



A Family Affair:

How one girl took action after her brother's OCD diagnosis



When nine-year-old Ruby Niosi rings a doorbell, she always says the same thing.

"Hello! OCD is obsessive compulsive disorder. Two hundred thousand people are diagnosed each year. One is my 10-year-old brother. I have been making and selling potholders to support OCD awareness. Would you like to help?"

For the past two years, the Madison, Wisconsin native has been going door to door in her neighborhood and beyond selling potholders to raise money for the International OCD Foundation. Her mission is simple: to raise awareness of the disorder that afflicts her now 11-year-old brother, Dexter.

IN THIS ISSUE

FROM THE FOUNDATION

A Family Affair.....	1
President's Letter	3
2021 Conference Series	5

PUBLIC POLICY CORNER

Spring Update.....	6
--------------------	---

FROM THE FRONT LINES

Growing Up Obsessive by JC.....	7
So You've Been Diagnosed—Now What?: Deconstructing Diagnostic Labels and Finding Social Support by Emma H. Palermo & Joshua S. Steinberg	9

THERAPY COMMUNITY

Institutional Member Updates	12
Expressive Arts Therapy in OCD Treatment: An Introduction by Kathryn Keniston, MA, LMHC, R-DMT	17

RESEARCH NEWS

Ocular Tourettic OCD by Dr. Jonathan Grayson and Melissa Price.....	19
Harnessing Virtual Reality Technology to Assess Interpretation Biases in BDD by Berta J. Summers, PhD	20
Research Participants Sought.....	23

FROM THE AFFILIATES

Affiliate Updates	26
-------------------------	----

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

President, IOCDF Board of Directors:
Susan Boaz

Chair, IOCDF Scientific & Clinical Advisory Board: Michael Jenike, MD

Newsletter Editor-in-Chief:
Jeff Szymanski, PhD

Newsletter Managing Editor:
Jessica Price, MA

Copy Editor:
Tiia Groden, MA

Layout Design: Fran Harrington

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.

CONTACT THE IOCDF:

Phone: (617) 973-5801

Email: info@iocdf.org

Website: iocdf.org

Facebook.com/IOCDF

Twitter: @IOCDF

Instagram: @IOCDF

YouTube.com/IOCDF

Twitch.tv/IOCDF

Mailing Address:

International OCD Foundation

P.O. Box 961029

Boston, MA 02196

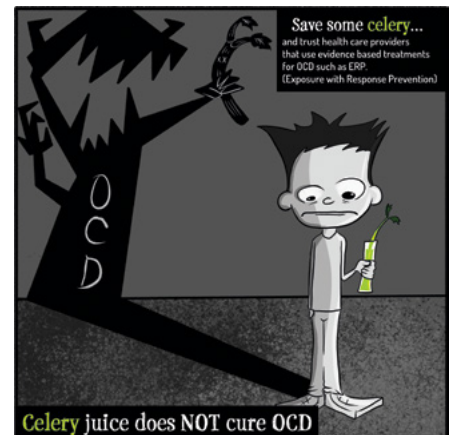
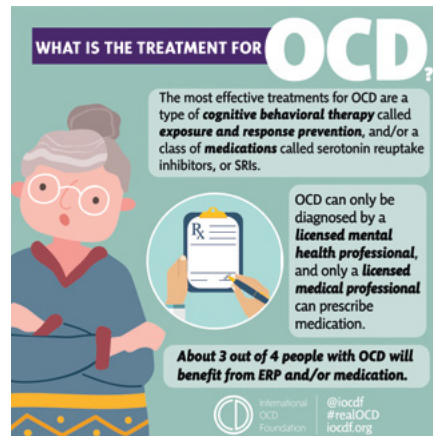
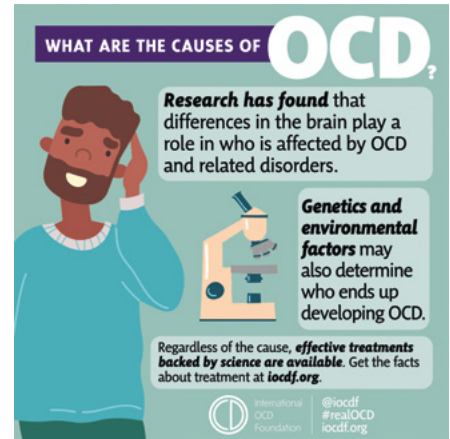
DISCLAIMER: *The IOCDF does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep you informed. We strongly advise that you check any medications, products or treatments mentioned with a licensed treatment provider.*

Copyright 2021 by the International OCD Foundation, Inc.

Help us share the truth about OCD!

False claims about OCD are harmful to our community and can prevent those impacted by OCD from receiving the treatment that they need and deserve.

Share our new graphics, which can be found at iocdf.org/ocdtruth, to help us raise awareness and fight misinformation about OCD.



@iocdf



Sean Shinnock Artist/Illustrator/Advocate

President's Letter

by Susan Boaz



Dear IOCDF Friends and Family,

It's almost spring (thank goodness!) and I'm writing this letter as we are making the tough decision to cancel our in-person Annual OCD Conference again in 2021. It was planned for NYC in July, but local ordinances

understandably make our dream of being in person this summer impossible.

While we won't be in person again until 2022 (seriously, I am making a promise here), we will be hosting our second Online OCD Conference this October — we hope you will attend! By going virtual last year, we had our largest and most diverse conference ever with over 3,000 attendees worldwide.

And, the proposals for speaking opportunities at the virtual conference this year have been overwhelmingly exciting and diverse. In addition to the extensive content, you will also have the opportunity to meet the IOCDF Board and Advocates in the Zoom rooms. We will be talking about programming the IOCDF has, answering your questions about specific challenges, connecting folks on topics, and learning more about each of you.

We will also be open to talking about some of our new task forces and how you can get involved. Here are two of them:

- The **Perinatal OCD Task Force** was newly founded in 2020. Many people do not know that OCD is a common issue experienced by parents both before and after their child is born. Since over 10% of women experience postpartum symptoms, it's critical to provide these moms and their doctors and therapists resources. We have partnered with 2020 Mom and formed three subcommittees to focus on research, clinical providers, and public awareness. Postpartum OCD is a particular interest of mine, and I am hopeful that the talent on these committees will create lasting change.
- We also formed a task force to look at the impact of **OCD in faith-based communities** and how best to support treatment in a respectful and educated way. This task force is being spearheaded by some of our IOCDF Advocates, most notably our Lead Advocate Valerie Andrews. It can be challenging to sort out scrupulosity versus the joy felt in religious ritual and spiritual support, and to make a place for being a person of faith with a mental health disorder. As always, it is our goal to support individuals in their quest for mental health in all parts of their lives, and we are open to seeing how we can best support the recommendations of this task force in 2021.

This leads me to our pediatric programming — always the most exciting part of this letter for me since you all know I'm a mama at heart. Every year at our Annual OCD Conference, I ask to help out in the "littles" room, where we plan a camp environment for kids aged 4–10. It's always an engaging room because many kids are newly diagnosed. There is so much excitement as the kids meet each other, and a deep sense of relief as the parents make new friends and find a community of their own, just as I did for the first time back in 2007.

In 2020, while we had good experiences building out programming and planning online events, we had not yet tried to develop a full weekend conference for our youngest members and their parents. So in January, we launched our OCD Camp for Kids (aged 4–10). To say it was inspirational does not even begin to do it credit! Over 250 kiddos and their parents, guardians, and siblings joined us for a full weekend of content. The mornings were tailored for the kids, with content from Dr. Aureen Wagner (*Up and Down Worry Hill*) and book readings. These were hosted by the 13-year-old author, CJ, who read her book *Practice Being Brave: Owning My OCD*, and author Brian Wray, who read *Unraveling Rose*, a story about a little stuffed bunny dealing with an obsessive thought. Kids also learned about the worry thermometer, had art time, and met new friends in the Zoom rooms.


The afternoons were focused on parents and guardians. Sessions were run by therapists and parents and included topics such as OCD treatment 101, family accommodation, and shaping bravery and nurturing self-kindness. We also had open Q&A, activities, and office hours run by teens and young adults, clinicians, and parents. As always, parents were especially interested in hearing from the teens and young adults who had already been through the journey of healing from childhood OCD. We are grateful to them for sharing so much of themselves.

I'll close with gratitude to this entire community. We are a small staff and board who try hard to stay open to ideas, learn from our mistakes, and embrace learning every day. We deeply love the OCD community that makes this possible. Our volunteers are the lifeblood of our daily activities, whether it's working at a conference, participating in respectful online discussions, sitting on a task force, or being an advocate. Each of you is part of our journey, and I look forward every day to where it will take us next.

Remember to be kind to yourself. You've got this, and we are here to share the journey with you. You belong to this community, and we are grateful you are here.

With love,

Susan Boaz

IOCDF Board President and mom to a fabulous teen 

FROM THE FOUNDATION

A Family Affair *(continued from front page)*



When they spoke to the IOCDF, Ruby and the rest of her family had just finished a month-long break from making potholders, which have been in high demand. Since they started selling potholders in October 2019, they have raised over \$2,400 for the IOCDF, and when they decided to take January off, Ruby and Dexter had just made 200 potholders in 10 weeks. "They were in such demand," said

their mom, Poppy, who has been helping her kids project manage each of which takes 30 minutes to complete.

What did they do with their time off? "We went sledding, played with the dogs..." Ruby said as she puts together a colorful potholder using cotton and nylon wraps on a frame (she chooses her own colors). As she talks, two dogs (Turbo and Cookie) pop in and out of frame, along with a cat named Spirit. Later, they introduce us to their many fish and Dexter's bearded dragon, a gift for graduating from inpatient treatment at Rogers. "Welcome to our zoo," said Poppy. "It's a madhouse."

From the looks of it, Dexter and Ruby are regular kids growing up in a fun, laid back household. But that belies the very serious nature of Dexter's disorder, and how seriously Ruby takes her job. When Dexter first went to treatment for compulsive "prayering" and the family realized how severe his OCD had become, Ruby didn't know what to do. "I wanted to take it from him and I'd rather have me have OCD instead of him," said Ruby.

That's when the stars aligned. It was 2019 OCD Awareness Week, and Ruby heard about a family friend with a cleft palate who raised money for Operation Smile. As Ruby contemplated what she could do for Dexter, "she was in the middle of making a potholder," Poppy said. A cousin had bought Ruby a potholder-making set for her birthday, and "I just started to make many potholders," she said.

Ruby and Dexter started taking her potholders door to door in a little red wagon, raising money and OCD awareness. "We started off in our neighborhood and people would give us popsicles," Ruby said. "Then we started going to

different neighborhoods." Word of mouth and social media helped spread the word, and then Ruby was featured on TV. Finally, their dad, Jason, decided to create a website (potholdersbyruby.com), which brought in even more orders. "Once we had the website, we had about like 15 orders the next day," said Ruby. "And one girl ordered 10, then 15, then another 15..."

Ruby puts a personalized thank you note in each order, and she has a map of the United States on her wall where she marks where each order comes from with a red star, with the goal of reaching all 50 states. So far, she's received orders from 14 states plus Canada and Australia. "Someday the whole map is going to be covered in red stars," said Dexter.

Ruby is proud of what she's achieved for her brother. "I've been really glad that I've been accomplishing stuff that not many children are able to accomplish," she said. And Dexter is, too. When he found out about Ruby's fundraising efforts, he said, he cried and hugged her. "I was very happy and grateful that Ruby noticed and she was trying her best to help," he said.

Dexter's recovery is ongoing. He helps Ruby make potholders, and Poppy said this is an exposure for him since it causes anxiety. He does virtual therapy due to COVID-19, and Poppy said the advocacy is helping, too: "It's amazing to see how doing things that advocate for OCD awareness is therapeutic for OCD at the same time," she said.

A passionate advocate himself, Dexter won't stop until everyone knows that OCD is not a joke. "It makes me mad when people joke around about OCD," he said. "Some people say OCD is a joke and stuff; it's just about being really clean. But that is not true. OCD is much bigger." 🗣️



If Ruby has inspired you, be sure to check out iocdf.org/ways-to-give for all the ways you can help fundraise for the IOCDF, including DIY fundraising!

FROM THE FOUNDATION

Mark Your Calendar: 2021 IOCDF Conference Series!

While the COVID-19 pandemic prevented us from meeting in person for the 2020 Annual OCD Conference, it also provided us with the opportunity to expand our conference programming into the virtual sphere.

Now, we are thrilled to offer a variety of events to encourage accessibility virtually. We are encouraging the global network of providers, educators, and people with lived experience to join us in community, collaboration, and education. Mark your calendars, and stay tuned for more information.

Please note: Proposal submissions for all events are now closed. Update your email preferences at iocdf.org/sign-up to make sure you get updates when the conference programming is announced!

Visit iocdf.org/conference for the full schedule of events and program descriptions.

We are thrilled to bring these exciting events to you. Stay tuned for more information, and we look forward to seeing you soon! 📍

Faith & Mental Health Conference: <i>Navigating Anxiety in Diverse Faith-Based Communities</i>	May 21st, 2021
Annual Research Symposium	July 8, 2021
Online OCD Camp (<i>Youth conference</i>)	July 10-11, 2021
Annual OCD Conference (in-person)	CANCELED
Annual Hoarding Meeting (in-person).....	CANCELED
Online Hoarding Meeting.....	August 7–8, 2021
Conferencia de TOC Online (<i>Spanish language conference</i>).....	September 11–12, 2021
Online OCD Conference.....	October 8–10, 2021
Online OCD Camp (<i>Youth conference</i>)	(new dates) January 21–23, 2022

WALK with us this fall

The 1 Million Steps 4 OCD Walk will return in person in September 2021.

Visit iocdf.org/walk for more information and find a walk in your area!



PUBLIC POLICY CORNER

Spring Update



The beginning of 2021 marked a time of transition to a new session of Congress, along with a change in the White House. For us at the IOCDF, this is a time for us to take stock of our public policy priorities for the next two years, and to introduce ourselves and our community to leaders in a new administration and Congress.

We were fortunate to have the opportunity to meet with members of the Biden transition team to voice our support for mental health policy changes that would benefit the OCD and related disorders community. IOCDF Program Director Stephanie Cogen joined with representatives of other national mental health organizations in urging a renewed focus on parity in insurance coverage for mental health treatment, and a permanent extension of many of the federal rules that have increased access to telehealth during the COVID-19 pandemic.

OTHER RECENT IOCDF PUBLIC POLICY ACTIVITIES:

We endorsed the Unified Vision for Transforming Mental Health and Substance Use Care, a comprehensive strategy crafted by the National Alliance for Mental Illness, the Well Being Trust, and 12 other leading mental health and substance use organizations. The Unified Vision proposes addressing the nation's mental health crisis by prioritizing policies, programs, and standards in seven key areas:

- Early identification/intervention, and prevention
- Integration of mental/behavioral health with physical health care
- Improved emergency response for people in crisis
- Reduction of disparities in treatment access and outcomes
- Evidence-based standards that increase care quality
- Workforce capacity to meet demand and community needs
- Equal insurance coverage for physical and mental health services

The Unified Vision is an effort to build consensus among mental health organizations and policymakers about pressing issues that must be addressed before we can meet the mental health needs of every American. We are excited to lend our support!

The IOCDF joined with other mental health organizations to weigh in on vaccination guidance from the US Department of Health and Human Services. We urged them to include mental health and addiction treatment providers, as well as patients in residential and community-based programs, in their recommendations for groups to receive priority COVID-19 vaccine distribution.

OTHER UPDATES:

- Rep. Katko and Rep. Thompson have reintroduced the Mental Health Access Improvement Act (H.R. 432). This bill is one of the IOCDF's legislative priorities. The bill would expand Medicare's mental health coverage to include services provided by LMFTs, LMHCs, and LPCs. Many of the therapists trained to provide ERP for OCD through the IOCDF's Behavior Therapy Training Institute (BTTI) hold these licenses.
- We expect most or all of our other priority bills from the 2019-20 session of Congress to be reintroduced in the weeks to come. Check out iocdf.org/public-policy for more information about our legislative priorities.

UPCOMING EVENTS:

- We're tentatively looking forward to returning to Washington, DC this fall for an in-person public policy event. Be sure to sign up for our email alerts at iocdf.org/public-policy to get the details in your inbox. 

Growing Up Obsessive

by JC



I cannot remember a time in my life where I wasn't experiencing symptoms of OCD. Years before I had any sort of name for it, OCD was already a huge part of my life.

One of my earliest memories is tainted with OCD symptoms. The memory takes place in the house my family lived in until I was seven. It was a small, one-story house with a finished basement. Some kids might be scared of the basement. It was cold and a little dark. But surprisingly enough, I felt safest when I was in the basement.

My biggest fear at the time was the top floor caving in while I was on it. Particularly, that the motion of falling would make me vomit.

Thinking back, that logic is nonsensical. Why would I want to be in the basement when the house collapsed? The truth is that the idea of vomiting was worse than whatever certain death came with the whole house caving in on me. I felt the same way about the school bus. The emergency exits on the bus ceiling were a daily reminder that buses don't always stay upright. Buses sometimes get in accidents and sometimes they flip onto their sides. I made it a habit to skip afternoon snack time for most of elementary school so that my stomach would be empty in the unlikely event that the bus would flip over.

I worried about a lot of things growing up, but the worries mostly revolved around my intense fear of vomit. I was scared that the world would randomly turn upside down and that being upside down would make me throw up. I was afraid that if my parents drove down a hill too quickly that it would make me sick. Most of my childhood was spent worrying about vomit.

When asked to recall my childhood, my father says there is a lot that he now recognizes as OCD that he never understood at the time. The one that sticks out to him the most is my long list of bedtime rituals. These had to be

done every night or I refused to go to bed. The bedtime ritual started as a simple bedtime routine of my parents singing "Twinkle Twinkle Little Star." Over time, the routine got longer and longer. Before long, my bedtime routine consisted of me saying good night to my horse stuffed animal in the closet, being "flown" into bed by my dad, touching each of the teddy bears on my bed, and then my parents could sing. My favorite line of the song was "like a diamond in the sky." I would make my parents sing that line over and over again after they finished the song because I was afraid I had missed it.

These rituals, that my dad and I now recognize as OCD, seemed like just a kid's way of delaying going to bed. Lots of kids avoid going to sleep and my parents thought it was just that. Looking back, these things that seemed so silly, were a sign of something much more serious that would affect me for the rest of my life...

THE HAPPIEST PLACE ON EARTH

My mom has always been a huge fan of Disney. We have a Mickey Mouse-themed bathroom at my parents' house. My parents even had their honeymoon there back when they first got married. Growing up, my family would go to Disney World often for family vacations.

While Disney World claims to be "The Happiest Place on Earth," for a kid with OCD, it can be a very challenging place to be. My family would stay in Disney for over a week every time we would go. My parents and my sister always seemed to be having the time of their lives, but it was a peculiar type of torture for me. I knew that an amusement park like that would be crawling with germs. We were eating out in restaurants for every meal, which made my anxieties around food hard to manage.

The thing that stressed me out the most was the rides. I loved roller coasters and wanted so badly to enjoy them. Even though I liked them so much, they caused me a

FROM THE FRONT LINES

Growing Up Obsessive *(continued)*

great deal of anxiety. Rides can make people sick and I was terrified of that prospect. I knew that I didn't have to go on anything I didn't want to, but I still felt pressure to do everything I possibly could to have a good time. My perfectionism tended to slip into my enjoyment of experiences in this way. I constantly felt like I had to make the most of every moment, especially on vacation. I worried about ruining each experience the same way I worried about ruining a blank sheet of paper. I was terrified of regrets. I worried that if I didn't enjoy something enough that I would regret it. That was the case with the rides in Disney World. I feared that if I didn't go on them, I would be missing out on something and I would regret it later. Deciding to go on each roller coaster was a major battle within my mind. I wanted to go on them not only because I enjoyed them but because if I didn't, I might regret it. On the other hand, I was terrified that it would make me throw up.

In order to make these vacations bearable, I decided to be more mindful of when I was eating. I would simply eat less during the week that we were there so that I could go on the rides without worry about getting sick. This plan would have worked if we had been visiting for a day. Eating almost nothing for a week was not sustainable. Getting me to eat on vacation was a struggle and my parents and I had a lot of fights about it. When we were there I wanted my constant feeling to be hunger so that I wouldn't have to worry about getting sick on the rides and I wouldn't have to worry about missing out on anything either.

“ I decided I wanted to enjoy my life and I wasn't going to at the rate that I was going. I finally was ready to admit that I needed help. ”

The summer before my junior year of high school, my family took one of our infamous Disney trips, this time including my grandparents on my mom's side. Though most family vacations were a struggle for me, this one was particularly difficult, all thanks to my worsening OCD. This particular trip was also difficult for my dad and his OCD. When asked to recall that trip, he says that during that time he was "spiraling." He remembers obsessively making my whole family frequently use hand sanitizer. He says he feels guilt about that trip because he can see now how his behavior was also feeding into my OCD at the time.

During that trip, I had a little bit of a breakthrough. My family was in line for a new ride that had just opened up and everyone was excited except me. We had eaten not very long ago and I didn't think that it was safe for me to go on a ride yet. As we got closer and closer to the front of the line, I went into panic mode. I was scared I would get

sick on the ride, but I was also upset that I wasn't enjoying myself as much as I thought I should be. I looked around at the 23 people in line around me and they seemed happy. I looked at my sister laughing with my grandparents and the way they all seemed to be enjoying each other's company. I was too anxious to enjoy anything. I was supposed to be in the Happiest Place on Earth and I was miserable.

It was right there that I told my mom I wanted to start seeing a therapist. I decided I wanted to enjoy my life and I wasn't going to at the rate that I was going. I finally was ready to admit that I needed help. When we got back from Florida, the hunt for a therapist began. 🕒

The full version of this story appears at iocdf.org/blog

So You've Been Diagnosed — Now What?: Deconstructing Diagnostic Labels and Finding Social Support

by Emma H. Palermo & Joshua S. Steinberg



You are struggling with unreasonable thoughts and fears that lead to compulsive behaviors; the presence of your obsessions (recurrent thoughts, urges, and impulses) cannot be ignored and your compulsions (repetitive behaviors or mental acts that you perform to reduce your anxiety) last at least one hour per day (DSM-5). No matter how hard you try, you can't seem to shake this cycle of obsession leading to compulsion. Your symptoms cause enough distress to warrant a trip to a clinician. You receive a label: obsessive compulsive disorder.

Receiving this label can cause a noticeable shift in the way that you think about yourself and the way that others think about you. Research has shown that being told that you have a mental health disorder can be difficult and even harmful for people who hold negative ideas and stereotypes about that disorder (Corrigan & Watson, 2002). People that hold these beliefs may judge themselves for their mental illness, or be concerned about judgment from others. Before receiving a diagnosis, you may be aware of the negative stereotypes surrounding various mental disorders, but not give them much thought. It might not be until you actually receive a diagnosis that these negative ideas are activated, harming your own self-esteem if you begin to associate yourself with the stereotypes you have been exposed to in the past (Ben-Zeev et al., 2010). However, is it not true that you suffered from OCD before being diagnosed? It seems that something about having the diagnosis itself caused a change in your mindset about the symptoms that you

had been experiencing. Because the label "OCD" simply describes a collection of different symptoms, it cannot be the label itself that causes your mental illness. So why should having a label drastically change how you view yourself or how some others view you?

Sociologists and psychologists who are trying to answer this question have come up with a few possible explanations for how a diagnostic label could affect a person's feelings and behavior. As we will explain in more detail later on, their ideas have shifted from thinking that labels themselves can affect behavior, to proposing that receiving a label triggers secondary effects that might explain why some people experience a worsening of their mental health after receiving a diagnosis. We will also explore an alternative idea of our own: that receiving a label could actually be something to embrace, as it can allow you to find a community of similar people.

One theory that attempts to explain the effects of labeling is the appropriately named Labeling Theory, pioneered by Scheff (1966). This theory refers to the idea that social reactions to "deviant"^[1] or "abnormal" behavior (i.e., a clinical diagnosis) lead the labeled person to unconsciously change their behaviors to fit their ideas about what it means to have their diagnosis, turning the diagnosis into a self-fulfilling prophecy. However, this theory has fallen out of favor due to the fact that individuals can display symptoms of a mental health disorder without the behavior ever being given a label. A modified version of labeling theory popularized by Link (1989) proposes that receiving a label leads to other negative outcomes for the person being labeled. This theory connects negative outcomes to "stigma," an increasingly popular term that refers to society's negative judgment of behaviors due to their divergence from how healthy people tend to function (Goffman, 1963).

FROM THE FRONT LINES

So You've Been Diagnosed—Now What? *(continued)*

Stigma around a condition can lead to social rejection, which can then reinforce and continue a cycle of isolation and negative judgments about one's self. Indeed, "when people enter psychiatric treatment and are labeled [society's] beliefs become personally applicable and lead to self-devaluation and/or the fear of rejection by others" (Link et al., 1987). However, the specifics of how a person's self-worth is impacted can vary depending on the mental illness.

In the context of OCD, Link's theoretical framework could operate as follows: the individual anticipates social rejection or judgment from others around their ritual of excessive hand washing. They know that the behavior is not typical, so they try to disguise it as normal, for example by telling others that they have some gross or dangerous substance on their hands. In order to avoid the negative social consequences of having others think of them as having OCD, they hide their rituals to pass as "normal" (Fennel & Liberato, 2006). In turn, the behavior persists, leading to a cycle of one creating excuses to hide the compulsion and then feeling a sense of increased isolation and discomfort from falsely justifying behaviors to others.

Though so far we have focused on how the individual may be affected by perceptions of their illness by others, stigma can also be directed toward one's self ("self-stigma") as an individual begins to believe the negative ideas and stereotypes about their mental illness that are held by others are true or correct. Having a label can lead an individual to feel more self-stigma as well as to perceive an increase in

stigma from others. When a person feels socially rejected, they tend to isolate themselves as a form of protection from the stigma surrounding their condition (State of Victoria Department of Health and Human Services, 2015).

However, these effects can be mitigated, and in some cases, reversed, when an individual uses their label to find others who can understand what they are experiencing. By taking ownership of one's own label, doors open: namely, finding

social support and empathy through a support system can help people weather stressful situations more easily (Heinrichs et al., 2003). By way of engaging in support groups for individuals with OCD, a label can actually serve to decrease self-isolation by creating a community of people who have the same label (Naslund, et al., 2014). By interacting with those in various stages of treatment, one can learn that they are not alone. Also, affiliating with others with a shared diagnosis can foster a sense of hope that treatment will ultimately

“ By way of engaging in support groups for individuals with OCD, a label can actually serve to decrease self-isolation by creating a community of people who have the same label. ”

be helpful. Being with other people who know what it is like to suffer from OCD can be refreshing when the vast majority of other people in your life can sympathize but can't truly empathize with your experiences. Without the label, it would be difficult to find a community of people to whom one could relate. Through the label, one may come to view the diagnosis as a unifying factor and find solidarity. Although solely relying on alternative mental health services such as support groups may inadvertently strengthen isolation from the broader community (Sheridan

So You've Been Diagnosed—Now What? *(continued)*

et. al., 2012), these resources have been found to be helpful (*Mental Health Foundation, 2012*) and should be used alongside increased engagement in social activities for those with long-term mental illness. These stories of people finding solidarity and social support once diagnosed with a mental illness are ubiquitous (*see: Walker, 2020*).

When I (Steinberg) was diagnosed with severe OCD in 2011, I felt relief but I also felt dread; I felt relief because receiving a label signified the first step toward receiving appropriate treatment, but I also felt dread because I now understood that the path forward would be very difficult. Learning about my disorder involved reading sources from professionals but it also sometimes meant learning how society views OCD. Representations of OCD on television became less lighthearted and more distressing to me as I began to realize that telling people of my diagnosis would only serve to conjure up images of Monica from *Friends* and Sheldon Cooper from *The Big Bang Theory*. Hearing people refer to their own personality traits as “so OCD” became more pointed. Overall, I did not feel that sharing my diagnosis would provide much sympathy or support. However, when I finally decided to share my story publicly after successfully completing treatment, I came to realize that labels can be unifying. For example, I found an amazing community of peers with OCD at the IOCDF’s Annual OCD Conference. I even decided to start my own support group for teenagers with OCD in order to use the label to bring people with similar experiences together.

Although labels can suggest negative things about a person to some, and individuals may at times feel rejected as a result, they are not going away. They help clinicians effectively communicate conditions, they determine health insurance coverage (*Dangor, 2019*), they help therapists choose appropriate treatment approaches, and they can bring people together. Though it is impossible to control how other people react to a diagnosis, you can focus on finding the silver lining. The message is this: when you are given a label, you can use it to your advantage by finding a community of people who understand what you’re going through; these people can offer support and solidarity. The IOCDF provides a list of resources at iocdf.org/find-help, and you can filter by type to display support groups. You have the symptoms and you have received a label: obsessive compulsive disorder. Now, use the label to your benefit. 🗨️

REFERENCES

- Ben-Zeev, D., Young, M. A., & Corrigan, P. W. (2010). DSM-V and the stigma of mental illness. *Journal of mental health* (Abingdon, England), 19(4), 318–327.
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World psychiatry : official journal of the World Psychiatric Association (WPA)*, 1(1), 16–20.
- Dangor, G. (2019). ‘Mental health parity’ is still an elusive goal in US insurance coverage. NPR. June, 7.
- Fennell, D., & Liberato, A. S. (2007). Learning to live with OCD: Labeling, the self, and stigma. *Deviant Behavior*, 28(4), 305-331.
- Goffman, E. (1963). Stigma: notes on the management of spoiled identity (No. HV4967 G6).
- Heinrichs, M., Baumgartner, T., Kirschbaum, C., & Ehlert, U. (2003). Social support and oxytocin interact to suppress cortisol and subjective responses to psychosocial stress. *Biological psychiatry*, 54(12), 1389-1398.
- Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American sociological review*, 96-112.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American sociological review*, 400-423.
- Mental Health Foundation (2012). Developing peer support for long term conditions final report. Retrieved February 01, 2021, from <https://www.bl.uk/collection-items/developing-peer-support-for-long-term-conditions-final-report>.
- Naslund, J. A., Grande, S. W., Aschbrenner, K. A., & Elwyn, G. (2014). Naturally occurring peer support through social media: the experiences of individuals with severe mental illness using YouTube. *PLOS one*, 9(10), e110171.
- Scheff, T. J. (1966). *Being Mentally Ill: A Sociological Theory*.
- Sheridan, A. J., Drennan, J., Coughlan, B., O’Keeffe, D., Frazer, K., Kemple, M., ... & O’Callaghan, E. (2015). Improving social functioning and reducing social isolation and loneliness among people with enduring mental illness: Report of a randomised controlled trial of supported socialisation. *International Journal of Social Psychiatry*, 61(3), 241-250
- State of Victoria Department of Health & Human Services. (2015, September 18). Stigma, discrimination and mental illness. Retrieved February 01, 2021, from <https://www.betterhealth.vic.gov.au/health/servicesandsupport/stigma-discrimination-and-mental-illness>
- Walker, A. (2020, March 30). In a time of social isolation, Mayor Walsh sends a message to those in recovery - *The Boston Globe*. Retrieved February 01, 2021, from <https://www.bostonglobe.com/2020/03/29/metro/time-social-isolation-mayor-walsh-sends-message-those-recovery/>

[1] In modern popular discourse, it is now considered more sensitive to refer to this type of behavior as problems in functioning or non-normative.

THEORY 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.

THE ANXIETY TREATMENT CENTER OF GREATER CHICAGO

707 Lake Cook Road.
Ste 310

Deerfield, IL 60015

(877) 559-0001

info@anxietytreatmentcenter.com
anxietytreatmentcenter.com

We are pleased to welcome Tammy Madrigano, MSW, APSW. Tammy received her masters of social work from the University of Southern California. She has been trained in cognitive behavioral therapy, non-violent crisis intervention, and dialectical behavior therapy. She is a certified grief counselor and has an extensive history of working as a behavioral therapist with autistic children. She also has experience providing addiction treatment, understanding the complex interactions between anxiety and substance use. She has worked in non-profit settings, outpatient clinics, and addiction treatment centers.

We are also happy to welcome back Sarah Peterman, MSW, LCSW. Sarah is an experienced licensed clinical social worker, having worked in a variety of inpatient and outpatient settings as well as in private practice. She received her masters of social work from the University of Illinois, Chicago, Jane Addams School of Social Work. She has received extensive training in cognitive behavioral therapy and has worked with clients struggling with all kinds of anxiety disorders. In addition, she has expertise in treating borderline personality disorder and clients who struggle with emotion regulation.

THE ANXIETY TREATMENT CENTER OF SACRAMENTO

10419 Old Placerville Rd, Ste 258

Sacramento, CA 95827

(916) 366-0647

drrobin@atcsac.net
anxietytreatmentexperts.com

The Anxiety Treatment Center has been thankful to remain open, treating patients in person during shelter-in-place for almost a year now in Sacramento County. As some of the local and surrounding counties are beginning to open their doors for students to be seen in the classroom, many feel unprepared as they have fallen behind in their coursework using the video platforms. Equally, for those who are struggling with depression and anxiety, symptoms have exacerbated due to the isolation and lack of mental health resources in the community.

To help these individuals, we are launching our Kids Conquering COVID Intensive Outpatient Track. The structure will include group and individual therapy with a special focus on the barriers preventing them from returning back to in-person instruction. Parents and caregivers will participate in family therapy to help them better understand how they can support their child to overcome their struggles, and support the use of coping skills needed for successful reunification back into the school setting.

This track is offered Monday through Friday from 9am–12pm or 1–4pm. For more information, contact us.

ARCHWAYS CENTRE FOR CBT

460 Springbank Dr, Ste 205

London, ON N6J 0A8

(519) 472-6612

info@archways.ca
archways.ca

Archways is thrilled to have recently been recognized by the IOCDF as an Institutional Member, only the third clinic in Canada to achieve this, and the only private outpatient clinic in Ontario.

COVID-19 challenged us to re-evaluate our OCD programming and shift 90% of our sessions online, using secure video-based therapy. This shift has led to two major benefits for our clients:

1. Increased treatment efficacy: we can help clients with their exposure work in their homes, where most of their compulsions are routed.
2. Greater access to evidence-based treatment: we can provide evidence-based therapy to clients living anywhere in Ontario.

We have two psychologists and one psychological associate all with 20+ years of experience working in the field of OCD and related disorders. Furthermore, we have two clinicians currently being supervised in the treatment of OCD. We work with individuals six to 65 years of age.

Given the ever-changing situation with COVID-19, sessions will continue to be virtual for the foreseeable future. Wishing everyone in the OCD community better times ahead!

BEHAVIOR THERAPY CENTER OF GREATER WASHINGTON

11227 Lockwood Dr

Silver Spring, MD 20759

(301) 593-4040

info@behaviortherapycenter.com
behaviortherapycenter.com

While this has certainly been a long year and winter, Behavior Therapy Center of Greater Washington and our clients enter spring more resilient and able to cope with the uncertainty and change we have been repeatedly reminded is an inherent part

Institutional Member Updates *(continued)*

of living. BTC quickly adapted to the transition to telehealth, and we continued to provide high-quality, evidence-based treatment for OCD and related conditions.

While continuing to offer services via telehealth, our clients have stayed connected through not only individual therapy but our ongoing groups as well.

BTC now offers a group therapy program for pre-teens and adolescents who struggle with body-focused repetitive behaviors (BFRBs), run by Sherrie Vavrichek, LCSW-C and Joseph Berliant, PsyD. The group includes a concurrent therapist-led educational and support group for parents.

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 PANDAS/PANS is suspected. This program involves a structured parenting group.

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

Contact us at info@behaviortherapycenter.com with any questions about our individual or group services.

BETTER LIVING CENTER FOR BEHAVIORAL HEALTH

1333 W McDermott, Ste 190

Allen, TX 75013

(469) 515-7504

info@betterlivingbh.org

betterlivingbh.org

Better Living Center for Behavioral Health provides day treatment, intensive outpatient, and individual therapy for OCD and anxiety disorders. Better Living Center for Behavioral Health offers in-person and telehealth services. We have adolescent and adult treatment at the day, intensive outpatient, and individual levels. Day treatment is now 9am–4pm, Monday through Friday. Intensive outpatient is offered morning (9am–12pm), afternoon (1pm–4pm), and nights (6pm–9pm). Individual sessions are based on clinician availability. We also offer group therapy for adults and adolescents. Group therapy topic varies by day of week and may include: ACT for anxiety, interpersonal skills, relapse prevention, and behavioral activation for mood regulation.

CENTER FOR ANXIETY

200 W 57th St, Ste 1008

New York, NY 10019

(646) 837-5557

info@centerforanxiety.org

centerforanxiety.org

Center for Anxiety started a virtual intensive outpatient program (IOP) that consists of a daily skills group for mindfulness, emotion regulation, and distress tolerance,

as well as weekly case management sessions. This group program is an effective supplement to exposure and response prevention treatment for individuals with OCD. This group can be done in tandem with an individual IOP or standard outpatient care. We have been able to service many patients with OCD and other co-occurring concerns. The data from the program thus far are telling: patients start out with "moderate" anxiety and "severe" depression, and end with "mild" anxiety and "moderate" depression. More importantly, 100% of our patients have experienced a decrease in symptoms over the course of the program.

We have also seen positive results from conducting virtual OCD treatment. We are able to treat patients in their own homes, and help provide support around and ultimately reduce compulsive behaviors that come up in their day-to-day lives in their own settings. OCD treatment can be provided weekly or more intensively as needed through an IOP.

THE CENTER FOR EMOTIONAL HEALTH OF GREATER PHILADELPHIA

1910 Rte 70 E, Stes 7 & 5

Cherry Hill, NJ 08003

(856) 220-9672

mail@thecenterforemotionalhealth.com

thecenterforemotionalhealth.com

601 Ewing St, Ste C-2

Princeton, NJ 08540

The Center for Emotional Health of Greater Philadelphia is delighted to welcome Hamish Gunn, PhD, Audrey Torricelli, BCBA, PsyD, and Jason Silverberg, PsyD to the CEH team as postdoctoral fellows!

Dr. Hamish Gunn joins us from the University of Massachusetts, Boston, with selected clinical experiences at Friends Hospital, Boston University Center for Anxiety and Related Disorders, McLean Hospital/Harvard Medical School, Massachusetts Mental Health Center/Harvard Medical School, and the University of Massachusetts Counseling Center.

Dr. Torricelli hails from Rutgers University, with selected clinical experiences at Friends Hospital, UPenn's COTTAGE, and NYU Langone Child Study Center's ADHD/Early Childhood Program as well as BCBA and PCIT certifications.

Dr. Jason Silverberg joins CEH from the University of Denver. He completed his internship at Terry Children's Center and has had a wide range of experience in clinical, school, and community settings, working with children and adolescents. Dr. Silverberg has advanced training in evidence-based mindfulness and acceptance-based therapies.

CEH has expanded its ability to access telehealth outpatient services via PsyPact. A number of staff psychologists have met the requirements to practice under the Authority to Practice Interjurisdictional Psychology (APIT) (15 states at present, with additional legislation in others pending).

THErapy COMMUNITY

Institutional Member Updates *(continued)*

CORNERSTONE OCD & ANXIETY GROUP

415 Railroad Ave S
Kent, WA 98032
(844) 623-9675
admin@cornerstoneOCD.com
cornerstoneOCD.com

We are happy to announce that we are fully up and running with our intensive outpatient program as of January 11, 2021. It has been going well with this online format and we're seeing good outcomes with patients so far. We have also started our second quarter of masters-level practicum/internship students. It is such a pleasure knowing these future therapists will know how to spot OCD, treat OCD, and advocate for OCD. By the time of this publication we will be able to take referrals for new IOP clients and hope to have a second iteration available for teens. We are also hiring full-time and part-time associate and fully licensed therapists, social workers, psychologists, and prescribers.

MCLEAN HOSPITAL OCD INSTITUTE

115 Mill St
Belmont, MA 01886
(617) 855-2776
ocdiadmissions@partners.org
mcleanhospital.org

The McLean Hospital OCD Institute and OCDI Jr. continues to accept in-person residential treatment for adolescents and adults on our Belmont campus. Adults are also being treated at our Houston, TX site. Partial hospital treatment is also available virtually.

McLean's OCD treatment programs continue to operate with all COVID-19 precautions in place. Despite a somewhat lower occupancy to provide for distancing, we are able to treat patients safely and effectively in our residential programs.

We are able to leverage our large group of practicum students for in-person coaching, which has led to more ERP coaching being available to all of our patients. Our treatment outcomes continue to show positive efficacy, including our virtual programs.

While we look forward to being able to have more patients being treated in person, we are constantly improving our virtual offerings and will continue to provide services in the format that allows us to treat the maximum number of patients.

Our Office of Clinical Assessment and Research (OCAR) has been able to resume some in-person work, and we look forward to the time when our entire group can be back in person.

NOCD

Nationwide
(312) 766-6780
care@NOCDHELP.COM
nocd.com

NOCD was proud to be a sponsor of the IOCDF's OCD Summer Camp for kids and families. We hope that you all enjoyed the toolkits! Also, NOCD is making improvements to the therapy tools section of the NOCD app. These tools are available to anyone and include places to store scripts and loop tapes. Further, NOCD is hiring therapists across the United States and, very soon, internationally. If you are interested in working with the NOCD Clinical Team under the direction of Dr. Patrick B. McGrath, please reach out to us at ben@nocdhelp.com.

NORTHWELL HEALTH OCD CENTER

75-59 263rd St
Zucker Hillside Hospital
Glen Oaks, NY 11004
(718) 470-8052
ocdcenter@northwell.edu
northwell.edu/ocdcenter

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.

During the COVID-19 pandemic, we have continued to conduct all services through video platforms and we have expanded our group therapy options. We currently offer seven virtual groups. These include three exposure practice and skills-building groups, a CBT group for patients with OCPD, a behavioral activation themed group for patients with OCD who are experiencing depressive symptoms, a group for patients who have graduated from individual therapy and are working towards independent maintenance of their progress amidst current stressors, and a multi-family skills group that facilitates family support without accommodation of compulsions. We are glad that amidst this ongoing pandemic, we have continued to meet the needs of our patients through teletherapy and we appreciate the ongoing support of IOCDF and its Affiliates. Please email us at ocdcenter@northwell.edu for more information or to schedule a confidential screening.

Institutional Member Updates *(continued)*

NW ANXIETY INSTITUTE

32 NE 11th Ave
Portland, OR 97232
(503) 542-7635
info@nwanxiety.com
nwanxiety.com

Beginning the new year, now immersed and more comfortable in this virtual world, NW Anxiety Institute (NWI) excitedly and successfully re-launched intensive outpatient programs (IOP) for both youth and adults. It has been a refreshing and rewarding experience, filling in that missing piece. All concerns about limitations due to the online format (such as losing clinical effectiveness) were alleviated. In fact, NWI clinicians have learned that exposure and response prevention (ERP) can be easily and effectively implemented virtually, while even providing some unique advantages!

NWI's IOP now integrates the existing intensive parent training program, which includes on-call coaching and consultation for parents of teens and young adults. The aim of blending the two programs is to offer intensive wrap-around support for the entire family, delivering content that is transparent, easily digestible, and paired with ample supportive practice outside of the therapy hours.

NWI is also grateful to Eli Lebowitz, PhD and team of the Yale Child Study Center for providing all NWI clinicians, students, and support staff a two-day intensive training on SPACE (supportive parenting for anxious childhood emotions).

It's been a whirlwind of a year, but we continue to face 2021 with renewed energy and curiosity for what's to come!

THE OCD & ANXIETY TREATMENT CENTER

1459 North Main St, Ste 100 11260 River Heights Dr
Bountiful, UT 84010 South Jordan, UT 84095
(801) 298-2000 (801) 298-2000
admissions@liveuncertain.com
theocdandanxietytreatmentcenter.com

In 2021, the OCD and Anxiety Treatment Center continues to provide evidence-based exposure therapy to children and adults suffering from obsessive compulsive spectrum disorders and anxiety-related disorders.

Our littlest clients continue to thrive as our superhero-themed "Lil' Intensive Outpatient Program" utilizes a combination of play therapy and exposure-based techniques to coach children as young as five years old through bravery challenges and worry monster battles.

In the fall of 2020, we were pleased to add two new clinical outreach coordinators to our team. This exciting addition has allowed our admissions team to bolster mental health education efforts and further develop critical partnerships with providers in the community.

In January of 2021, The OCD and Anxiety Treatment Center officially launched our trauma program. Our specialized team of expert therapists utilizes DBT-PE with highly effective prolonged exposure techniques to serve individuals suffering from trauma disorders.

We are thrilled to now be in-network with most major commercial insurance companies, as well as offer new affordable financing options in order to expand access to quality mental health services for as many individuals as possible. As the COVID-19 pandemic continues, we remain available for telehealth and socially distanced on-site appointments for our intensive outpatient and outpatient programs.

PALO ALTO THERAPY

407 Sherman Ave, Ste C 940 Saratoga Ave, Ste 240
Palo Alto, CA 94306 San Jose, CA 95129
(650) 461-9026
info@paloaltotherapy.com
paloaltotherapy.com/ocd

At Palo Alto Therapy, we specialize in cognitive behavioral therapy and have many years of experience in the field of behavioral health helping children and adults overcome anxiety, depression, OCD, panic, social anxiety and other stress-related problems.

Our newest additions: We are glad to introduce our newest members in both of our locations — therapists Nadia Lau, LMFT and Elisa Richards, AMFT, and care coordinators Emma Schmidt and Angie Muro. We are excited to have them join our ever-growing practice with their experience and backgrounds.

Parent OCD support group: This NEW group connects parents of children of all ages with OCD who are struggling with similar situations. Living with someone with OCD can be challenging, so this group helps provide strength and community for you! This group will run the last Saturday of each month via video.

We are hiring! We are hiring new therapists to create a quality team that will match the success of the incredible therapists that we already employ. If you happen to be, or know of any good candidates, please send them our way!

For more information on our individual, couples, family, and group or video therapy, please feel free to contact us.

RENEWED FREEDOM CENTER FOR RAPID ANXIETY RELIEF

1849 Sawtelle Blvd, Ste 710
Los Angeles, CA 90025
(310) 268-1888
info@renewedfreedomcenter.com
renewedfreedomcenter.com

Renewed Freedom Center is currently accepting in-person IOP patients while remaining available via telehealth and in person for weekly outpatient treatment.

THERAPY COMMUNITY

Institutional Member Updates *(continued)*

We are excited to announce our new skills-building and peer support group for young adults trying to juggle OCD and anxiety while making the transition into adulthood. This group provides a safe place for participants to connect with their peers while building skills needed to successfully and confidently make the transition in/out of college, into the workforce, and gain financial and social independence. The virtual group meets bi-monthly on Mondays from 4:45pm–6pm (PST).

To inquire about services and groups, please contact us at (310) 268-1888 or at info@renewedfreedomcenter.com.

ROGERS BEHAVIORAL HEALTH

34700 Valley Rd
Oconomowoc, WI 53066
(800) 767-4411

rick.ramsay@rogersbh.org
rogersbh.org

Rogers Behavioral Health's newest clinic, located in the Seattle area, offers partial hospitalization care for children, adolescents, and adults for OCD and anxiety.

This summer Rogers also plans to open its Sheboygan, Wisconsin outpatient clinic and first-ever supportive living environment. The clinic is currently accepting patients for virtual treatment through Rogers Connect Care.

This summer, Rogers will open the Ladish Co. Foundation Center. Located on its Oconomowoc campus, the Ladish Center will serve as a resource for patients and their families, and it will house the Rogers Behavioral Health Foundation and Rogers Research Center.

During the COVID-19 pandemic, Rogers has offered free webinars on a variety of topics. In 2020, Rogers hosted presentations on recent empirical findings and clinical applications as well as another on treating patients with moderate to severe symptoms of OCD that may require a higher level of care.

Rogers kicked off its 2021 free webinar series with "Workplace anxiety during a pandemic" in late January, offering the opportunity to earn CE credits. The webinar was presented by Jerry Halverson, MD, FACP, DFAPA, chief medical officer; and Brenda Bailey, PhD, clinical supervisor. Recordings of each webinar are available at rogersbh.org/resources.

STANFORD TRANSLATIONAL OCD PROGRAM

— RODRIGUEZ LAB

401 Quarry Rd
Stanford, CA 94305
(650) 723-4095

ocdresearch@stanford.edu
rodriguezlab.stanford.edu

The Stanford Translational OCD program utilizes an interdisciplinary approach to find new treatments for patients

suffering from OCD and hoarding disorder. We invite you to find out more about our current research studies by calling or emailing. We also invite you to follow us on Twitter and Facebook @RodriguezLabSU.

We are delighted to welcome Idalia Lopez-Martinez to our lab as a research assistant. She was selected to be a part of the new Neuroscience Research Opportunity (NeURO) program through the Wu Tsai Neurosciences Institute at Stanford.

Warm wishes to our former postdoctoral fellow Hannah Raila, who recently began her new position as an assistant teaching professor in the Department of Psychology at UC Santa Cruz and has launched the Emotion, Cognition & Psychopathology Lab there.

UNIVERSITY OF SOUTH FLORIDA ROTHMAN CENTER

601 7th St S, Ste 425
University of South Florida Rothman Center
St. Petersburg, FL 33701
(727) 767-8230


rothmanctr@usf.edu
health.usf.edu/medicine/pediatrics/rothman

The USF Rothman Center is offering telehealth therapy and physician services statewide due to the pandemic. This includes the CBT with ERP program. In addition to OCD, patients with tics seeking CBIT, and those with anxiety, hair pulling, misophonia, PANS/PANDAS, and related problems are welcome to call for a personalized telephone intake.

YALE OCD RESEARCH CLINIC

34 Park St CMHC, 3rd Flr CNRU
New Haven, CT 06519
(203) 974-7523

OCD.Research@yale.edu
ocd.yale.edu

The Yale OCD Research Clinic has a long history of research advances in the understanding and treatment of OCD, including demonstrating the efficacy of medications that are now considered standard treatments for OCD — SSRIs and neuroleptics. The research site fosters clinical investigations into OCD in the hope that we can help expand our knowledge and provide new treatment options for patients, especially those for whom symptoms are refractory to proven psychological and pharmacological approaches. In recent years we have investigated a new class of medications, glutamate-modulating agents, in the hope that they will provide new treatment options for those whose symptoms are refractory to proven psychological and pharmacological approaches. Funded by the National Institute of Health, other organizations, and donations, our research continues this tradition, as we seek to better understand the brain processes that have gone awry in OCD, and to use this knowledge to ultimately develop new treatments. Please visit ocd.yale.edu for more information or call toll free 1-855-OCD-YALE. 

Expressive Arts Therapy in OCD Treatment: An Introduction

by Kathryn Keniston, MA, LMHC, R-DMT



I first started working with individuals seeking OCD treatment at McLean Hospital's OCD Institute as a graduate student in an Expressive Arts Therapy (EAT) program with Lesley University. A lifelong dancer, I was interested in incorporating movement and other art forms with supporting people struggling with their mental health. From there, I discovered EAT.

EAT uses creative approaches to externalize internal experiences beyond what a participant may be able to verbalize. Modalities include art, music, theater, writing and dance/movement therapy. While this can sound intimidating, it is important to keep in mind you do not need to be a classically trained artist in order to access the benefits of a creative supplement to therapy.

Traditionally, EAT focuses on the process and analyzing what comes up in a way that could be counterintuitive for OCD treatment. When using EAT with OCD treatment, a more behavioral or acceptance and commitment therapy (ACT) informed approach is taken. Keeping this in mind, EAT can support OCD treatment and work with people looking to reclaim a sense of empowerment and autonomy in their lives.

Max Roberts received his MA in clinical mental health counseling with a specialization in art therapy from Lesley University. Max has utilized EAT in a group setting at McLean

Hospital's OCD Institute. "You discover creativity in people, and they rediscover it in themselves," Roberts states. Roberts also believes that incorporating EAT can add a focus of humanity to the treatment. This is important because we know there are difficulties with some individuals in terms of engaging them in the behavior therapy treatment and keeping them compliant with their treatment plan.

Engaging in an EAT session, both individually and in a group, can be an exposure in itself for multiple reasons. EAT can use a different approach to mindfulness and ACT practices in order to increase cognitive flexibility that can carry throughout treatment. Depending on the experiential, the arts materials used might tie in to an individual's struggles with contamination, an acting activity can target social anxiety, or it may be a more general practice in willingness to participate in something new and uncomfortable. Roberts highlights that there is an element of the unknown when entering an EAT group and the opportunity to challenge uncertainty.

Dede Booth, LMHC, REAT works as a coordinator of group therapy at McLean Hospital's OCD Institute. She highlights the primary EAT component of externalizing internal experiences when leading EAT groups and utilizing this approach as a supplement to individual exposure sessions. One experiential in particular involves an individual creating a clay model of their brain incorporating their intrusive thoughts. An imaginal dialogue can then be created as a way to talk to their OCD without interpreting what their thoughts mean. This dialogue can incorporate "thought

Therapy Community

Expressive Arts Therapy in OCD Treatment: An Introduction *(continued)*

defusion,” a treatment strategy in ACT that helps the individual create distance from their intrusive thoughts and overwhelming distress.

Booth and Roberts encourage using EAT through an ACT lens, often using thought defusion. This can include an arts-based approach like taking a thought and creating space from it using a poem. The thought is still there, but it doesn't have to exist as the only part of what a person can hold in their mind and focus.

The most memorable experiences for me have been working to reconnect individuals with their values and a part of themselves they may have lost touch with. For many, art, music or dance were an interest that struggles with OCD took away. I remember working with one person in particular who had a background in dance, and because of their struggles with OCD, being connected with their body and movement was challenging. Using a dance/movement therapy approach wasn't about jumping into a kick line. It was a slower start in utilizing mindfulness practices to reconnect physically through deep breathing, guided meditation and moving through imagery that would come up throughout. These movements could be small gestures or walking in space. It did not need to be a return to ballet technique — rather, it was an opportunity for self-exploration.

When working as a group, members can learn more about each other through arts-based experientials. Roberts would often hold open studio sessions where participants could create something meaningful for them. This would often spark conversations between group members and foster deeper connections with each other as well as for the individual. “It helped to foster relationships faster than I think would happen otherwise,” Roberts states.

In both my and the experiences of the expressive arts therapists I spoke with, varied responses are common. Some look forward to utilizing the arts and for others resistance to trying out this approach comes up. Some individuals we've

worked with felt it erred on the infantile side to incorporate drawing, playing instruments and acting role plays to their treatment. Booth encourages honesty in how uncomfortable of an approach it can be. “Validate the cynicism,” she states. “Normalize that this is a wonky type of therapy.”

As a facilitator it is important to cultivate an environment for individuals to push themselves beyond their comfort zone, much like more traditional exposures. It is also important to keep in mind that a limitation of EAT is that it is often very broad in terms of directive and materials used that may not always be helpful. This can be tweaked to give some more set guidelines. As Booth states, “It's really important to verbally get across the WHY.” With an EAT approach she finds it can be more challenging for individuals to connect the dots on their own with WHY a certain arts-based approach is taken.

Roberts reports that many whom he worked with would surprise themselves in their willingness and ability to find something helpful in the groups. It is also helpful to see peers engaging in a group setting and can support reducing stigma or feeling childish using EAT. “It has a lot of similarity to exposure in that you just have to try and see,” he states.

For anyone considering EAT as an approach to try, it is important to look for expressive arts therapists who understand OCD and OCD treatment in order to utilize these creative approaches in a way that can be helpful. As previously stated, EAT is oftentimes heavier in processing thoughts that come up in a way that is not beneficial for OCD treatment. An expressive arts therapist who has knowledge and experience in OCD treatment can foster a group or individual directive that supports people in reconnecting with their values. 🌱

Do You Want Your Article Featured in the OCD Newsletter?

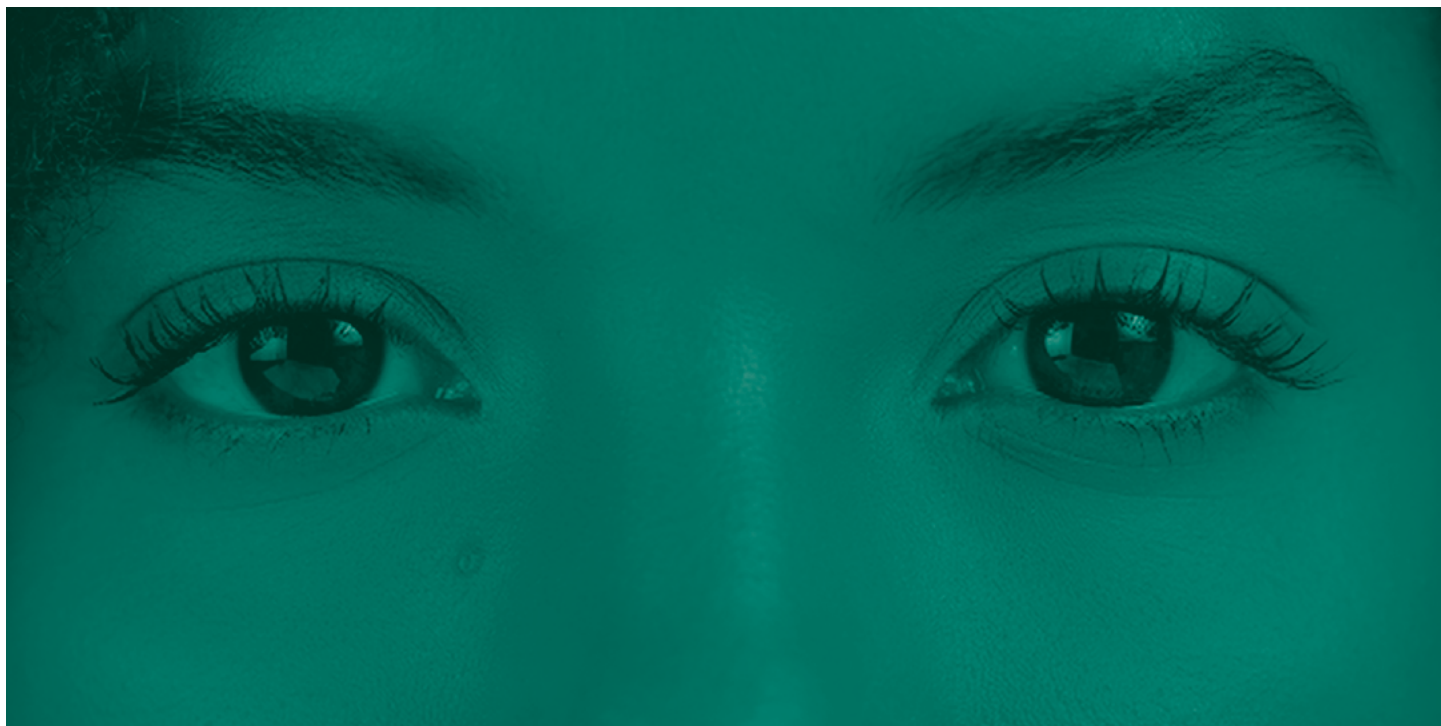
The IOCDF is accepting personal stories, poems, therapy and research article submissions for upcoming Newsletter editions.

Submissions can be sent to editor@iocdf.org.



Ocular Tourettic OCD

by Dr. Jonathan Grayson and Melissa Price



Ocular Tourettic OCD (formerly known as OCD Staring) is a form of OCD where sufferers repeatedly stare at objects in the periphery of their vision or at socially inappropriate parts of other people's bodies. They may find that they are unable to look away even though they want to, and may ruminate about potentially negative social results of staring.

Ocular Tourettic OCD (OTO) has received little attention from researchers and clinicians, and not much is known about it. Dr. Jonathan Grayson and Melissa S. Price hope to change that. We are sharing a short survey that Melissa created for sufferers of OTO that asks about their experiences with this form of OCD, and the therapies and medications that they have tried.

MORE ABOUT OTO

Some people with OTO are hyper aware of people in the periphery of their vision. Another group fears that they are staring at people inappropriately, including repetitively looking at people's "private" areas in a way that feels out of their control. A subset believes that they are staring at others, but they are not actually staring. Another group does stare, and their behavior is recognized by others.

As OTO takes hold, many sufferers will begin to avoid all social situations, losing employment opportunities and cutting off

contact with friends and family members. Some sufferers are fired from their jobs, or ostracized in their communities. In extreme cases, they become reclusive or suicidal.

There is virtually no research on OTO and very little information available about treatment. OTO may be a widespread condition, but sufferers are unwilling to discuss it — even with their therapists.

Hopefully, armed with more facts, therapists and doctors will become interested in researching OTO and developing new avenues of therapy.

COMPLETE THE SURVEY

The survey is completely ANONYMOUS. Melissa and Dr. Grayson will not be gathering any identifying information, and emails will not be collected with responses. The survey is made with Google Forms, so respondents can check the official privacy policy if they have concerns.

Take the survey at: iocdf.org/staringsurvey. ©

To learn more about OTO, see Melissa's blog at melissasprice.com or email her at eyeshaveit.blog@gmail.com.

Dr. Jonathan Grayson's website is laocdtreatment.com.

RESEARCH NEWS

Harnessing Virtual Reality Technology to Assess Interpretation Biases in BDD

by Berta J. Summers, PhD



Many people have probably had a strange experience where they wondered whether someone they didn't know was looking at them in a negative way, or if two people whispering and laughing in public might actually be talking about them. For people with body dysmorphic disorder (BDD), these experiences aren't rare. In fact, they happen frequently, and are a core part of how the disorder affects their relationships and daily activities.

In BDD, people are “biased” in their interpretations of social cues, meaning that they are more likely to come to certain conclusions about a social interaction, even if there is no evidence to support how they feel about it. **To people with BDD, even ambiguous social interactions — those that don't carry clear meanings or are open to multiple interpretations — are often perceived as negative, threatening, or rejecting** (Buhlmann, McNally, et al., 2002; Buhlmann, Wilhelm, et al., 2002a). These interactions can be as simple as a comment, a neutral facial expression, or a glance from a stranger.

Researchers have focused on these patterns of thinking, called “interpretation biases,” because of their impact on the well-being of people with BDD. People with BDD are preoccupied with flaws that they perceive in their physical appearance and engage in time-consuming rituals meant to check, fix, or hide areas of concern. They find “evidence” for their interpretations of social interactions in the flaws that they perceive in their skin, hair, face, or other features, concluding that these flaws are the reason for the negative reactions they are receiving from friends, coworkers, and strangers. This not only creates distress and discomfort in the moment, but causes lasting

harm to people with BDD by reinforcing ideas about distorted self-image and social undesirability. **In fact, researchers believe that interpretation biases fuel BDD symptoms and keep them going after the disorder first sets in, making these thought patterns an important target for treatment and continued research** (Buhlmann et al., 2006; Buhlmann et al., 2011; Buhlmann et al., 2013).

One of the challenges we face in studying interpretation biases is finding ways to test for them or measure how strong they are. It's not practical to follow patients or research participants around in public and ask them questions about what they are thinking and feeling. Even if we could, no two social situations would be exactly the same, so we wouldn't be able to compare how different people or groups of people reacted. Instead, we ask patients or research participants to recall how they felt and behaved in experiences they've had in the past, or to imagine how they would react if they were in a fictional (but realistic) social situation that we describe to them. These approaches have helped us learn about interpretation biases in BDD, but they are removed from real-world social situations, and they rely upon the accuracy of a patient or research participant's memory or imagination. **Until now, we have not had a good way to study interpretation biases in the moment, as they happen.** Virtual reality (VR) technology has created an exciting new opportunity for us to study interpretation biases in real time, in a manner that doesn't rely on memory or imagination.

VR provides an immersive, 3D virtual environment with human-computer interaction that can simulate real-world situations that trigger disorder-specific symptoms (e.g., anxiety, distress, paranoia, or cravings). VR has been used to assess, research, and treat psychiatric conditions like anxiety, post-traumatic stress disorder, psychosis, and substance-use disorders (Freeman et al., 2017; Meyerbröker & Emmelkamp,

Harnessing Virtual Reality Technology to Assess Interpretation Biases in BDD *(continued)*

2010; Powers & Emmelkamp, 2008). An advantage of VR is that individuals are more willing to enter into a VR environment simulating a difficult situation than a real-life difficult situation, as they understand that a computer environment is “safe.” However, the individual’s mind and body behave as if the environment is real (Powers & Emmelkamp, 2008), which affords a unique opportunity to pinpoint and study how various environments affect the ways we think and feel. VR has the potential to overcome the challenges associated with studying interpretation biases, and in the long term, to improve existing treatment approaches for BDD.

Our research team at the OCD and Related Disorders Program at Massachusetts General Hospital/Harvard Medical School, with funding support from the IOCDF, recently completed a study where we developed a new way of triggering and measuring interpretation biases in BDD using VR (Summers *et al.*, 2021). We recruited 25 people with BDD to take part in the study, as well as 25 healthy individuals to serve as a comparison group. Participants completed a series of questionnaires designed to detect and confirm whether they had any mental health disorders, and two additional questionnaires that measured their interpretation biases (the IQ, and the BDD-WSAP). **They also completed a brand new, 30-minute test that we developed to measure their interpretation biases using VR.**

The VR test involved 13 brief scenes that included different types of social interactions and experiences. The scenes were scripted by the study team and recorded using a 360-degree camera to film the scene from the participant’s point of view. They depicted a variety of everyday situations, including scenes that took place in a work meeting, a convenience store, an elevator, a waiting area, a mailroom, a street, and a bar. Importantly, the scenes were designed to include social interactions with unclear meanings that the participant would need to interpret. Examples included a coworker who comments on a change in the participant’s appearance, a stranger who does a double-take looking in the participant’s direction, and an individual who sits close to the participant in a waiting area and looks angry and upset for an unexplained reason.

Following each of the 13 scenes, participants were shown two different possible explanations for the parts of the social interaction that were open to interpretation. For example, one scene set at a train station shows a man passing the participant who does a double-take in the participant’s direction. After watching this scene, participants were shown a neutral/healthy explanation (“the man walking by thought he recognized me”) and a negative/appearance-related explanation (“the man walking by was evaluating my

Past research has discovered some basic patterns in how people with BDD interpret social cues and interactions:

- People with BDD commonly misinterpret facial expressions, and tend to misinterpret neutral facial expressions as being angry, disapproving, or expressing a strong feeling of dislike aimed at them (Buhlmann *et al.*, 2006)
- They tend to relate ambiguous social situations to themselves or engage in “mind reading” (e.g., “those two strangers must have been talking about me” or “that angry-looking person in the train station was angry at me”)
- They are more likely to incorrectly interpret interactions in terms of their own appearance (e.g., “they are acting that way because of how I look,” or “they are judging me based on my appearance”) (Phillips, 2009)
- They are more likely to interpret events and experiences as threatening than healthy individuals and people with OCD (Buhlmann, Wilhelm, *et al.*, 2002a)

appearance”). Each participant was then asked to rate the likelihood of that thought coming to mind for them during the scene (0 “not at all”–10 “extremely”). Participants also rated their level of discomfort during the scene (i.e., distress, fear, perceived threat, urge to check their appearance, urge to avoid the situation; scale 0–10).

People with BDD responded in ways that showed they had greater threat interpretation biases (they were more likely to see the interactions depicted in the scenes as threatening) and higher discomfort ratings compared to healthy individuals who took the same VR test. Participants’ interpretations of the VR scenes and their levels of discomfort during them aligned with how they answered the older, non-VR questionnaires about interpretation bias (IQ & BDD-WSAP). **This pattern gives us early evidence that the VR test is able to do what we designed it to do — accurately measure interpretation biases in BDD.** We also found that the differences in interpretation bias and discomfort between the BDD and healthy groups were large, which points to the strong effect that BDD can have on how an individual interprets ambiguous social situations, and how different this experience can be from that of a healthy individual.


Importantly, participants thought that the VR experience was acceptable, engaging, realistic, similar to experiences they’ve encountered, and indicated they felt a sense of “presence”

RESEARCH NEWS

Harnessing Virtual Reality Technology to Assess Interpretation Biases in BDD *(continued)*

in the virtual environment. **This feedback, together with the results that show interpretation bias in BDD can be triggered and measured using VR, point to the promise of this technology for studying and even treating unhealthy interpretation biases in BDD.** The inherent advantages of using VR to simulate social situations in real time, rather than asking participants to recall past experiences or imagine themselves in fictional social situations, bring us closer than ever to being able to recreate and study these experiences as they happen in real life.

This study represents a first step in the long-term goal of using VR technology to improve existing treatment approaches for BDD. Recent studies have examined techniques for correcting unhealthy interpretation biases in BDD by training patients to have healthier interpretations of ambiguous social cues and interactions (Buhlmann et al., 2011; Dietel et al., 2018; Premo et al., 2016; Summers & Cogle, 2016). Patients use a computer during these training sessions, but don't use VR to simulate real life experiences. Treatment research in people with other mental health disorders indicates that VR-enhanced treatments can help patients make significant behavior changes in real-life situations (Morina et al., 2015), so we think that adding VR to existing BDD treatments could be helpful as well.

The next step that naturally follows from this work will be to build VR into computer-based treatments that are intended to address and change unhealthy interpretation biases in BDD (e.g., *Interpretation Bias Modification, or IBM; Summers & Cogle, 2016*). **With VR, patients could practice overriding their bias toward seeing situations as threatening (e.g., fear of negative evaluation, rejection sensitivity) in a realistic, personalized environment.** While traditional IBM helps train thinking with the aid of an interactive computer program, virtually placing patients in realistic scenarios has the potential to add a behavioral element to this therapy. VR-enhanced IBM could also help patients learn that their fears about social situations are not realistic and are unlikely to come true. In this way, a VR-enhanced IBM program could teach skills that apply to many different types of situations patients will encounter in daily life, and even achieve a broader reduction in symptoms than traditional IBM. Additional studies are needed to test these hypotheses and pinpoint exactly how interpretation training reduces BDD symptoms so that it can be made more effective. We plan to continue to develop this line of research in the coming years. 

Berta J. Summers, PhD is an assistant professor in the Department of Psychology at the University of North Carolina Wilmington and affiliated with the OCD and Related Disorders Program at Massachusetts General Hospital.

REFERENCES

- Buhlmann, U., Etcoff, N. L., & Wilhelm, S. (2006). Emotion recognition bias for contempt and anger in body dysmorphic disorder. *Journal of Psychiatric Research, 40*(2), 105-111. <https://doi.org/http://dx.doi.org/10.1016/j.jpsychires.2005.03.006>
- Buhlmann, U., GleiB, M. J. L., Rumpf, L., Zschenderlein, K., & Kathmann, N. (2011). Modifying emotion recognition deficits in body dysmorphic disorder: An experimental investigation. *Depression and Anxiety, 28*(10), 924-931. <https://doi.org/http://dx.doi.org/10.1002/da.20887>
- Buhlmann, U., McNally, R. J., Wilhelm, S., & Florin, I. (2002). Selective processing of emotional information in body dysmorphic disorder. *Journal of Anxiety Disorders, 16*(3), 289-298. [https://doi.org/http://dx.doi.org/10.1016/S0887-6185\(02\)00100-7](https://doi.org/http://dx.doi.org/10.1016/S0887-6185(02)00100-7)
- Buhlmann, U., Wilhelm, S., McNally, R. J., Tuschen-Caffier, B., Baer, L., & Jenike, M. A. (2002a). Interpretive biases for ambiguous information in body dysmorphic disorder. *CNS Spectrums, 7*(6), 435-436, 441-443. <https://doi.org/http://dx.doi.org/10.1016/j.psychres.2013.12.030>
- Buhlmann, U., Wilhelm, S., McNally, R. J., Tuschen-Caffier, B., Baer, L., & Jenike, M. A. (2002b). Interpretive Biases for Ambiguous Information in Body Dysmorphic Disorder. *CNS Spectrums, 7*(6), 435-443. <https://doi.org/http://dx.doi.org/10.1017/S1092852900017946>
- Buhlmann, U., Winter, A., & Kathmann, N. (2013). Emotion recognition in body dysmorphic disorder: Application of the reading the mind in the eyes task. 8 247-250. <https://doi.org/http://dx.doi.org/10.1016/j.bodyim.2012.12.001>
- Clerkin, E. M., & Teachman, B. A. (2008). Perceptual and cognitive biases in individuals with body dysmorphic disorder symptoms. *Cognition and Emotion, 22*(7), 1327-1339. <https://doi.org/http://dx.doi.org/10.1080/02699930701766099>
- Dietel, F. A., Möbius, M., Steinbach, L., Dusen, C., Wilhelm, S., & Buhlmann, U. (2018). Effects of induced appearance-related interpretation bias: A test of the cognitive-behavioral model of body dysmorphic disorder. *Journal of Behavior Therapy and Experimental Psychiatry, 61*, 180-187. <https://doi.org/http://dx.doi.org/10.1016/j.jbtep.2018.07.003>
- Freeman, D., Reeve, S., Robinson, A., Ehlers, A., Clark, D., Spanlang, B., & Slater, M. (2017). Virtual reality in the assessment, understanding, and treatment of mental health disorders. *Psychological Medicine, 47*(14), 2393-2400. <https://doi.org/10.1017/S003329171700040X>
- Marques, L., LeBlanc, N., Robinaugh, D., Weingarden, H., Keshaviah, A., & Wilhelm, S. (2011). Correlates of quality of life and functional disability in individuals with body dysmorphic disorder. *Psychosomatics, 52*(3), 245-254. <https://doi.org/http://dx.doi.org/10.1016/j.psychsym.2010.12.015>
- Meyerbröker, K., & Emmelkamp, P. M. G. (2010). Virtual reality exposure therapy in anxiety disorders: a systematic review of process-and-outcome studies. *Depression and Anxiety, 27*(10), 933-944. <https://doi.org/10.1002/da.20734>
- Morina, N., Ijntema, H., Meyerbröker, K., & Emmelkamp, P. M. (2015). Can virtual reality exposure therapy gains be generalized to real-life? A meta-analysis of studies applying behavioral assessments. *Behav Res Ther, 74*, 18-24. <https://doi.org/10.1016/j.brat.2015.08.010>
- Phillips, K. A. (2007). Suicidality in body dysmorphic disorder. *Primary Psychiatry, 14*(12), 58-66. <https://doi.org/http://dx.doi.org/10.1176/appi.ajp.163.7.1280>
- Phillips, K. A. (2009). Understanding body dysmorphic disorder. Oxford University Press.

Harnessing Virtual Reality Technology to Assess Interpretation Biases in BDD *(continued)*

Phillips, K. A., Menard, W., Fay, C., & Pagano, M. E. (2005). Psychosocial functioning and quality of life in body dysmorphic disorder. *Comprehensive Psychiatry*, 46(4), 254-260. <https://doi.org/http://dx.doi.org/10.1016/j.comppsy.2004.10.004>

Phillips, K. A., Menard, W., Quinn, E., Didie, E. R., & Stout, R. L. (2013). A 4-year prospective observational follow-up study of course and predictors of course in body dysmorphic disorder. *Psychological Medicine*, 43(5), 1109-1117. <https://doi.org/http://dx.doi.org/10.1017/S0033291712001730>

Phillips, K. A., Quinn, G., & Stout, R. L. (2008). Functional impairment in body dysmorphic disorder: A prospective, follow-up study. *Journal of Psychiatric Research*, 42(9), 701-707. <https://doi.org/http://dx.doi.org/10.1016/j.jpsychires.2007.07.010>

Powers, M. B., & Emmelkamp, P. M. G. (2008). Virtual reality exposure therapy for anxiety disorders: A meta-analysis. *Journal of Anxiety Disorders*, 22(3), 561-569. <https://doi.org/https://doi.org/10.1016/j.janxdis.2007.04.006>

Premo, J. E., Sarfan, L. D., & Clerkin, E. M. (2016). Training interpretation biases among individuals with body dysmorphic disorder symptoms. *Body Image*, 16, 54-62. <https://doi.org/http://dx.doi.org/10.1016/j.bodyim.2015.11.004>

Summers, B. J., & Cogle, J. R. (2016). Modifying interpretation biases in body dysmorphic disorder: Evaluation of a brief computerized treatment. *Behaviour Research and Therapy*, 87, 117-127. <https://doi.org/http://dx.doi.org/10.1016/j.brat.2016.09.005>

Summers, B. J., Schwartzberg, A. C., & Wilhelm, S. (2021). A virtual reality study of cognitive biases in body dysmorphic disorder. *J Abnorm Psychol*, 130(1), 26-33. <https://doi.org/10.1037/abn0000563>

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.

Study for Pregnant Women

Are you in your first or second trimester of pregnancy? You may qualify for a research study on OCD during pregnancy and after having your baby. The study will take place entirely remotely and there will be no need for any in-person study visits.

Participants will be asked to do the following:

- During your second trimester (around 20 weeks of pregnancy), we will ask you some questions about your mental health, your general functioning, and we will provide materials for you to send us biological samples (such as saliva).
- At about 34 weeks of pregnancy, and twice after your baby is born (six weeks and six months) we will send you questionnaires to complete online and call you for a telephone interview that will last less than 30 minutes. We will also provide materials for you to send us biological samples.

You can still participate even if you are not experiencing anxiety or depression.

You will receive \$250 compensation for completing the full study.

If you are interested and live either in the Baltimore (Maryland) area or Raleigh-Durham (North Carolina) area, visit go.unc.edu/mom2be to take a survey to see if you are eligible to participate.

Please email us at mom2be@unc.edu with any questions or concerns.

“Effects of Symptom Change on Cognitive Flexibility in Obsessive-Compulsive Disorder: An Evaluation of the Executive Overload Model” Protocol CHP19-200

Purpose: The purpose of this study is to learn how stress or symptoms influences our ability to think.

Who: Participation is voluntary and you must be 18 years or older to participate, be able to read and understand English, and be diagnosed with at least one of the following diagnoses: obsessive compulsive disorder, a mood disorder such as major depressive disorder, or an anxiety disorder such as generalized anxiety disorder, panic disorder, social anxiety disorder, or a diagnosed phobia. Participants must be willing to download a program called “TeamViewer” to participate.

Time commitment: Participation includes several surveys, four computer tests, and observing photos of everyday objects which is estimated to take up to 1 hour.

Compensation: Participants will receive \$10 compensation for their participation.

If you are interested in participating, please contact us and leave a message with how you would like us to return your message at CalamariResearchLab@gmail.com or call us at (847) 231-2346.

If you have any questions about your rights when participating in a research study, please contact the Rosalind Franklin University IRB office at (847) 578-8713.

Continued on next page>>

RESEARCH NEWS

Research Participants Sought *(continued)***Play Entertaining Smartphone Games and Help Understand the Brain Mechanisms Underlying OCD**

Why does OCD so often arise during adolescence? And which brain processes are critical for OCD? Help us answer these important questions by playing the Brain Explorer app.

What is this app? Brain Explorer is an app for your smartphone and tablet with entertaining games exploring outer space. Play the games and fill out questionnaires to help us understand how the brain works and how it is linked to mood and behavior. Brain Explorer is a Citizen Science project, and everyone who plays the games (young and old; affected by OCD or not) can help us better understand the brain processes involved in OCD.

With the Brain Explorer App (brainexplorer.net), everybody can contribute to OCD research by playing entertaining games on their smartphone —and win medals!

Who are we? We are neuroscientists from University College London (UCL). We are particularly interested in why so many mental health problems begin in childhood and adolescence, and how this is related to brain and cognitive development. For more information about the research group, please see devcompsy.org.

How does it work? Simply go to the links below and download the app on your phone or tablet. Once installed, simply click on the app and start your adventures in outer space!

Please download the app now and share it with your friends and family!

Website: brainexplorer.net

Android: bit.ly/BrainExpl

Apple: bit.ly/BrainExpiOS

Category Learning, Ageing, and Hoarding Symptoms

Would you be willing to participate in a research study?

The study is intended to help better understand why some people have significant difficulty organizing their things. Sometimes this difficulty can lead to problems with hoarding. The study is being conducted by a researcher at Rosalind Franklin University of Medicine and Science's Psychology Department. The study is titled Category Learning, Ageing, and Hoarding Symptoms.

You are invited to participate in a research study. Taking part in this research project is voluntary. In order to participate in this research study, you must be 18 years or older and be able to read and understand English. Additionally, to

participate in the study you must experience significant problems with the hoarding of possessions, or experience the symptoms of obsessive compulsive disorder, or have an anxiety condition. If you choose to participate, you will be asked to 1) fill out surveys, 2) complete a computer test that evaluates people's abilities to organize and categorize things, and 3) answer questions about symptoms you may or may not experience. The whole study will take approximately 65 minutes. You will also need to be willing and able to download the "TeamViewer" application to your personal computer to participate from home. A researcher will help you download and remove the application from your computer. You will be compensated \$10 for participation in the study. Compensation can be delivered through email or mail.

If you might be interested in participating, please inform a clinical staff member in your program. You may also obtain more information about the study by calling (708) 247-5947 or by emailing adam.mathy@my.rfums.org.

Seeking Volunteers for a Study on Risk Factors for Obsessive-Compulsive Disorder

Do you suffer from OCD? Researchers at Kent State University have a new study aiming to better understand factors that influence an individual's susceptibility to the disease. OCD is a complex disorder with many underlying causes and risk factors, and these factors might be accentuated during the current global pandemic (COVID-19). With your help, we hope to develop a better understanding of these causes and risk factors and how they manifest during stressful times to improve available treatments to better help others in the future. The study consists of a 45-minute online survey that asks about emotional experiences, common types of recurring thoughts/obsessions, and experiences in romantic relationships. This study has been approved by Kent State University's Institutional Review Board.

Eligibility:

1. You must be 18 years or older.
2. You must have a current diagnosis of OCD.

Benefits:

While there is no direct benefit to you, your participation in this research will provide important information that may help individuals in the future who suffer from similar experiences.

Research Participants Sought *(continued)*

If you are interested in participating, you may visit kent.qualtrics.com/jfe/form/SV_3rPkXSSMLDut8Nv. That URL will take you directly to the informed consent form, and then to the survey. For more information, please email Ben Mitchell at bmitch27@kent.edu.

Study for OCD Treatment Providers

Hello Mental Health Providers:

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 neurosurgical procedures represent one treatment modality that is open to such patients. We are seeking to gain a better understanding of providers' knowledge of and attitudes toward psychiatric neurosurgery for OCD so that we can understand referral patterns and awareness about this treatment option for intractable 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: redcap.carene.org/surveys/?s=WYRCHYAWK9

Study on Late-Life OCD

Are you 65 years or older and experiencing symptoms of obsessive compulsive disorder (OCD), such as intrusive thoughts that make you uncomfortable or feeling the need to repeat certain behaviors to feel better?

The centre for emotional health at Macquarie University is conducting research on late-life OCD to understand the experience of people with OCD and the impact on their families and friends, in order to develop better treatments.

Participation will take around 2.5 hours and involve completing some questionnaires and an interview over the phone or videoconference. You will be paid \$30 via a virtual gift card for your time.

For more information, please contact Dr. Ron Smith at ron.smith@mq.edu.au.



IOCDF Merch!
shop.iocdf.org

FROM THE AFFILIATES

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 ARIZONA

ocdarizona.org

OCD Arizona would like to thank everyone for their patience in 2020 in establishing the Affiliate. We are so grateful to those who have reached out expressing interest in being a part of OCD Arizona. We are in the final stages of establishment and will be looking for the support from our community in Arizona soon!

OCD CENTRAL & SOUTH FLORIDA

ocdcsfl.org

Affiliate leaders were excited to participate in the IOCDF's Online OCD Camp, which was held virtually on 1/30–1/31/2021 and was geared towards youth with OCD and their families. We also held a contest to sponsor five kids/families for this event. OCDCSFL has hosted several virtual events over the recent months. Recordings of all these events are available on our website if you missed them! Currently, OCDCSFL is busy planning events to be held throughout 2021.

Given that our Affiliate spans a large region, a current goal for OCDCSFL is to build a base of volunteers to help with our cause. This might involve helping to host events in your area, presenting on a relevant topic, or working with us behind the scenes. If you are interested in getting involved, please email us at info@ocdcsfl.org.

Check out ocdcsfl.org for information about our events, and to learn more about OCD Central & South Florida. You can also find us on Facebook @OCDCSFL. Contact us at info@ocdcsfl.org if you have any questions!

OCD JACKSONVILLE

ocdjacksonville.com

OCD Jacksonville brought a few exciting initiatives to fruition at the end of 2020. We were scheduled to host a BTTI in December but it was postponed due to COVID restrictions. Knowing it would be another year before we could train clinicians via BTTI, we looked to other options to familiarize area clinicians with ERP. OCD Jacksonville offered scholarships to The ERP School (Kimberley Quinlin's online course). We provided a total of 18 scholarships, 14 to clinicians and four to individuals

with OCD. We also provided five copies of Edna Foa's Exposure Response Prevention for Therapists and five copies of Bruce Heyman's OCD Workbook to the staff at the Sulzbacher Center. Our most joyful accomplishment was the establishment of an endowment, The OCD Jacksonville Innovation Fund, at the University of Florida. This fund will support programming for the Center for OCD, Anxiety and Related Disorders (COARD). We were also honored to pledge annual support for Fear Facers Camp, an annual two-week event for children with OCD and anxiety disorders. We will be traveling to Gainesville in March for a formal announcement!

Our team has been moved by the racial and cultural inequities in the treatment of OCD and related disorders. OCD Jacksonville was able to establish a Minority Mental Health initiative with the IOCDF by making a donation towards specific minority research, and a fund that will help establish protocols for the treatment of minority populations. To launch this project, we will be working with the IOCDF to create a scrupulosity event this spring. We hope all the Affiliates will get involved and be part of the event. Watch for further information on IOCDF and OCD Jacksonville social media, and in email communications. Our website was recently updated and we invite you to log in to see updates in programming!

OCD LOUISIANA

ocdlouisiana.org

OCD Louisiana is pleased to announce that Caitlin Bussey, Chance McNeely, Ashley Rush, and Ashley Talley will be joining Michele Carroll and Kristin Fitch on the board of directors. The addition of our new members brings renewed energy and new ideas to the Affiliate. We continue to offer our virtual consultation group for professionals treating OCD and related disorders. More information can be found on our website. If you are interested in becoming involved in any of our activities this year, please complete our brief survey at forms.gle/7MAEGDS4RJhn5nJB9.

Affiliate Updates *(continued)*

OCD NEW JERSEY

ocdnj.org

OCD New Jersey welcomes 2021, looking toward expanding community outreach and engagement with changes to our board of directors. We welcome our Affiliate's leadership team to their new roles: Marla Deibler, PsyD, President; Jordan Levy, PhD, Vice President; Rachel Strohl, PsyD, Secretary; Robert Zambrano, PsyD, Treasurer; Allen Weg, EdD, Past President; Nicole Torrella, Event Coordinator.

We thank Allen Weg, EdD for his years of service as president of OCDNJ. His commitment to the organization, along with its other founding members, has ensured that so many residents of NJ have access to resources for OCD and related disorders. We look forward to his continued contributions to the governance of the organization.

OCD OREGON

ocdoregon.org

- OCD Oregon is proud to announce that their website has undergone a significant overhaul resulting in a brand new user experience.
- OCD Oregon is looking forward to hosting the next BTTI training scheduled for October of 2021.
- OCD Oregon's partner, Northwest PANDAS/PANS Network, is excited to support House Bill 2390 which will ensure access to care for the sickest children with PANDAS/PANS. The bill has received endorsements of support from the IOCDF, Oregon NAMI, Oregon School Nurses Association, Oregon Nurses Association, Oregon Pediatric Nurse Practitioners, Oregon School Counselors Association and Easterseals Oregon. Similar legislation has been passed in eight other states.

OCD PENNSYLVANIA

ocdpennsylvania.org

OCD Pennsylvania hosted two online panel discussions with Q&As this past winter related to living with OCD and living with a family member with OCD. We enjoyed this so much, we plan on making it a yearly event.

In March we will be hosting a virtual presentation to support those with OCD during the pandemic, titled Covid and OCD: Surviving One Year Later. You can find information about all of our events on our website or Facebook page: OCD Pennsylvania.

OCD SACRAMENTO

ocdsacramento.org

OCD Sacramento will continue our annual presentation lineup as we move into 2021:

- On February 23rd, Dr. Robin Zasio, PsyD, LCSW will host a discussion titled Introduction to OCD.
- On March 23rd, we are pleased to host Valerie Andrews and her presentation, titled OCD and the Strong Black Woman: The Cost of Wearing the Crown, the Burden, the Myths, and the Truth.
- Thomas Smalley will present Redefining the Term "Mental Toughness; Breaking Down the Macho Man Culture in Athletics," on April 20th.
- On May 25th, Clint Malarchuk will share his journey, triumphs, and tribulations while managing his OCD, titled From Hopeless to Hope: What Has Kept Me Strong in My Battle with OCD.
- On June 22nd we will welcome Phyllis and Erik Duarte, a mother and son team who will be talking on BDD: The Road to Recovery.
- On July 20th, Chanel Taghdis, AMFT will cover Trichotillomania: My Personal Recovery and Experience Treating Others.

All presentations will be from 5:30–6:30pm via Zoom and are free and open to the public. Codes will be posted on Facebook and on our website.

OCD SOUTH CAROLINA

ocdsc.org

OCD South Carolina hosted a virtual screening of *Uncovering OCD: The Truth About Obsessive Compulsive Disorder* followed by a Q&A panel with our board members. This event brought together OCD clinicians and those living with OCD to discuss access to treatment and hope for recovery.

OCD SOUTHERN CALIFORNIA

ocdsocal.org

Our board of directors would like to give a huge thank you to Barbara Van Noppen, PhD, who served as OCD Southern California's president for over three years. Barbara is stepping down as president now that her responsibilities at the University of Southern California have increased. However, we are happy to say that she will remain active with OCD So Cal and will remain a member of our board of directors! We are excited to announce that our secretary, Melissa Mose, LMFT, was nominated, and has accepted, the president's role. We look forward to Melissa's continued dedication to the OCD community in southern California in her new role as president!

The board of directors would also like to thank both Jenny Yip, PsyD and Sean Sassano-Higgins, MD, for their immense contributions to our Affiliate. Both board members have chosen to step down, and we thank them for their tireless efforts in growing OCD So Cal and serving the local OCD community.

FROM THE AFFILIATES

Affiliate Updates *(continued)*

As we continue into 2021, still in a state of uncertainty, OCD So Cal commits to providing more community, outreach, and educational events for our local area, utilizing the virtual platform until it is safe to meet in person. We are currently focused on planning this year's OCD Southern California virtual conference that will be held in July. We will also be active during OCD Awareness Week and at the 1 Million Steps 4 OCD Walk, both to be held in October.

To find out more about this year's virtual conference, as well as more information on what OCD So Cal has planned for this year, please visit our website and our social media sites:

[Instagram.com/OCDSOcal](https://www.instagram.com/OCDSOcal) and [Facebook.com/OCDSOcal](https://www.facebook.com/OCDSOcal). Also, please email us at info@OCDSOcal.org if you are interested in getting involved with the Affiliate in any manner. Thank you!

OCD TEXAS ocdtexas.org

OCD Texas is thrilled to announce further growth of our board and volunteers, with Mikayla Leech as communications chairperson and Katy Rothfelder as our Austin ambassador. Mikayla will continue to represent the mission of OCD Texas with her strong online presence, and Katy's sights are set on furthering OCD awareness for clinicians in training.

Embracing the new year, we kicked off a year-long educational series, Learn-At-Lunch: Nourishing Your Brain with OCD Texas on the first Friday of every month. Mental health providers, clinicians-in-training, and clinical graduate students are invited to join us on these first Fridays, and continuing education credits are provided for licensed clinicians in Texas. Our first events were held on February 5th, featuring Saharah Shrout, LPC and Katy Rothfelder presenting OCD 101, and March 5th, with Ginny Fullerton, PhD presenting Accepting the Unacceptable. Check out our social media pages or website to learn more.

OCD Texas remains proud to sponsor the Behavior Therapy Training Institute (BTTI) this December. We have awarded four scholarships to providers across the state in order to further enhance the treatment possibilities for OCD sufferers in Texas: Crystal Nicole Gayle, PhD in Addison, Tara Joiner, LPC in San Angelo, Ashley McElroy, LMFT in Lubbock, and Chelsea MacCaughelty, PhD, LCSW in Houston.

OCD UTAH

The OCD Foundation of Utah would like to announce its newest member, Neeta Lal, MD. She comes from Newport Beach, CA, and has studied across the country, including college at Harvard University, medical school at Northwestern University, and neurology residency at Washington University in St. Louis/Barnes Jewish Hospital. She has resided in Salt Lake City, UT since 2016, and lives with her husband, a hand surgeon, and their four young children.

Having suffered from lifelong OCD, at times more severe than others, Dr. Lal is a wounded healer. Additionally, in 2018 she gave birth to identical triplet girls at 25.5 weeks who have defied all odds and are thriving. The triplets are currently two years old and her son is five. Due in large part to her life-changing experience with therapy and awareness of the needs of the community, she paused her medical work and returned to my alma mater, University of Southern California, to complete her MSW with the goal of serving the OCD population.

She will provide the communities of Utah another loving and experienced approach to effective treatment and will be a huge asset for the Foundation.

OCD WASHINGTON ocdWASHINGTON.org

OCD WA welcomed a new board member for 2021. Elaine Cheung, LICSW is serving as our new secretary. Elaine has been practicing since 2003, working with children, adolescents, and adults. She brings a background of DBT and trauma treatments as well as wanting to increase a specialty in OCD. When she's not doing therapy, Elaine enjoys running the trails of the beautiful Pacific Northwest with her dog. We welcome Elaine to the board!

In other news, we are preparing for 2021 in this pandemic world with plans for a walk as part of OCD Awareness Week this fall. Also, we are seeking volunteers interested in contributing to our newsletter or social media presence. If interested in joining our fun team, please contact Erjing Cui, current vice president, at erjing@ocdWASHINGTON.org. We'd love to have you!

OCD WISCONSIN ocdwisconsin.org

We participated in the first virtual 1 Million Steps 4 OCD Walk and had a successful turnout. Part of the promotion for the event was our Instagram feed — @OCDWisconsin. We are monitoring COVID-19 activity in the state so as to inform our event planning this year.

There has been a lot of movement in our board of directors rounding the corner into 2021. Several of our inaugural members' terms were up, and we've been fortunate to recruit a number of people passionate about OCD and serving the community. We are engaging new members in a variety of ways, including managing social media accounts and speaking and moderating our popular Ask the Experts panel event, which was held online for the first time.

Finally, we have established a rate sheet for sponsorship levels that we intend using this year to broaden our donation and support base to bolster the type and breadth of programs and initiatives we're able to facilitate. 🍷