyone can benefit from coping skills, meditation, calm breathing, and healthy distraction at the right moment; but know that effective anxiety treatment and maintenance centers on facing fears head-on and living with uncertainty. Unfortunately, relaxation or distraction activities only work short-term and may reinforce the idea that the emotional experience was too difficult. This will teach avoidance or escapism, keeping your child in a loop.
7. **Know the difference between "scary safe" and "scary dangerous."** Anxiety treatment and management doesn't aim to shut down our fear centers, but rather to recalibrate the false alarms of the anxious brain. Helping a child reframe these non-dangerous situations as "scary, but safe" provides a foundation that teaches them to move towards situations that normally would cause them to freeze, get stuck, or avoid.

THE THERAPY COMMUNITY

Raising Resilience: 25 Tips for Parenting Your Child with Anxiety or OCD *(continued)*

8. **Be ready for conflict from your child — but know your job is to de-escalate.** The only thing anxiety and OCD want is certainty or absolution. Though parent-child conflict is a common experience, the anxious brain feeds on conflict because conflict ALWAYS ends. It doesn't always end kindly or immediately, but it always ends. Using punishment in moments when OCD or anxiety flares up conveys that this moment is your child's fault while putting you on opposite teams. When you take the bait to escalate or punish the conflict, OCD or anxiety wins. You and your child lose.
9. **Don't underestimate the importance of education and understanding.** When parents show up for that first session, they are often looking for the quick fix, understandably. However, the first few sessions are intentionally all about educating you and your child about anxiety or OCD. It's critical to learn the ins and outs of bodily responses, false alarms, rituals, and avoidance. Don't overlook its value and don't rush through it. Psychoeducation IS the first treatment phase.
10. **Know what you are fighting for.** Helping your child identify healthy goals and values-based behaviors that honor their belief system will keep everyone focused and motivated when times get tough.
11. **Learn the vocabulary of an anxiety specialist, starting with the BIG three: T's, O's, and C's.**
 - *T's are the triggers. Triggers are the internal or external things that bother us; T's elicit the initial fear response. Almost any thought, thing, or experience can be a trigger.*
 - *O's (which can also be F's) represent obsessions or fears. These are the worries, images, feelings, beliefs, or physical sensations that are unwanted, unintentional, and make the person feel nervous, guilty, fearful, disgusted, and more.*
 - *C's (which can also be R's or SB's) are called Compulsions, Rituals, or Safety Behaviors. These are intentional actions and thoughts (the latter are called mental rituals) that are used to temporarily avoid distress. These actions are the fuel that's maintaining anxiety or OCD.*

Knowing the difference between a T, O, or C is foundational for a child (and the parent) to gain insight and have a better understanding of what is being addressed through treatment.
12. **Rituals, compulsions, and safety behaviors come in many shapes — don't be fooled.** Worries and obsessions are A problem, but THE problem is avoidance, compulsions, rituals, and safety behaviors. In OCD and anxiety disorders, the problem is not the content of the worry, but the repetitive cycle of endless actions (mental or behavioral). Naming and reducing rituals is critical for your child to succeed in managing anxiety or OCD.
13. **Mental rituals are not obsessions.** Although you can't see your child do these invisible rituals, mental rituals (MR) have the same effect as compulsive hand washing, checking, confessing, or other observable rituals: they keep your child stuck. MR examples include excessive repeating of words in their head or replaying events in their mind, over-monitoring their bodily reactions, wondering if they were misunderstood, and many other mental actions that are used to reduce negative feelings associated with the core fears. Naming and reducing them can be difficult, but with skills and practice, it will help break the cycle of repetitive mental actions.
14. **Family accommodations (FA) keep the family stuck.** Family accommodations, also known as FA, are the actions, gestures, or statements we use as loved ones to rescue anxious children from uncertainty or distress. Over 90% of families with anxious children report offering FA. While the intent is to stop the distress, these actions actually make the problem worse (and leave families feeling exhausted and manipulated!). Being able to identify and shift away from accommodations is one of the first and most important steps to changing the cycles parents unknowingly engage in with their anxious children.
15. **Reassurance seeking (RS) is tricky, we know!** When your child is curious, asking questions is a great way to explore. But when your child is getting stuck, believes their own terrifying thoughts, or can't find a way to accept uncertainty, reassurance seeking (RS) becomes the quickest way to get through the moment, creating a ritual cycle. As the caregiver, being able to differentiate between RS and genuine questions is difficult, so in an active phase of treatment with your child, assume that most questions around topics that are triggering are nothing more than RS.
16. **Naming the OCD or worry monster can bring you and your child together.** Personifying your child's

Raising Resilience: 25 Tips for Parenting Your Child with Anxiety or OCD

worry allows them to create distance from it while also creating a common enemy you can fight together. Encouraging a discussion of your child's worries, in limited doses, can be helpful. Create a daily "Worry Time" that lasts about 5-10 minutes, if necessary. Ignoring worries doesn't help, so creating a worry character can help acknowledge the worry without indulging it.

17. **Allow for corrective experiences.** Your child is more resilient than you might think! If we rescue them from scary safe experiences, we rob them of the ability to see their own bravery and resilience.
18. **Though all beliefs are thoughts, not all thoughts are beliefs.** With some anxiety themes, the content may feel taboo, embarrassing, or perverse. Most people have these kinds of thoughts, whether they admit it or not, but there is often significant shame associated with them. An open discussion about these tough topics is validating, normalizing, and increases a sense of hope and acceptance. Accepting the presence of thoughts that evoke shame or disgust is not the same as endorsing them or acting on them.
19. **All family members are affected by a child's anxiety/OCD.** If there are other children or family members in the home, your child's O's and C's are affecting them as well. This gives you a chance to have an open family discussion about the OCD or anxiety plan with all family members. This will create space for questions or concerns and it will reveal if anyone else in the family needs support in the process of getting your child proper care and support.
20. **The anxious brain doesn't always make much sense, so be prepared to encourage your child to do the opposite.** Even when no danger is present, the anxious brain still reacts to the flight-fright-freeze response. Brain chemistry tricks us into taking actions that are not only unhelpful, but create more problems. Be ready to support your child in making decisions that seem opposite to what feels like the right thing to do. With practice, this gets easier.
21. **Exposure therapy is not harmful; in fact, it's the MOST effective treatment for OCD and most anxiety disorders.** There are many wonderful therapists and therapy approaches for children, but if your child has OCD or anxiety, finding a therapist who is knowledgeable and trained in exposure and response prevention (ERP) gives you access to effective treatment for your child's struggles. Exposure therapy is not only safe, it is the most evidence-supported treatment for anxiety disorders and OCD.
22. **Consider involving your medical care team.** Medication can be an effective part of the treatment solution when anxiety or OCD is severe or frequent. Consult with your child's physicians for medication treatment options and openly share your concerns about medication with them. In certain situations, OCD or anxiety shows up so quickly, almost out of the blue, that it might indicate an underlying medical condition. This might require a medical evaluation and treatment before starting psychotherapy.
23. **Look for and praise big and small successes.** This applies not only to the brave moments that you see in your child, but also in the patience and compassion that you and other family members provide to your child. Frustration and fatigue are expected, so look for those small wins and breakthrough moments in your child's newly learned skills as well as in your own parenting moments.
24. **Be ready to apply parenting skills and ERP to the next OCD problem area.** Throughout childhood, anxiety and OCD shapeshifts, morphs, and latches onto the next "theme of the week." Most of the skills you and your child learn will apply to any new themes that arise down the road. Don't get caught thinking every crisis requires a completely new plan. When you chase symptoms, it will look like a game of Whack-a-mole. Symptom morphing/hopping is expected, so be prepared.
25. **There are key ingredients to effectively treating pediatric OCD or anxiety, whether your child sees a therapist or not.** Your job as the parent or caregiver is to provide a plan that gives you, your child and your family the best chance at taking back control. Facing fears, tolerating distress, living with uncertainty, and taking active steps that are aligned with your healthy values is the complete package to beating anxiety, but it does take practice and patience. Take brave actions with your child, use humor when appropriate, and be compassionate to yourself and your child in the process of beating anxiety together. You can do this! 🕒

THE THERAPY COMMUNITY

Institutional Member Updates

Institutional Members of the International OCD Foundation are programs or clinics that specialize in the treatment of OCD and related disorders. For a full list of the IOCDF's Institutional Members, please visit iocdf.org/clinics.

ARCHWAYS CENTRE FOR CBT

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Springtime Greetings from the Great White North!

Based in Canada, Archways Centre for CBT is a private clinic focussed on delivering evidence-based treatment to help individuals get well and stay well. Our OCD Clinic is one of only three sites in Canada recognized by IOCDF as delivering specialized assessment and treatment for OCD and related disorders.

We are now able to offer more in-person sessions; however, most of our clients will continue to be seen virtually. This is partly due to a very gradual lifting of pandemic restrictions here in Ontario, but also because our clients are simply enjoying the convenience of online therapy! Additionally, video therapy allows us to engage in ERP inside client's homes, where patterns of compulsions are most ingrained.

We are in the process of seeking another full-time psychologist to provide stellar treatment for our clients (adults and youth) with OCD and/or BFRBs. At that point we will be able to develop our OCD Clinic programming further.

Wishing everyone in the OCD community good mental and physical health!

BAYLOR COLLEGE OF MEDICINE OBSESSIVE-COMPULSIVE AND RELATED DISORDERS

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We are excited to announce several project updates. First, we are currently conducting a study of adaptive Deep Brain Stimulation (DBS) for treatment resistant OCD and have published initial findings from the first five participants in the journal *Nature Medicine* (Provenza et al., 2021). We are still enrolling and more information about the study can be found at Clinicaltrials.gov under #NCT04806516.

Second, we have started recruitment for our NIH funded study of the genetics of OCD among children and adults who are Latin American. Led by Drs. Eric Storch (Baylor) and Jim Crowley (UNC), this project involves over 55 sites across 13 countries. For more information, email LATINOSTUDY@BCM.EDU.

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(301) 593-4040

Behavior Therapy Center of Greater Washington (BTC) — also known as the MidAtlantic Center for Treatment of OCD and Related Conditions — is excited for spring!

BTC is excited to welcome to our clinical staff Dr. Jeannette Reid, a graduate of Fordham University's doctoral program. Also, Ms. Ruth Golomb, one of our seasoned experts on OCD and related conditions, was recently a panelist for a webinar celebrating International Women's Day highlighting the work of female scientific practitioner pioneers for the TLC Foundation for BFRBs.

Our Disruptive Behavior Management Program, under the direction of Dr. Noah Weintraub is intended for children with OCD, Tourette's or an anxiety disorder in combination with externalizing behaviors (e.g., anger outbursts, defiance), and is appropriate for families in which PANS/PANDAS is suspected. This program involves both individual sessions and a structured parenting group.

BTC's professionally-assisted GOAL OCD support group continues to run strong.

Due to unprecedented demand for our services since the start of the pandemic, we are looking for an experienced clinician expert in treating OCD and related conditions. If you might be interested, please contact Dr. Weintraub at nweintraub@behaviortherapycenter.com.

THE CENTER FOR OCD & ANXIETY AT SHEPPARD PRATT

6501 North Charles Street

Baltimore, MD 21204

sheppardpratt.org/care-finder/ocd-anxiety-center

Rebecca.BillerioRiff@sheppardpratt.org

(410) 927-546

NEW Spring OCD Lecture Series: Join us for a six lecture deep dive into OCD. Topics covered will include moral scrupulosity, acceptance and commitment therapy, Tourette's OCD, innovative treatment strategies, co-existing eating disorders

Institutional Member Updates

and OCD, and OCD in autistic individuals. Lectures begin April 15; visit cme.sheppardpratt.org to register.

NEW team member! Please join us in welcoming Amy Mandelberg, LGPC, to the team. Meet Amy: sheppardpratt.org/why-sheppard-pratt/our-experts/details/amy-mandelberg-lgpc.

NEW psychoeducational support group: we are now offering a bi-weekly psychoeducational support group for family members of OCD sufferers. Held virtually, this support group is open to anyone in the country. Register: sheppardpratt.org/care-finder/ocd-anxiety-center/support-groups-for-ocd.

THE CHILD MIND INSTITUTE INTENSIVE OCD PROGRAM

101 East 56th Street
New York, NY 10022

childmind.org/care/areas-of-expertise/anxiety-disorders-center/intensive-treatment-ocd/qa

info@childmind.org
(212) 257-9436

The Child Mind Institute Intensive OCD Program offers children and their families an immersive, holistic experience that can make an extraordinary difference in a short period of time. The program is back to seeing clients fully in person and is open to children and young adults. We provide individual CBT/ERP treatment for three hours a day, five days a week. The Intensive OCD Program ranges from 1 to 4 weeks and sees a wide range of severity levels. Families from outside the New York City area are welcome to reach out for treatment. We include parents and family members in every stage of a child's treatment. OCD intensive services are available in English and Spanish. The Child Mind Institute offers a financial aid program to help families with the cost of services.

EUGENE CENTER FOR ANXIETY AND STRESS

101 E Broadway, Suite 400
Eugene, OR 97401

eugeneanxiety.com
info@eugeneanxiety.com

(541) 357-9764

Eugene Center for Anxiety and Stress (ECAS) has two updates to share with the IOCDF community. First, our new postdoctoral training program will be starting this Fall, and we have three postdoctoral residents joining our staff. This will increase access to care for those seeking OCD treatment and bring more expertise in treating OCD to the Oregon area. Second, ECAS will be opening an Intensive Outpatient Program (IOP) for treatment of OCD this summer to help those for whom once-weekly individual therapy is insufficient!

GENESEE VALLEY PSYCHOLOGY

200 White Spruce Boulevard, Suite 220
Rochester, NY 14623

gviproc.org
drwadsworth@gviproc.org
(585)201-8017

Genesee Valley Psychology (GVP) has expanded its social justice commitment by taking 90 percent of Rochester Area insurances, including Medicare and Medicaid, and offering a sliding scale rate to all clients. We had a busy winter in our OCD IOP and continued to expand our Comprehensive DBT Program. We are excited to have two staff psychologists, four postdoctoral fellows, and a number of practicum students joining us in the fall as we double our office space. We have enjoyed ongoing research collaboration on the overlap of OCD and Trauma with researchers at Rogers and McLean Hospital/Harvard Medical School.

NEUROBEHAVIORAL INSTITUTE (NBI)

2233 N. Commerce Parkway #3
Weston, FL 33326

nbiweston.com
info@nbiweston.com
(954) 217-1757

We're continuing the ongoing expansion of the scope and quality of services at NBI by implementing a highly specialized program for co-occurring eating disorders and OCD. This program is offered on an intensive outpatient basis or in conjunction with NBI Ranch, our residential supportive living program.

We welcome our latest post-doctoral trainees, Sarah Gaumer, PsyD and Chris Varghese, PsyD, who have been a great addition to our team. We can hardly believe it ourselves, but NBI Ranch just celebrated its fourth anniversary. We couldn't have made it through all the pandemic-related challenges without the great support we received from our colleagues, so a heartfelt thanks to you all! Looking forward to seeing everybody at the IOCDF's 2022 Annual OCD Conference in Denver!

THERAPY COMMUNITY

Institutional Member Updates *(continued)*

NOCD

treatmyocd.com
care@nocdhelp.com
(312) 766-6780

NOCD is proud to once again be the Marquee Sponsor for the One Million Steps for OCD Walk. We hope that you will take the time to join a walk and raise funds for OCD awareness and join us as we partner with the IOCDF to raise funds to help research and treat OCD

NOCD is also looking forward to seeing you and being a sponsor of the IOCDF's Annual OCD Conference in Denver this July. Please stop by our booth and set up a time to say hi to your NOCD Therapist in person! Many of our team will be at the conference and we look forward to connecting with you and celebrating a great weekend filled with hope and education.

NORTHWELL HEALTH OCD CENTER

**75-59 263rd Street, Zucker Hillside Hospital
Glen Oaks, NY 11004**
northwell.edu/ocdcenter
ocdcenter@northwell.edu
(718) 470-805

The Northwell Health OCD Center offers evidence-based, comprehensive outpatient treatment for OCD and obsessive-compulsive personality disorder (OCPD). It is one of the only specialized OCD facilities in the New York metropolitan area to accept most health insurance plans, including Medicare and Medicaid. Treatment options include individual and group cognitive behavioral therapy as well as medication management.

We have continued to conduct all services through video platforms and we now offer ten virtual therapy groups of various themes (e.g., ERP practice, skills-building, OCPD treatment, family education and support without accommodation, and maintenance of improvements). This February, Dr. Pinto, our clinic director, was invited to be the lead presenter at a one-day virtual conference on understanding and treating OCPD, sponsored by the Gunderson Personality Disorders Institute at McLean Hospital. Our team feels fortunate to be able to contribute to advancing research and training in the treatment of OCPD, with Dr. Pinto at the helm. Please email us at ocdcenter@northwell.edu for more information or to schedule a confidential screening.

THE OCD AND ANXIETY TREATMENT CENTER

**1459 N Main Street, Suite 100 11260 River Heights Drive
Bountiful, UT 84010 South Jordan, UT 84095**
theocdandanxietytreatmentcenter.com
admissions@liveuncertain.com
(801) 298-2000

TOATC continues to provide evidence-based exposure therapy to children and adults suffering from obsessive-compulsive spectrum disorders, anxiety-related disorders, and trauma disorders.

From officially becoming a Mental Health Access Provider with the Jordan School District to joining the Utah Chapter of Pediatrics Network, our team is continuing to prioritize connection opportunities that allow us to provide specialized, prompt, and effective mental health treatment to school-aged students in our community.

As the year progresses, our outreach efforts have kicked into full gear. In February, our Clinical Outreach Specialists were invited to present to and network with several groups of educators at the Utah Association of Career and Technical Education in Southern Utah. We look forward to attending the Generations conference in May and are excited to continue fostering our connections with a variety of community partners.

We are thrilled to share that preparation for the opening of our third and newest location is underway! TOATC looks forward to officially announcing the center's official opening date and location in the summer newsletter.

As the COVID-19 pandemic continues, we remain available for respectfully distanced in-person appointments as well as telehealth visits.

OCD INSTITUTE MCLEAN HOSPITAL

**115 Mill Street
Belmont, MA 2478**
mcleanhospital.org/ocd
ocdiadmissions@partners.org
(617) 855-2776

The OCDI at McLean Hospital is happy to be returning to full capacity following our scale-back during COVID. This will allow wait times, especially for residential treatment, to return to somewhat more normal levels. We are continuing to offer our Partial Hospital Program virtually, but also hope to be able to add in-person PHP very soon. We plan to continue to offer virtual PHP even after in-person treatment resumes, as we feel it is an added benefit to our patients in MA.

Institutional Member Updates

If you are interested in applying for treatment, or want to refer a patient, please contact our Admissions Office at ocdiadmissions@partners.org or (617) 855-2776. Admissions staff Liz and Megan will be happy to guide you through the process!

RENEWED FREEDOM CENTER FOR RAPID ANXIETY RELIEF

1849 Sawtelle Boulevard, Suite 710

Los Angeles, CA 90025

renewedfreedomcenter.com

info@renewedfreedomcenter.com

(310) 268-1888

Renewed Freedom Center (RFC) is hiring! We are seeking experienced master's- and doctorate-level clinicians to provide individual and family therapy to patients with severe OCD and anxiety disorders including, Panic Disorder, Social Anxiety, Agoraphobia, Separation Anxiety, Specific Phobias, BDD, and GAD.

RFC's mission is to provide the most effective, state-of-the-art, brief treatment with benefits that last beyond the termination of therapy. We see our patients as students learning to master a set of skills to manage distressing symptoms that interfere with daily functioning. With the tools acquired through treatment, patients are able to apply them to other situations and future circumstances.

We are looking for someone with experience in exposure and response prevention (ERP), CBT, mindfulness training, and/or family systems to join our team. Training will be provided, although a strong conceptualization and application of behavioral and cognitive therapies are required.

If interested, please submit your CV and a cover letter to AshleyBramhall@RenewedFreedomCenter.com.

ROGERS BEHAVIORAL HEALTH

34700 Valley Road

Oconomowoc, WI 53066

rogersbh.org

rick.ramsay@rogersbh.org

(800) 767-4411

Rogers Behavioral Health is expanding its OCD and anxiety services in 2022 with the addition of a new outpatient center this fall in Denver and a 32-bed residential care center expansion to its Brown Deer, Wisconsin campus in summer.

Rogers locations in Sheboygan, Wisconsin and Skokie, Illinois, are adding additional programs to treat OCD. The outpatient clinic in Sheboygan now offers a virtual-only OCD and anxiety care program for children and adolescents and plans to add an in-person partial hospitalization program this summer. Rogers

in Skokie is also opening a virtual-only intensive outpatient program to treat adults with OCD and anxiety.

Researchers at the Rogers Research Center recently published two studies investigating the effectiveness of virtual treatment for OCD and anxiety: "Efficacy of intensive CBT telehealth for obsessive-compulsive disorder during COVID-19 pandemic" was featured in the January issue of the Journal of Obsessive-Compulsive and Related Disorders, and "Comparing efficacy of telehealth to in-person mental health care in intensive-treatment seeking adults" was included in the January edition of the Journal of Psychiatric Research.

In early March, Rogers sponsored a session of OCD Wisconsin, Beyond Treatment Network, which was focused on incorporating gains into post-treatment life.

STANFORD TRANSLATIONAL OCD PROGRAM - RODRIGUEZ LAB


401 Quarry Road

Stanford, CA 94305

rodriguezlab.stanford.edu

ocdresearch@stanford.edu

(650) 723-4095

The Stanford Translational OCD program utilizes an interdisciplinary approach to find new treatments for patients suffering from OCD and hoarding disorder. We have many new exciting research studies and invite you to find out more by calling (650-723-4095) or emailing (ocdresearch@stanford.edu or clutterhelp@stanford.edu). We also invite you to follow us on Twitter and Facebook @RodriguezLabSU. Dr. Rodriguez enjoyed participating in the IOCDF Hoarding Disorder Research Roundtable March 9th with Dr. Randy Frost and moderated by Kyle King and Dr. Jonathan Abramowitz. We look forward to seeing you at the 27th Annual OCD Conference in Denver July 8-10th, 2022! 

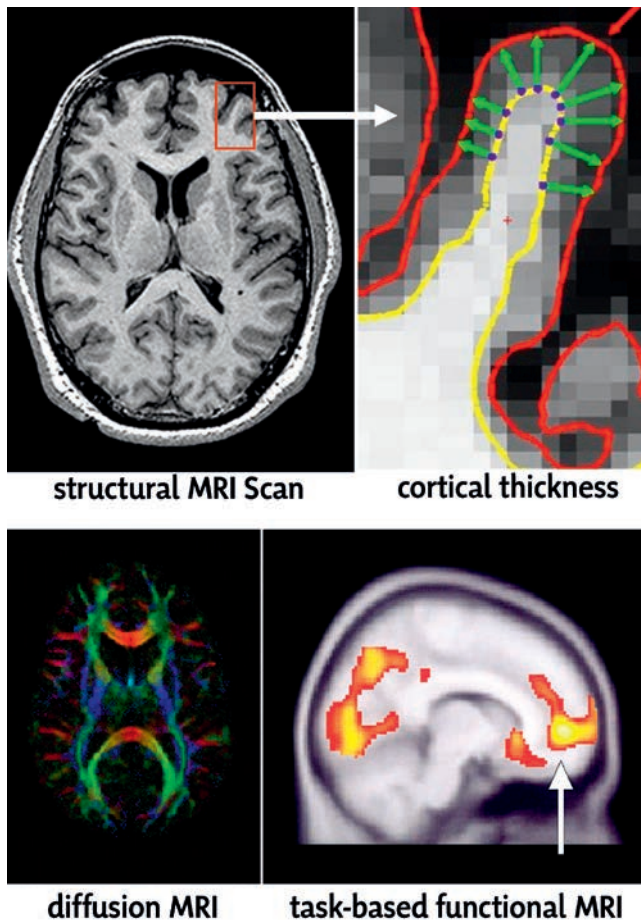
RESEARCH NEWS

How Disease and Medication Shape the Brain in OCD: Learning from Global Collaboration *(continued from front page)*

by Odile A. van den Heuvel, MD PhD; Chris Vriend, PhD; Nadza Dzinalija, MSc; H. Blair Simpson, MD PhD; Ilya M. Veer, PhD; Henrik Walter, MD PhD; Iliyan Ivanov, MD; Paul M. Thompson, PhD; Dan J. Stein, MD PhD

This research has pointed to specific brain structures and patterns of brain activity (in specific brain circuits) that may be involved in OCD symptoms and has suggested ways to target brain circuits with treatment approaches including medication, psychotherapy, and neurostimulation (e.g., deep brain stimulation or transcranial magnetic stimulation) (Stein *et al.*, 2019). Currently, magnetic resonance imaging (MRI, see Figure 1) is the most used brain imaging technique. With structural MRI it is possible to study the size and shape of the different structures and regions of the brain. With “diffusion MRI” we can visualize the white matter tracts (the highways in the brain) that connect the superficial and deep structures. With a technique called functional MRI (fMRI), it is possible to observe a “live” picture of brain activity as it is triggered by various situations and experiences (for example, the areas of the brain are most active when OCD symptoms are triggered).

Figure 1: Examples of different MRI techniques



MRI and fMRI are powerful tools for advancing our understanding of OCD as well as developing new treatment targeting specific brain circuits. However, brain imaging research has some serious limitations. The time it takes to collect data from participants and the enormous cost of MRI equipment are critical barriers. As a result, most imaging studies in OCD are rather small and limited to strictly defined groups. This limits the “statistical power” of brain imaging studies, making it more difficult for researchers to draw conclusions about whether the differences they see in the brains of people with OCD are real causes and consequences of OCD or are just due to random variations that happen from person to person.

To better understand why statistical power is so important, consider what happens when you step outside on a day when the temperature is much colder than it was the day before. You don’t need a thermometer to know that it is colder outside than it was yesterday — the temperature change is so great that it’s obvious to you just from the way the air feels on your skin. But what if the temperature had only changed by one or two degrees instead? In this case, you may not be able to tell that it’s changed at all. A research study with low statistical power is just like this. It may be able to find big differences between groups, but it will not be able to draw conclusions about small changes with any real confidence. Now, consider the example above, but this time you have a digital thermometer with you when you step outside. The thermometer is sensitive enough to detect small changes in temperature. This is like a study with high statistical power. Statistical power doesn’t just come from the accuracy of the tools available to researchers, but also from the number of participants who they are able to include in their research. Since MRI is not a very sensitive tool and the alterations in OCD are small and dependent on multiple variables, in imaging research we need big samples to get reliable results.

The first large MRI study of OCD focused on detecting physical differences in the brain’s structures included data from a single research center (Pujol *et al.*, 2004). A total of 72 people with OCD and 72 healthy individuals (controls) participated. This study found that some regions of the brain were smaller or bigger in people with OCD when compared to participants in the healthy control group. People with OCD had, on average, smaller prefrontal

How Disease and Medication Shape the Brain in OCD



regions (areas relevant for emotional processing, located near the forehead) and larger striatum (a set of regions deep within the brain known to be involved in repetitive behaviors). Research studies that analyzed data from the results of multiple, independent MRI studies in OCD were subsequently published (e.g., *Radua et al., 2009*). These studies used statistical methods to estimate the overall degree of difference between people with and without OCD. The first study in which researchers pooled and analyzed raw MRI data from multiple sites around the world was performed by the OCD Brain Imaging Consortium (OBIC) — the initial attempt to bring OCD scientists together to work on brain imaging data that they had already independently collected (*de Wit et al. 2014*).

In 2009, Paul Thompson and colleagues initiated the ENIGMA (Enhancing Neuroimaging and Genetics through Meta-analysis) consortium, which has grown to include more than 2,000 scientists from 45 countries who study the human brain in health and disease (*Thompson et al., 2020, 2022*). The initial aim was to perform large-scale imaging and genetics research by pooling worldwide data, resources, and expertise; and to answer clinical and fundamental questions related to psychiatric and neurological disorders. Now the consortium has more than 50 working groups that focus on 1) specific psychiatric and neurological disorders, 2) trans-diagnostic constructs (e.g., suicidality, lifespan), and 3) the development of analysis pipelines to make it easier to harmonize data across different working groups. Harmonization ensures that data collected at different sites around the world is used and analyzed with a consistent set of techniques, allowing researchers to make “apples to apples” comparisons, even when data has been collected by different research teams at sites many thousands of kilometers apart.

In 2013, Odile van den Heuvel, MD, PhD and Dan Stein, PhD initiated the ENIGMA-OCD working group by bringing in OBIC and inviting new members to contribute. As of 2021, ENIGMA-OCD consists of data from 48 cohorts of research participants from 36 institutes in 15 countries on five continents, with a total sample of 4,669 with MRI data of 2,334 OCD patients (1,835 adults (>18 years), 359 adolescents (12-17 years), 140 children (<12 years) and 2,335 healthy controls (1,734 adults, 325 adolescents, 166 children). The ENIGMA-OCD consortium is the largest worldwide collaboration on brain imaging in OCD and, with a large set of high-quality imaging data from so many research participants around the world, is able to analyze imaging results with high statistical power in a cost-efficient way. New members are continuously welcomed, and with an open structure, ENIGMA-OCD represents a unique and highly productive example of team science (see Figure 2).

Figure 2: ENIGMA-OCD collaborators, worldwide



RESEARCH NEWS

How Disease and Medication Shape the Brain in OCD *(continued)*

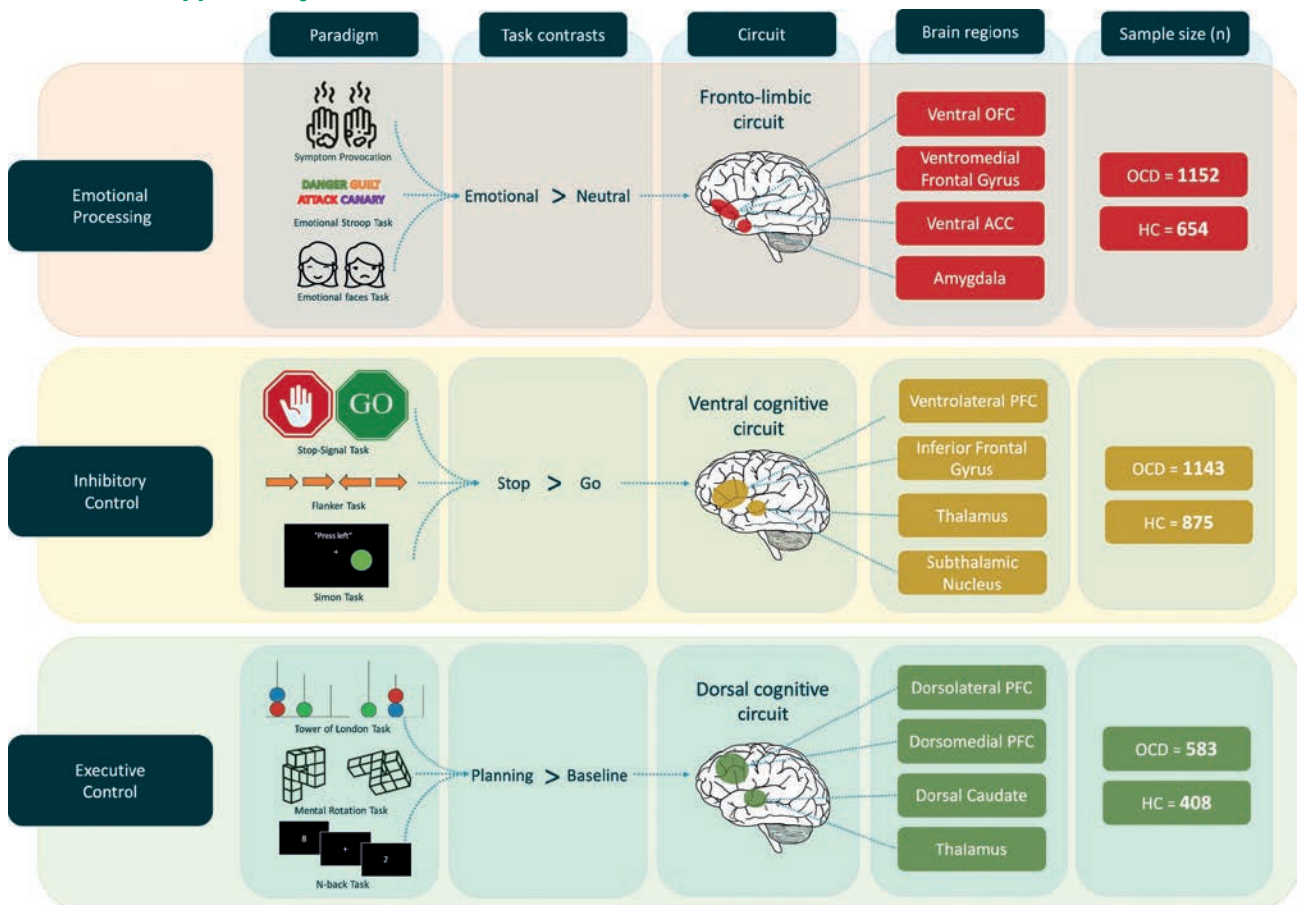
FIRST FINDINGS ON BRAIN STRUCTURE IN OCD

We recently summarized the findings of the first five years of ENIGMA-OCD in a review paper (*van den Heuvel et al. 2022*). The first analyses of the ENIGMA-OCD consortium focused on the size of brain regions deep within the brain, such as the thalamus (*Boedhoe et al. 2017*). We found clear differences between children and adults with OCD: pediatric OCD was associated with a larger thalamus, but this was only detectable when comparing unmedicated children with OCD to healthy children (differences between medicated children with OCD and healthy controls were not detectable). We recently replicated this finding with data from the Generation R cohort in the Netherlands, in which children with probable OCD (scoring above the cut-off on the short OCD screener) also had a larger thalamus (*Weeland et al. 2020*). This may suggest that the brain develops differently in children prone to develop OCD. Adults with OCD on average had a smaller hippocampus (a part of the brain important to forming long-term and visual memories), and this difference was more obvious in patients with comorbid depression. A smaller hippocampus

has also been reported by the ENIGMA working groups for schizophrenia, bipolar disorder, major depressive disorder, and posttraumatic stress disorder, and so may be related to the chronic distress that is present in all these disorders. We also observed that adults with childhood onset OCD were more likely to have a larger pallidum (a part of the brain that helps regulate voluntary motor movement), possibly due to chronic engagement in compulsions or medication use.

The second analysis focused on the cortex, which is the outermost layer of the brain. We showed that people with OCD (both children and adults) have a thinner bilateral inferior parietal cortex, a part of the cortex located near the temples that's responsible for a range of brain functions, including interpreting sensations or experiences (*Boedhoe et al. 2018*). Whether or not a patient was taking medication had a strong effect on the findings: compared to healthy controls, children with OCD using medication showed widespread surface area differences (mainly in regions at the front of the brain) and medicated adults with OCD had a thinner cortex, especially in regions near the forehead,

Figure 3: Research Supported by our 2021 IOCDF Innovator Award



How Disease and Medication Shape the Brain in OCD

temples, and back of the head (frontal, temporal, parietal, and occipital regions). In contrast, unmedicated children and adults with OCD did not differ from controls in the thickness and surface area of the cortex. These medication effects should be interpreted with caution because the study represents a snapshot in time, rather than a long-term study that tracks changes over the course of medication use. However, what we found suggests that medication can physically change the brain and reorganize the ways in which it functions in both children and adults.

Importantly, although the differences we observed between the brains of healthy individuals and people with OCD were often subtle, the increase in statistical power achieved through the ENIGMA-OCD collaboration made it clear that these changes were both real and linked to OCD in some way.

After completing research on the sizes of different brain structures in OCD, we began investigating how these structures were physically interconnected with one another. We analyzed data from studies that used imaging techniques that reveal the physical networks that exist in the brain (Yun *et al.*, 2020; Piras *et al.*, 2021). These networks can tell us important information about how the brain is developing and maturing and are of great interest to researchers studying disorders like OCD that affect brain development and have chronic symptoms over the course of a person's life. Our findings showed that individual networks in the brain were less compartmentalized and more interconnected in OCD than in healthy individuals, and that the distribution of central network "hubs" was different in OCD (Yun *et al.* 2020). We also found that these differences in OCD were associated with how old an individual was when they developed OCD and how long they had had the disorder, leading us to believe that these changes are more likely a consequence of having OCD than the cause of the disorder itself (Piras *et al.*, 2021).

To summarize, the ENIGMA-OCD consortium has demonstrated the power of global collaboration. By combining already collected structural imaging data, we have shown that some alterations in brain structure in OCD patients likely arise as the brain develops in childhood and adolescence, and that other changes are likely due to the effects of having a chronic mental health disorder for many years, and still others may result from medication use. These findings have important consequences. First, they highlight the importance of conducting long-term studies that examine and track the effects of medication on the developing brain over time. Second, they underscore the

urgent need to intervene early and reduce the amount of time that it takes to begin effective treatment after the first symptoms of OCD set in (e.g., by increasing access to exposure and response prevention [ERP] treatment across the globe). The need to prevent OCD from altering the brain is critical and must be accomplished by connecting people to evidence-based treatment early on, as well as by developing innovative treatments for those who do not respond to existing first-line interventions like ERP and medication.

PROJECT ON BRAIN FUNCTION FUNDED BY THE 2021 IOCDF INNOVATOR AWARD

In 2021, the International OCD Foundation (IOCDF) awarded a \$300,000 research grant (the Innovator Award) to the ENIGMA-OCD consortium (PIs: Odile van den Heuvel, MD, PhD and Chris Vriend, PhD) to support the next stage of worldwide collaboration. In this project, we will investigate brain function in OCD and study the connections between brain function and our previous findings about the brain's structure. We will use functional MRI (fMRI) scans to study the brain activity of participants during specific cognitive and emotional tasks.


Task-based fMRI has greatly advanced our understanding of how the brains of people with OCD work differently from healthy individuals; however, previous task-based fMRI studies were limited by small samples. In the IOCDF Innovator Award project, we will bring together fMRI data from sites around the world to increase the statistical power of our research on brain activity in OCD. Our research will focus on emotional processing, the processes that enable individuals to resist engaging in compulsions, and higher-order thinking processes that enable people to interpret and respond to the world around them (see figure 3). We will address three crucial questions: 1) How does obsessive and compulsive behavior shape the brain? 2) How does medication used to treat OCD alter brain function? 3) Can brain function predict an individual's treatment response?

First, we expect that people with OCD will show different brain activation when compared to healthy controls during tasks that tap into patterns of thinking and emotional processing that underlie OCD symptoms, and that these differences will depend on age (stage of brain development) and disease duration (how long a person has had OCD). Second, we expect that brain activity will differ between people with OCD who use medication as compared to those without medication. Third, we expect that some patterns of brain activity in OCD will be linked to better response to ERP and serotonin reuptake inhibitor medications. In particular,

RESEARCH NEWS

How Disease and Medication Shape the Brain in OCD *(continued)*

we believe that individuals who have more activity in the amygdala (involved in memory, emotional processing, and fear and anxiety responses) and dorsal prefrontal areas (involved in working memory and planning) when processing emotions will respond better to these treatments.

To conclude, ENIGMA-OCD has brought together OCD experts from all over the world to re-analyze historical MRI data using a range of statistical methods, increasing the statistical power of OCD brain imaging research and improving our ability to make important discoveries about this disorder using MRI. The IOCDF Innovator Award will bring this research to the next level by enabling us to study brain function with the same approach. Our ultimate goal is to translate knowledge on brain structure and function involved in the causes and consequences of OCD, leading to better outcomes for people living with OCD. 

AUTHORS:

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4. Charité-Universitätsmedizin Berlin, corporate member of Freie Universität Berlin and Humboldt-Universität zu Berlin, Department of Psychiatry and Clinical Neuroscience, Berlin, Germany.
5. Icahn School of Medicine at Mount Sinai, New York, New York, United States of America.
6. Imaging Genetics Center, Mark & Mary Stevens Institute for Neuroimaging & Informatics, Keck USC School of Medicine, Marina del Rey, CA, United States of America.

7. SAMRC Unit on Risk & Resilience in Mental Disorders, Department of Psychiatry & Neuroscience Institute, University of Cape Town, Cape Town, South Africa.

* = See: enigma.ini.usc.edu/ongoing/enigma-ocd-working-group

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Introducing: Research Roundtable

by Kyle King, Yale OCD Research Clinic Undergrad Assistant and IOCDF Advocate



When I was diagnosed with OCD at age 13, my parents reacted by learning everything they could about the disorder and its possible treatments. And when I say everything, I mean *everything*. Terribly concerned, they took to online databases and journals in an attempt to learn the latest information about my OCD. Often, though, the latest information — the stuff my worried parents needed most — was packed in dense research papers, too long and tedious and filled with jargon for them to wade through, and thus inaccessible.

As a student researcher, I've personally found the academic literature on OCD to be overwhelming. Scientific papers are challenging and there are a seemingly infinite number of topics under active investigation, making it feel impossible to stay up-to-date.

MAKING RESEARCH ACCESSIBLE

To address these problems, UNC Professor of Psychology and Neuroscience Jonathan Abramowitz, PhD, and I recently started the IOCDF Research Roundtable, a monthly livestream that provides an accessible overview of topics within the broader OCD literature. Each month, Dr. Abramowitz and I select a rapidly evolving topic we feel

needs explaining and invite two experts in that specific topic to join the livestream as panelists. What follows is an hour-long discussion of the month's topic with expert panelists providing a digestible overview of key research insights. If our guests start to use research jargon, Jon or I (but normally me, because I'm easily confused) bring the discussion back to Earth for non-researchers to follow.

Jon and I aren't the only ones who get to ask questions — audience participation is encouraged! So, the program isn't only a way to learn about a developing field without having to wade through scholarly articles; it's also an opportunity to ask clarifying questions about evolving subjects to the researchers that know the fields better than anyone.

SUBSCRIBE & JOIN US!

Whether you have OCD, love someone with OCD, treat patients with OCD, or research OCD, learning about and understanding the disorder is the first step to beating it. And since new research is published daily, there are always new and important things to learn. Subscribe to the IOCDF's YouTube channel at youtube.com/iocdf to get notified when we go live the second Wednesday of each month at noon ET. We hope to see you there! 🎧

RESEARCH NEWS

Research Participants Sought

The IOCDF is not affiliated with any of the following studies, although we ensure that all research studies listed on this page have been reviewed and approved by an Internal Review Board (IRB). The studies are listed alphabetically by state, with online studies and those open to multiple areas at the beginning.

If you are a researcher who would like to include your research listing in the *OCD Newsletter*, please email Will Sutton at wsutton@iocdf.org or visit iocdf.org/research.

Do You Have Obsessive-Compulsive Disorder (OCD)?

Researchers at Baylor College of Medicine are interested in reproductive decision-making of adults with OCD. This study involves a brief, online anonymous questionnaire about your knowledge and attitudes towards genetic risk factors of OCD and how that informs your decision about having children. To be eligible for this study, you must be over 18, have a diagnosis of OCD, be in a situation where you could have a biological child now or in the future, and speak English.

To participate, please visit: <https://redcap.research.bcm.edu/redcap/surveys/?s=X3AMHCHW3FT8ERW8>

For more information, please contact the study coordinator Minjee Kook, Ethan Schweissing, Madeleine Fuselier atminjee.kook@bcm.edu, ethan.schweissing@bcm.edu, madeleine.fuselier@bcm.edu

Are You an Adult with "Pure O" OCD?

Would you be willing to answer some questions about your experiences?

Adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD/pure obsessional OCD/ obsessions without visible compulsions) are invited to take part in an anonymous online survey for a doctoral research project.

The survey questions will be open-ended and ask you about what it is like to live with pure O including topics such as your friendships and relationships and what it has been like to seek support (if you have).

Research participants often report that they enjoy taking part in research studies and sharing their experiences. It is hoped that you will value contributing to developing understandings of an important psychological issue.

To Take Part in this Study, Participants Need to:

- Either self-define as having Pure O or have a diagnosis of OCD where you have obsessions without clearly visible compulsions.
- Be 18 or over
- Be willing to take part.

To read the participant information sheet and take part in the

survey, please click this link or scan the QR code: www.tinyurl.com/pureosurvey

If you would like any further information, please contact me via email: Virginia2.guy@live.uwe.ac.uk



Deep Brain Stimulation for Obsessive Compulsive Disorder

Deep brain stimulation (DBS) is an advanced medical treatment that uses electrical impulses to ease symptoms from a variety of neurologic and psychiatric disorders. We design a treatment plan specific to you and your obsessive-compulsive disorder (OCD) symptoms to achieve the best results while minimizing side effects.

How does it work?

We start by pinpointing (via brain scans) the exact spot in the brain that is causing the problem. Then, we implant two electrodes into that area of the brain, which connects to a neurostimulator. The neurostimulator is implanted just under your skin, near the collarbone—like a pacemaker. This enables us to send electrical currents to your brain to ease your symptoms. Once the device is placed, we program the location, amplitude, duration, and frequency of the electrical pulse for the best result.

Is it effective?

On average, 60% of severely ill and treatment-resistant OCD patients see results with DBS. Most patients feel symptom relief soon after the procedure, and the relief is typically long-term. DBS also often enables patients to reduce medication (and its unpleasant side effects).

Is it safe?

Yes. The FDA has approved DBS for treatment-resistant OCD under a Humanitarian Device Exemption (HDE). The HDE recommends that treatment be rendered at institutions that have experience with this intervention. Mount Sinai is one of the few experienced institutions where DBS for OCD is available, and we have been using this procedure for more than a decade. There is a minimal chance that placing the stimulator may cause bleeding (1%) or infection (3%) in the brain— both of which usually do not have permanent

Research Participants Sought

consequences. DBS itself has minimal side effects, and most patients with OCD consider DBS to be overall less burdensome than medication.

Who is eligible?

You are eligible for DBS if you have had severe OCD for at least 5 years, and you did not respond to all of the treatment methods below:

- Cognitive behavioral therapy (CBT) with exposure and response prevention by an expert therapist for at least 25 sessions
- Two treatments with an SSRI at maximum dosage, for 18 weeks
- Treatment with an SSRI at maximum dosage, combined with an antipsychotic
- Treatment with clomipramine at maximum dosage, for at least 12 weeks

How do I make an appointment?

Call our office at 212-659-8810 or email our research coordinator Sonia Olson at sonia.olson@mssm.edu, and have the last few notes from your psychiatrist or primary care physician faxed to us at 212-523-8342. After we have reviewed your records, we will call to set up an appointment for further assessment. DBS for OCD at Mount Sinai is covered by Medicare, Medicaid, and most insurance companies on a case-by-case basis

OCD & Mental Health Apps: The perspectives of people with OCD on using mobile applications to support their mental health

Do you have experience of living with obsessive-compulsive disorder?

Have you used any mobile apps in the last 12 months to help manage your distress?

I am a trainee clinical psychologist currently enrolled on the Doctorate in Clinical Psychology programme at Lancaster University.

For my thesis I would like to explore the views of people who have been diagnosed with or self-identify as having OCD and have used mental health apps in the last 12 months.

I hope to find out what makes mental health apps helpful or unhelpful, so that treatments for people with this diagnosis can be better in the future.

If you would like more information, please contact Faromarz Nasiri by email at: f.nasiri@lancaster.ac.uk

Survey of Patient Attitudes Towards Psychiatric Neurocircuitry-based Procedures for OCD

Have you been diagnosed with Obsessive-Compulsive Disorder (OCD)? For many patients with Obsessive-Compulsive Disorder (OCD), medication and/or CBT and ERP are effective treatment options. For some, these treatments are ineffective, and they are severely disabled by their OCD. Psychiatric neurocircuitry-based procedures (e.g., TMS, neurosurgery) represent one treatment modality that may be available for individuals not amenable to standard treatments. We are seeking to gain a better understanding of the knowledge of and attitudes toward neurocircuitry-based procedures in those with OCD. We would appreciate your time in filling out this survey to help us reach this goal, no matter your level of knowledge or expertise on the topic.

Survey Link: <https://tinyurl.com/patientperspectives>

An Investigation into Social Support, Possessions & Obsessions

Can you help us? We are researchers at the University of Oxford interested in learning more about the role of social support in obsessions, compulsions and over acquiring and keeping possessions. This is because the support we receive (or don't receive) can have a big impact on our thoughts and experiences. We are hoping to develop a deeper understanding of factors that may contribute to distress, with the hope of tailoring and improving treatments.

We are interested in hearing from people based in the UK aged 18 and over who identify as having:

- obsessional and compulsive problems
- difficulties with over acquiring and keeping possessions
- neither of the above

Participating in the research involves a brief telephone discussion (approximately 15 minutes) and online questionnaires (approximately 30-40 minutes) although for some people it may take longer. Paper questionnaires can also be sent by post if you prefer.

For more information, including a link to the participant information sheet, please visit: <https://tinyurl.com/pfdwfp7k>

To register your interest or for further information, please contact: victoria.edwards@hmc.ox.ac.uk

Hi everyone!

We're looking for participants to fill out a survey as part of a study on adolescent mental health and wellbeing.

RESEARCH NEWS

Research Participants Sought *(continued)*

Unrecognized and untreated mental health struggles among teens is an all-too-common issue. With this study, we are hoping to extract larger themes surrounding adolescent mental health in an effort to eventually create tools to improve pediatric mental health screening, monitoring, and early intervention.

Specifically, we're hoping to have parents of teens aged 14-18 to fill out the survey. The survey should only take 10-15 minutes to complete, is completely anonymous, and can be done from wherever you are located. This study has been approved by the Research Ethics Board at the McGill University Health Center.

If you'd like to participate, follow this link to fill out the consent form and the survey: <https://forms.gle/6eChCePBKoBQZ5S6A>

If you have any questions, please don't hesitate to message me or to email TrakadisLab.fmhs@mcgill.ca. We'd greatly appreciate your help!

All the best,

The Trakadis Lab

We are actively screening individuals with OCD for our NOOC (Nitrous Oxide in Obsessive Compulsive Disorder) Study.

Stanford Research Study

Rodriguez/Translational Therapeutics Laboratory

Purpose: To understand whether inhaled nitrous oxide may bring about rapid improvement in OCD symptoms

You may be eligible for this study if:

- You have OCD
- 18-65 years old
- Currently off medications

Contact: 650-723-4095 or ocdresearch@stanford.edu for more information.


Physician Investigator: Peter van Roessel, M.D, Ph.D.,
Stanford Medical Center

<https://profiles.stanford.edu/peter-van-roessel>

<https://med.stanford.edu/rodriguezlab.html>

Funding: Brain & Behavior Research Foundation

Stanford IRB# 48077

For Participant's rights questions please contact 1-866-680-2906. 

Do You Want Your Article Featured in the OCD Newsletter?

The IOCDF is accepting personal stories, poems, therapy and research article submissions for upcoming Newsletter editions.

Submissions can be sent to editor@iocdf.org.

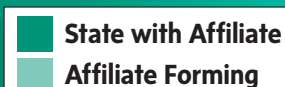


Affiliate Updates

Affiliate Updates

Our affiliates carry out the mission of the IOCDF at the local level. Each of our affiliates is a non-profit organization run entirely by dedicated volunteers. For more info, visit:

iocdf.org/affiliates



OCD JACKSONVILLE

ocdjacksonville.com

facebook.com/OCDJAX

Instagram: @ocdjax

OCD Jacksonville is excited to announce our 2022 Board of Directors: Mike Vatter (President), Mona Bennett (Vice President), Catherine Porter (Treasurer), Tiffany Wood (Secretary), and Nathan Woods (IT Director). We would like to acknowledge our heartfelt appreciation and gratitude to retiring board members Kim Vincenty, Frank Morelli, and Mike Bennett for their decades of commitment to OCD Jacksonville. They have been instrumental in leading our outreach, education, and community initiatives.

In 2021, OCD Jacksonville and Baptist Health led a BTTI which resulted in 14 clinicians becoming certified in the North Florida area. In 2022, OCD Jacksonville will proudly serve as the title sponsor for the IOCDF's Faith & Mental Health Conference for the second consecutive year.

OCD Jacksonville's amazing group of volunteers will continue hybrid (virtual/in-person) community engagement with expanded virtual peer-led support groups, the award-nominated podcast OCD: SOS and "Bikes without Borders," a cross-country bicycle ride for awareness from Florida to California.

OCD RHODE ISLAND

ocdri.org

facebook.com/OCDRhodeIsland

Instagram: @ocdrhodeisland

OCD Rhode Island recently celebrated its 5th anniversary! As we look back on the past five years, we would like to thank all of you who have made OCD Rhode Island a success. Your continued support has allowed us to educate the public about OCD through our Lecture Series and has helped us connect countless individuals with qualified providers who specialize in evidence-based treatments for OCD and related disorders.

We want to extend our gratitude to Barbara-Ann and Sherry for facilitating a monthly peer-support group and being flexible throughout the pandemic in ensuring continued access to a safe space.

In March, OCD Rhode Island completed our executive board elections and are excited to announce our executive board: Carla Kenney, LMCH (President), Ryan Glode, LMCH (Vice President), Jayme Valdez, LMHC (Director), and Barbara-Ann Borden, MA (Director). We are currently looking to elect a Treasurer to the Board of Directors. If you are interested or know someone who would be a potential candidate please email ryan.glode@gmail.com for more information.

OCD MID-ATLANTIC

ocdmidatlantic.org

OCD Mid-Atlantic is continuing to provide virtual content when and where we can. On March 1, 2022, we sponsored a Lunch and Learn with the Black Mental Health Alliance at which psychologists Kevin Chapman and Magda Rodriguez spoke. We continue to highlight our Board Members' personal stories on our facebook page. The Board is in the process of updating our website so look for our new and improved site in the near future! OCD Mid-Atlantic would like to thank Dr. Michael Labellarte for his time and service on the Board. Finally, we are starting to plan now for OCD Awareness Week events, including a return to an in-person Walk!

OCD MASSACHUSETTS

ocdmassachusetts.org

facebook.com/OCDMassachusetts

Instagram: @ocdmassachusetts

OCD Massachusetts is excited to continue expansion of our online resources and offerings. We now have recordings of our monthly lecture series uploaded to our YouTube channel, with new videos being added each month. Additionally, we have been honored to have members of our community share their stories of recovery and hope through a new section of our website, Community Stories: Messages of Recovery & Hope. To keep up to date with OCD Massachusetts, check out our website and follow us on Facebook, Instagram (@ocdmassachusetts), and Twitter (@OCDMass).

FROM THE AFFILIATES

Affiliate Updates *(continued)*

OCD TEXAS

ocdtexas.org

facebook.com/ocdtexas

Instagram: [@ocd_texas](https://www.instagram.com/ocd_texas)

OCD Texas is off to a fresh start after a productive 2021. Our Learn-at-Lunch series has ended, but select videos are available on our YouTube channel and/or social media pages for further viewing. Thank you to all of our 2021 presenters and participants!

COVID-19 thwarted our spring conference agenda, but we are determined to support our communities. Plans are under way for supporting Texas clinicians in gaining specialized OCD training, with preference determined for providers in underserved regions. Stay tuned for more information about the next steps of the Mary Kathleen Norris Scholarship Committee.

Join us this fall for the Annual One Million Steps for OCD Walk taking place across major Texas cities. We look forward to reuniting with you on October 1! Anyone interested in sharing ideas or getting involved with OCD Texas is welcomed to reach out to us at info@ocdtexas.org.

OCD CONNECTICUT

ocdct.org

facebook.com/OCDConnecticut

OCD Connecticut recently relocated from Old Saybrook to Fairfield and a new Executive Board has been elected: Laura Damm and Ann Yacoviello (Co-Presidents), Urb Leimkuhler (Vice-President), and Rocco Clericuzio (Treasurer and Webmaster). OCD CT was founded as an by Susan Schuster, and up through 2021 it was led by Jennifer Piper and Michelle McLain (Co-Presidents), Susan Schuster (Vice President), Collin Schuster (Secretary), and Robert Schuster (Treasurer). Under their leadership, OCD CT mobilized educational programs and support resources for the people of Connecticut, including a grant to the Fairfield County OCD Support Group to offer virtual meetings via Zoom during the Pandemic. The Clinical and Scientific Advisory Board members, led by Christina Taylor, PhD and Diane Sholomskas, PhD, who will continue to serve include: Amy Cawman, LCSW; Heidi Grantz, LCSW; Christopher Pittenger, MD, PhD; and Denis G. Sukhodolsky, Ph.D. As a first order of business under the new leadership, OCD CT is planning to join in with OCD Massachusetts and OCD Rhode Island in fundraising for the 2022 Boston OCD Walk scheduled for June 11, 2022 at Carson Beach.

OCD SOUTHERN CALIFORNIA

ocdsocal.org

facebook.com/OCDSocal

Instagram: [@ocdsocal](https://www.instagram.com/ocdsocal)

OCD SoCal is holding our 6th Annual (Virtual) OCD Conference on Saturday, April 30, 2022, from 9 am to 6 pm PT! The conference registration is low-cost, and scholarship tickets are available. Since it is virtual, anyone from anywhere can attend! Talks will include presentations by some of the top OCD experts on navigating OCD treatment, medications, family accommodation, virtual treatment, OCD documentaries, and more.

We are thrilled to present a diverse panel of keynote speakers who will share inspirational stories about their struggles and triumphs with OCD. Following the keynote speakers, there will be a total of 30 break-out sessions and seven presentations available for continuing education (CE) credits during the conference.

Visit our website for answers to all your FAQs and to find the link to our EventBrite registration page to sign-up. In addition, you may email us at: info@ocdsocal.org.

OCD SoCal will also participate in the IOCDF's One Million Steps for OCD Walk to raise OCD awareness! We offer walks in four counties in our catchment area: Los Angeles, Orange, Inland Empire, and San Diego — all on Saturday, June 4, 2022. You can sign up and walk with us in person, or you can donate to support our cause!

OCD CENTRAL & SOUTH FLORIDA

ocdcsfl.org

facebook.com/OCDCSFL

OCD Central & South Florida hosted an Affiliate Town Hall on March 6, 2022, which consisted of two segments: 1) individuals affected by OCD and their family members, and 2) professionals and students. This event was an open, informal discussion to discuss interests and needs of members in our region as well as ways to strengthen our OCD community.

We have been busy planning additional programming for 2022, which will include hosting a One Million Steps for OCD Walk during OCD Awareness Week, a presentation on Comorbidity of OCD and PTSD, and a Community Awareness and Advocacy event. Please check our website for more details!

If you are interested in getting involved in OCD Central & South Florida, either as a Board member or a volunteer, please email us at info@ocdcsfl.org.

Check out our website for information about our events, and to learn more about OCD Central & South Florida. You can also find us on Facebook @OCDCSFL.

FROM THE AFFILIATES

Affiliate Updates

OCD NEW HAMPSHIRE

ocdnewhampshire.org

facebook.com/OCDNH

Instagram: @ocd_nh

With spring on the horizon, OCDNH is looking forward to creating more opportunities for social and educational events both in person and virtually. Our monthly virtual education series, geared towards those with OCD and their loved ones, has been well attended and continues into June. Upcoming topics include:

Nature, Art, and OCD

Neurodiversity and Friendships: Becoming an Ally for Yourself and Others

Book reading and author discussion

Dealing with the Heat (and OCD & Anxiety-Related Disorders)

Coming soon (date TBD) we will host a virtual screening of unstuck: an OCD kids movie and panel discussion with OCD specialists, parents, and kids with OCD. We plan to hold more "Exposure Hikes" this spring, a challenge by choice opportunity to do some exposures while enjoying the beauty of the White Mountains. Our One Million Steps for OCD Walk will be held June 12 from 2 to 4pm ET at White Park in Concord, NH. This October, we will hold our second annual clinician training for those professionals interested in learning more about ERP and ACT for OCD (date, time, location TBD). For more details on all of the above, please visit ocdnewhampshire.org or follow us on social media.

OCD MIDWEST

ocd-midwest.org

facebook.com/OCDMidwestAffiliate

OCD Midwest sponsored a very successful Pediatric BTTI in Chicago in December 2021 and supported three scholarship winners from Indiana in attending. We are looking to develop our committee-based work and will be choosing a new president-elect to join our executive Board over the coming months. Board President, Gabriella Faggella, was able to present three CEU workshops to the Akron-Canton Area Agency on Aging focused on BFRBs, Hoarding, and OCD as well as a presentation on OCD to an Akron-Canton-based OCD and Scrupulosity Support Group. Immediate Past-President Dr. Patrick McGrath presented on OCD Subtypes and the Relevance of ERP for AMITA Health. Planning is under way for multiple OCD Walks in June. 🕒

MERCH!



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27TH
ANNUAL

OCD

CONFERENCE

DENVER

July 8–10, 2022

Learn more and register:
iocdf.org/ocdcon2022

For those with lived experience of all ages, their family members and supporters, researchers, and therapists who work with OCD.

The Annual OCD Conference is the largest national event focused solely on obsessive compulsive disorder (OCD) and related disorders. This extraordinary event brings together individuals with OCD, their loved ones, and mental health professionals under the same roof with the goal of educating attendees about the latest treatments, research, and practice in OCD and related disorders.