

International OCD Newsletter

Volume 32 | Number 4

Winter 2018

THE BERGEN 4-DAY OCD TREATMENT: THE USA JOURNEY STARTS IN HOUSTON

by Gerd Kvale, PhD, Bjarne Hansen, PhD, and Thröstur Björgvinsson, PhD, ABPP



From Left to Right: Bjarne Hansen, PhD; Gerd Kvale, PhD, & Thröstur Björgvinsson, PhD, ABPP

Ten years ago, OCD patients in the country of Norway did not have access to evidence-based treatment, leading to prolonged, unnecessary suffering. As the dean of the Faculty of Psychology at University of Bergen, Norway, Gerd Kvale had long been working with concentrated treatment formats for anxiety disorders. In 2009, she was awarded two years of sabbatical, which she donated to Haukeland University Hospital to establish an evidence-based outpatient OCD clinic working with concentrated treatments. After she completed her sabbatical, Haukeland decided to extend the project for two additional years.

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

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The mission of the International OCD Foundation (IOCDF) is to help all individuals affected by obsessive compulsive disorder and related disorders to live full and productive lives. Our aim is to increase access to effective treatment, end the stigma associated with mental health issues, and foster a community for those affected by OCD and the professionals who treat them.

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

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OCD Awareness Week 2018

Photos from #OCDWeek October 7-13, 2018



Advocacy Capital Walk.



Capital Walk attendees posing in front of the Capitol Building in Washington D.C.



IOCDF National Ambassador, Ethan

OCD Rhode Island posing with IOCDF Smith, talking about #RealOCD in a signs during OCD Awareness Week.

video for OCD Awareness Week.

Young attendee holding hand-made

sign created at the Capital Walk.



Author Ryan Bernstein at a book reading hosted by OCD Oregon as part of OCD Awareness Week.

Watermelon eating contest held during an OCD Awareness event hosted by OCD Southern California.



President's Letter

by Susan Boaz

There isn't much that is more important to me than raising awareness about OCD. Although the average time between onset of symptoms and access to effective treatment is currently 14–17 years, I believe every effort by our community to raise awareness about real symptoms of OCD helps to shorten this time. Once

someone understands that they have OCD, they are able to access effective care and begin to heal. This month, I'm writing to thank all of you for your amazing advocacy in raising awareness about OCD and related disorders — you make my heart happy!

Each year during the 2nd week of October, the International OCD Foundation (IOCDF) invites community groups, service organizations, and clinics across the US and around the world to participate in International OCD Awareness Week. This week has continued to grow and gain momentum each year since its inception in 2009; however, there was one activity this year that really stood out to me. In collaboration with our newly-formed IOCDF Ambassador Program, we launched our **#RealOCD** campaign. The inspiration for this campaign came from the countless stories we hear from all of you in our community about what you want the general public to know about what having OCD is really like. Following the lead of our amazing Ambassadors, the #RealOCD campaign allowed all members of the community to share short videos and posts on social media telling others "What I want you to know about having #RealOCD." The goal was to help educate the general public about what it's really like to have OCD in order to dispel common myths, stigmas, and misinformation.

Thanks to the support of the community, the #RealOCD campaign reached millions of people, achieving exactly what it set out to do. Here are just a few of the amazing statistics from the campaign:

- #RealOCD had over 12,600 mentions across the internet and social media
- #RealOCD reached over 26 million people
- The IOCDF received 27 #RealOCD videos for YouTube, which together had over 7,000 views
- Over 2,000 people visited iocdf.org/realocd to view community videos and posts.

Not only was the campaign effective in reaching a wide audience, but it led some individuals with OCD to find resources they were previously unaware of and ultimately seek the help they needed. Here is just one example of the immediate impact of this campaign:

"I just wanted to tell everyone at the IOCDF how awesome I think the #RealOCD campaign is! I've watched all the videos posted on the IOCDF website and they are really powerful. This is genius and I can't believe no one has thought of it before. I made and posted a video on Facebook and Instagram and got so much positive feedback. My stepmother shared it on her Facebook page and someone came out to her about his struggles with OCD. I also had

an old friend contact me through Facebook asking for advice for his 8-year-old daughter who has OCD and ADHD. Of course, I directed him to the IOCDF website. But I can't tell you how amazing that felt. Just by posting a little video, I made a difference in (at least) two people's lives!

Keep up the amazing work because it's definitely being recognized."

- Leslie Arturi, long-time volunteer and member of the IOCDF

I want to let all of the community members who participated in this campaign know that your stories have made a huge difference in the lives of people around the world. We are looking forward to continuing the #RealOCD campaign and educating an even greater audience.

Along with the #RealOCD campaign, the IOCDF kicked off OCD Awareness Week with the Mental Health Advocacy Capital Walk in Washington, D.C. This year, in addition to co-hosting with our affiliate, OCD Mid-Atlantic, we invited our partners at Tourette Association of America (TAA), Picking Me Foundation NFP, PANDAS Network, and the TLC Foundation for Body-Focused Repetitive Behaviors (BFRBs) to join us in expanding our advocacy efforts to an even greater community of those affected by all mental health disorders in addition to OCD and related disorders. Representatives from each partnering organization shared their story and why advocacy is important to them before the entire group walked on the National Mall from the Washington Monument to the Capitol Building. We are looking forward to expanding this event year over year with even more organizations whose missions align with that of the IOCDF, and hope to someday have walkers fill the National Mall!

Finally, the IOCDF hosted live Q&As throughout the week where the community was invited to pose live questions. Chris, Charlotte, and Vanessa Baier from UNSTUCK: An OCD Kids Movie; IOCDF Board Member Elizabeth McIngvale, PhD; and IOCDF National Ambassador Ethan Smith all participated in Facebook Live events with over 10,000 views combined. We also wanted to thank Denise Egan Stack, LMHC, a member of our Scientific and Clinical Advisory Board as well as the IOCDF Board of Directors, for her participation in our second Reddit AMA, or "Ask Me Anything," where she answered questions about OCD and our new Anxiety in the Classroom program.

We had over 60 events submitted by our local affiliates and partners around the globe in celebration of OCD Awareness Week. More than ever, this year's OCD Awareness Week felt like a united community effort. We are so thankful to all of you for helping us to end stigma, educate the public, and help more people affected by OCD and related disorders get diagnosed and treated sooner.

Congratulations to all of us for a job well done! With love,

Susan Boaz

IOCDF Board President and Mom

Susan M Boa

2018: A Year in Review

by Elijah A. Peterson, IOCDF Grant Writer & Philanthropy Officer





As 2018 draws to a close, I'm approaching my oneyear anniversary of working with the IOCDF. I'm amazed at how much we have accomplished since I joined the Foundation on January 2, 2018. That's why I was so excited to hear that I'd be writing 2018's "A Year in Review" article! Without further ado, here are some highlights from the year that was.

- We held our 25th Annual OCD Conference in Washington DC, with a record-breaking 1,973 attendees from 51 U.S. states and territories and 18 countries (including the U.S. and Canada)!
- Thanks to the generosity of our donors, we expanded our Behavior Therapy Training Institute (BTTI) program from five sessions a year to eight, and trained 240 new clinicians in exposure/response prevention techniques this year alone. Sessions were held in Houston, TX; Oconomowoc, WI; Portland, OR; Brooklyn, NY; Reykjavik, Iceland (our first BTTI outside North America!); Belmont, MA; Nashville, TN; and another in Houston, TX that focused on training community-based therapists.
- Over 400 people enrolled in online courses and more than 25 clinicians participated in online case consultation groups through the IOCDF Training Institute.
- The 1 Million Steps 4 OCD Walk entered its sixth year
 at our flagship location in Boston, MA, with IOCDF
 affiliates holding another 26 walks nationwide. All
 told, over 1,200 total walkers raised more than
 \$175,000 to support the programs of the IOCDF and its
 local affiliates.
- In addition to awarding four Young Investigator grants as part of our ongoing Research Grant program, we debuted a new \$500,000 "Breakthrough Award" for senior researchers.

- As part of OCD Awareness Week, the IOCDF launched our #RealOCD campaign to educate people about what it means to have OCD. Community members were asked to tag #RealOCD in videos and social media posts throughout the week, and the campaign had amazing success: #RealOCD received over 12,600 mentions across social media and the web and reached over 25,000,000 people!
- To kick off 2018 OCD Awareness Week, we co-hosted the Mental Health Advocacy Capital Walk with our local affiliate, OCD Mid-Atlantic, on the National Mall in Washington, DC. This year, we partnered with four other mental health advocacy organizations to expand the event's reach and advocate for not just OCD and related disorders, but all those affected by mental illness. Partners included the Tourette Association of America (TAA), Picking Me Foundation NFP, PANDAS Network, and the TLC Foundation for BFRBs
- This fall, we launched Anxiety in the Classroom, a new online resource that provides information and resources on anxiety and OCD in a classroom setting for school personnel, students with OCD, and their parents. Content for parents and students will be available in 2019. Learn more at anxietyintheclassroom.org.
- We welcomed three new staff members to the IOCDF team: Kristen Lynch, our Annual Fund Officer; Will Sutton, our Research Coordinator; and yours truly as our Grant Writer & Philanthropy Officer.

As always, we are tremendously grateful to all the donors, supporters, sponsors, stakeholders, and community members who make our work possible! We have high hopes for 2019, and are excited to continue providing resources, information, and support to everyone affected by OCD and related disorders. •

Are You Interested in Presenting at the 26th Annual OCD Conference? Submit your proposal beginning January 2, 2019!

by Alex Bahrawy, IOCDF Community Support Specialist



In July of 2019, the International OCD Foundation (IOCDF) will be holding our 26th Annual OCD Conference in Austin, TX! The Conference is our largest event of the year, and we invite the OCD community to come together to learn, train, network, and socialize. We are thrilled to begin planning for the Conference; however, in order to create a compelling program that will engage both new and returning attendees, we first need to open a call for presentation and workshop proposals!

As the Community Support Specialist here at the IOCDF, I have had the pleasure of speaking with many of you on the phone, via email, and at our events. In fact, at our 25th Annual OCD Conference held in Washington, D.C. this past summer, I spoke with many of you about submitting proposals for 2019. As I listened to all of your wonderful and creative ideas for presentations and activities, it made me even more enthusiastic about the planning process! With 2018 coming to an end, I'm excited to say it's finally time to start thinking about proposals for workshops, support groups, and activities for this summer's Conference.

The 26th Annual OCD Conference will take place Friday through Sunday, July 19–21, 2019, at the JW Marriott Austin in Austin, TX, with pre-Conference activities taking place Thursday evening, July 18. We will be accepting submissions starting on Wednesday, January 2, 2019 through our online proposal system, which will remain open until Monday, February 4, 2019 at 5pm ET.

We received a record number of proposals for the 2018 Conference (over 500!), and are hoping to keep that momentum going for 2019. Unfortunately, this also means that the process has become a bit more competitive than in previous years. In order to increase the chances of your talk being accepted, we've crafted a list of do's and don'ts for you to consider.

TIPS FOR SUBMITTING A PROPOSAL

These suggestions come directly from feedback we receive from Conference attendees and Conference Planning Committee members each year. Whether you're a proposal submitting rookie or a seasoned pro, below are key tips and tricks to consider when crafting your submission.

<u>DO</u> TRY TO CREATE A PROPOSAL CENTERED AROUND AN UNDERREPRESENTED TOPIC.

Every year, we get multiple requests for specific topics to be represented at the Conference, but then do not receive adequate proposals centered around these specific topics. A great way to increase your chances of being selected is to center your proposal around one of these underrepresented topics. Below are topics that have been frequently requested by attendees but may have been underrepresented in previous years:

- Multicultural and diversity issues
- Co-occurring issues with OCD (e.g. substance use disorder, intellectual disabilities, eating disorders, autism spectrum disorders, PTSD, depression, other mental health conditions, etc.)
- OCD and intimacy (e.g. dating, marriage, sex)

Are You Interested in Presenting at the 26th Annual OCD Conference? (continued)

- OCD and aging
- OCD & legal issues (including insurance and disability information)
- Translational talks about turning research findings into clinical practice
- Topics related to "Life after treatment: Now what?"
- Family issues, especially around couples, siblings, and the entire family system

Remember that this is not an exhaustive list! There could very well be another underrepresented topic not listed above, so we encourage you to think outside the box.

<u>DON'T</u> FEEL AS THOUGH YOU NEED TO UTILIZE THE TRADITIONAL LECTURE FORMAT.

As someone who absolutely loves reading all the Conference evaluations we receive each year, I can tell you with confidence that our attendees enjoy presentations that switch things up. While a traditional lecture format is tried and true, you can really capture the audience's attention with something like a breakout activity or even a live demonstration. When preparing your proposal, think about creative ways to actively engage your audience. Try to think about which specific things you would find engaging when attending a talk. You can engage with audience members, show a video clip, or even preform a skit.

DO CREATE A DIVERSE PANEL OF SPEAKERS.

While it can be tempting to submit a solo presentation, it's actually much more impactful and helpful for the attendees to hear as many varying viewpoints as possible. The goal is to have every attendee of the Conference walk away satisfied and feeling as though they are not alone. By teaming up with a diverse panel of speakers, this greatly increases the chance that your presentation will have more of an impact on the community. **Consider some of the following examples:**

- Are you an individual with OCD or a related disorder?
 Team up with a fellow individual, family member, and/ or professional to provide a well-rounded talk about your different experiences and perspectives.
- Are you a clinician? See if one or more of your patients and/or colleagues would like to join you on a panel to discuss an issue from several sides.
- Are you a researcher? Work with other researchers to discuss your various studies and findings around a single theme.

Typically, the ideal panel size is between 3–4 presenters — any more than that, and you may find it difficult to cover your topic adequately. We cap the total number of presenters at 5, so bear that in mind when assembling your team.

DON'T OVER OR UNDERESTIMATE THE DIFFICULTY OF YOUR TALK.

Every presentation at the Conference is classified according to difficulty level (introductory, intermediate, or advanced) and it's up to you to specify the difficulty level when submitting your proposal. A surefire way to get negative attendee feedback is to have the content of your talk not match the difficulty level you chose. Advanced-level sessions should not cover the basics, and introductory-level sessions should not get too complicated. We aim for the full spectrum of difficulty levels when setting the Conference program, so be sure to take enough time to decide which difficulty level best suits your talk.

DO MIX IT UP FROM PREVIOUS YEARS.

While we do get new attendees every year, we also see an increasing number of Conference-goers coming back time and time again. Thus, it is our goal to provide fresh offerings each year that will appeal to both newcomers and Conference veterans. This means we are unlikely to accept the same presentation year after year, even if ratings and attendance were high. Simply changing your title is not enough — use this as an opportunity to mix it up and explore fresh content or even add additional perspectives.

DON'T FORGET ABOUT EVENING ACTIVITIES AND SUPPORT GROUPS.

While daytime presentations are the most popular choice when submitting a proposal, I would urge you to also consider submitting an evening activity or support group. These events are just as vital to the community as the educational workshops, and provide opportunities for attendees to have fun, socialize, network, and bond after a great day of learning.

- Support groups can be led by professionals and peers alike, and we welcome submissions for groups of all ages, types, and compositions.
- Evening activities have ranged from group exposures to artistic expression activities, from film screenings to story hours.

For example, one of our most well-attended sessions during the 2018 Conference in Washington, D.C. was an Open Mic Night. This was an amazing opportunity for Conference

Are You Interested in Presenting at the 26th Annual OCD Conference? (continued)

attendees to share their experience while showing off their talents in the forms of poetry, live performances, and more.

DO SUBMIT TO OUR INNOVATIVE YOUTH PROGRAM!

Beginning in 2017, we switched up the way we provide programming for youth at the Conference. Instead of a "Kids & Teens Track" and separate art therapy rooms, we combined them to create integrated programming for three distinct age groups: elementary-aged kids, middle schoolers, and high school-aged teens. Each program spans all three days of the Conference and youth are treated daily to a wide variety of activities in a camp-like structure. For 2019 we encourage you to submit proposals that provide engaging content and activities that are both fun and appropriate for a specific age group.

AND **DON'T** FORGET...

Myself and the rest of the Education & Training team here at IOCDF are happy to assist you with crafting your proposal. Whether you're unsure of the correct difficulty level to apply to your presentation or simply want some direct feedback on your ideas, we're here to help. Good luck, and we hope you see you in Austin!

If you have a question that is not answered by this article, the Conference website (ocd2019.org), or the instructions in the proposal system, please feel free to reach out to us by e-mail at conference@iocdf.org or by phone at (617) 973-5801.





Pre-conference Activities July 18



Three (Very) Easy Ways to Give Back to the IOCDF!

by Kristen Lynch, IOCDF Annual Fund Officer

Give back to the IOCDF through ANY purchase.

The IOCDF has partnered with RoundUp, a "spare change" service that allows you to effortlessly donate the change from your credit and debit card purchases to benefit the IOCDF. Simply install



the RoundUp app at *iocdf.org/roundup* and RoundUp will automatically select the IOCDF as your charity of choice to make a tax-deductible donation of your spare change direct to the Foundation. It only takes a minute to securely link your bank account, debit, and/or credit cards and users are able to set a cap for the maximum amount to give in a month. The average donor ends up contributing \$20-\$30 per month just by donating their spare change. The RoundUp app will tally the total change of your transactions at the end of the month and send a deposit directly to the IOCDF — it does all the work for you! While this may not seem like a lot, it has a significant impact over time, allowing the IOCDF to provide resources to more people affected by OCD. Visit *iocdf.org/roundup* to get started today!

2 Support the IOCDF through a Facebook birthday fundraiser!

There has been a surge in charitable giving via Facebook, particularly among those who have chosen to "donate their birthday" to the IOCDF. In fact,



this year alone, Facebook users have created nearly 150 online fundraising campaigns that raised over \$20,000 for the IOCDF. For anyone who has already created a fundraiser for the IOCDF — thank you for your support! For those interested in creating a fundraiser, Facebook makes it easy to create a fundraiser or "donate your birthday" to a cause. Just follow these steps:

- Login and visit facebook.com/IOCDF and click "Fundraisers" in the left-hand menu.
- 2. Click the blue "+Raise Money" button on the left and edit the details of your fundraiser.

The "International OCD Foundation" will automatically be chosen as your charity of choice with a default goal

of \$200 and fundraiser end date a week from its start
— challenge yourself and raise the goal to \$500 or even
\$1,000!

Personalize your fundraiser's description and let your Facebook friends know why supporting the IOCDF is important to you. Make sure to choose a cover photo for your fundraiser — maybe a photo of you at an IOCDF event or with your support system.

3. Click "Create" and you're ready to start fundraising!

That's it! Once your fundraiser is created, you can start fundraising and encouraging your social network to support the IOCDF. It's a simple way to make a BIG difference!

Support the IOCDF when you shop online.

When you shop using **iGive** or **AmazonSmile**, you can select the IOCDF as your charity of choice and a percentage of your purchase will be donated automatically to the IOCDF. These services are free and do not incur any additional costs — simply shop at one of the 1,700+ online retailers through iGive or shop through AmazonSmile (just like you would through regular Amazon). When you register and make a purchase on either site, a portion of your proceeds are automatically





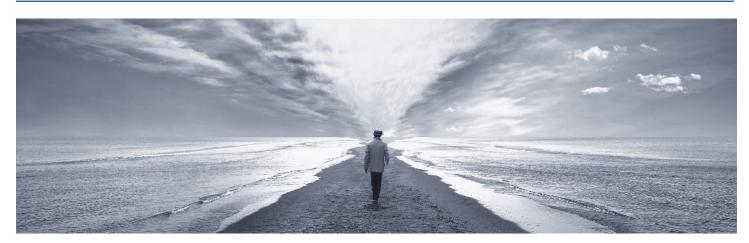
donated to the IOCDF. Pro tip: Make sure to install the iGive button on your browser! This is a tiny addition with a large impact that automatically tells you which stores can help you support the IOCDF through iGive. Bookmark *smile.amazon.com* on your browser to ensure that 0.5% of your regular Amazon purchases come back to the IOCDF whenever possible!

Finally, thank you to all of our supporters and to everyone who has donated or fundraised for the IOCDF! Every dollar raised helps the IOCDF provide resources for those affected by OCD and related disorders. Learn more about ways to donate by visiting <code>iocdf.org/ways-to-give</code>. \circ

FROM THE FRONT LINES

My OCD Story

by Jonathan



I don't often talk about my OCD or depression with anyone, unless I am suffering. Though I wish it was not the case, stigma still exists around mental illness, and while I wish that more people could understand what it's like and have compassion, I am happy to know that there exists a community of people that I can openly share my story with. I've dealt with OCD/depression for many years and had three major episodes where it got to the point of hospitalization. My recovery was a long and slow journey, but through it I have learned much about myself and about OCD.

One of the most important things I have learned is that whatever OCD tells you is a lie. Whether your OCD is telling you that you're a terrible person, or that you ran someone over, none of what it says is true. OCD will even tell you that you don't have OCD, and your case is special. It isn't. You have OCD. And while people experience different forms of OCD, at the core of it all, it's a glitch in your brain that repeats the same message over and over, like a broken record, all day long, all night long, everywhere you go. The harder you try not to think of it, the louder and more distressing the thoughts become. My OCD comes in waves, but I deal with it every day, and if there is one thing I am certain of, it's that no amount of testosterone, getting over it, or forgetting about it will achieve the goal of getting better.

Now 35 years old, OCD first impacted my life in 2002. Before my sophomore year of college, I started getting panic attacks and having repetitive thoughts about mistakes and missed opportunities in my life. I developed pathological guilt. I saw a few psychologists about my issues; however, none of them

ever mentioned OCD to me. I eventually had to take a year off from college because the panic was so bad. Over time, I managed to go back and graduate. However, I still had not been diagnosed or received treatment, and I continued to experience panic on a regular basis.

After graduating from college in 2006, I began studying for the LSAT with the plan of attending law school, but my symptoms returned even worse than before. I once again developed pathological guilt and was flooded with thoughts that things I did had caused other people to die. I worried that potholes or bumps in the road were people I had hit, or that things I had done had caused people to commit suicide. At the time, I still did not know that what I was experiencing was OCD. After spending time researching online with my mother, OCD seemed to coincide with what I was experiencing. I found the OCD program at Massachusetts General Hospital (MGH) and, after speaking over the phone with them and answering questions, I was added to the wait list. By this time, I had applied and was accepted to law school, but instead of enrolling in school I made the decision to attend the OCD program at MGH in 2008 — a decision that saved my life.

It wasn't until I got to MGH that I was officially diagnosed with OCD. At MGH, I learned to manage my OCD with behavioral activation, medication, exposure and response prevention, and time. When I was able to leave the program, the medication, combined with the tools I had learned, helped me continue to effectively manage my symptoms for several years. However, during my last major episode in 2017, even these proven methods were ineffective. I was dealing with pathological guilt, depression, anxiety, and OCD. Living in my head felt like being in hell and I was desperate to escape my thoughts.

FROM THE FRONT LINES

My OCD Story (continued)

That summer, I was admitted to the OCD Institute at McLean Hospital. I was thankful to be admitted to the program, but aside from attending group sessions, I sat with my head in my hands most days. I didn't think I could make it through treatment. I was scared of death and of the pain that my family and loved ones would have to endure if I died. Despite this, the torture of constantly battling my thoughts and the overwhelming depression eventually led me to give up. I left the OCDI on my own without permission

one day. I went in to the woods where I figured I would become homeless and eventually die. Fortunately, my girlfriend called me, found me, and convinced me to return to the hospital.

Upon my return, I was admitted to the

short-term unit at McLean. It was there that someone came to speak to me about trying Electroconvulsive Therapy (ECT). During my first treatment, I sat in the lobby thinking this was another failed attempt at becoming myself again. I had my head in my hands, disgusted with myself and how my life got to this low point. I was at rock bottom, again. I complained to the nurses that this was nonsense, ECT was for depression, but I had OCD, why would this work? As it turned out, my OCD was lying to me yet again. I was depressed beyond what I knew, and treating the depression was imperative to my getting well.

The ECT didn't work right away, but I am stubborn and all that I had left to do was try. After about 10 treatments, I began to see a faint light at the end of the tunnel. It was far away, but instead of my mind going 100 mph, it was going 75. It was enough of a change for me to have hope. Through ECT, my depression continued to lessen, and eventually it became controlled enough that I was able to resume focus on ERP to battle my OCD. I now understand how critical managing my depression was to my overall recovery, and that ECT saved my life.

For anyone who is reading this and struggling, have hope that you too can beat OCD. Be stubborn, don't give up, and get the help you deserve. When I was at my lowest point, I didn't think I would ever get better. It took time and effort, but I finally got the help I needed — the help that OCD

had told me I didn't deserve. I will always have OCD, but now that I no longer have crippling depression, I am able to challenge my thoughts and label them as OCD. OCD has made my life difficult in many ways, but it has also taught me to persevere. I had to leave college because of my OCD, but I still graduated. My OCD prevented me from going to law school, but I found another career, which I enjoy even more. I even had to take leave from my current job because of OCD, but after ECT and treatment I returned.

lessen, and eventually it became controlled enough that I was able to resume focus on ERP to battle my OCD. I now understand how critical managing my depression was to my overall recovery, and that ECT saved my life. ??

Mental illness doesn't care who you are. Kate Spade, Chester Bennington, Chris Cornell, and Philip Seymour Hoffman were all amazing and brilliant people. Unfortunately, they all suffered from mental illness to

the point that they believed suicide was the only answer. If you are struggling like I was, don't be ashamed to let others know what you are going through. Please get the help that you deserve and that is out there. You matter. Your thoughts matter. People care.

Don't give up. I didn't, and I'm still here. •

Jonathan is a web developer living in the greater Boston area. He recently volunteered his time to help the IOCDF develop their new Anxiety in the Classroom website.

The Bergen 4-Day OCD Treatment (continued from front page)



Around the same time, Bjarne Hansen was heading the inpatient OCD clinic at St. Olav's Hospital in Trondheim, Norway and launching the national OCD treatment implementation project. In collaboration with the Norwegian OCD Foundation, he suggested that health authorities should establish 30 OCD treatment teams to ensure that evidence-based treatment was available for all OCD patients in Norway. In 2011, after hearing about Bjarne's work, Gerd invited him to join the Bergen clinic. They were dedicated clinicians and researchers with the same goal: to improve treatment, carefully explore success rates, and optimize dissemination.

Currently, Gerd Kvale (together with Bjarne Hansen as coleader and Thröstur Björgvinsson as a partner) is leading a national dissemination and research project in Norway entitled "Changing the specialist mental health care: The concentrated treatment format", which is being financed by the National Board of Health Authorities. This project will build upon OCD research and allows for the Bergen 4-Day Treatment (B4DT) to be tested and disseminated for a variety of disorders.

THE CONTENT OF THE B4DT: HARD, BUT LIFE-CHANGING

The B4DT is best described as an individual treatment delivered in a group setting; it is delivered simultaneously to 3-6 patients by the same number of therapists. The 1:1 ratio between therapists and patients ensures individually tailored and therapist-assisted exposure training, while simultaneously taking advantage of the group setting. Prior to undergoing the treatment, the patients are thoroughly educated and prepared for what to expect, and have made the decision to dedicate four full days to working towards change. The program is set up in the following way:

- The first day is allocated to education and preparation.
- The two middle days are one prolonged treatment session interrupted by the natural occurrence of sleep.

This ensures that the therapist has enough time to assist the patient in the OCD demanding settings, and to help the patient become aware of all the micro-choices that they face when they are tempted to engage in subtle avoidance strategies or mental/overt rituals. These micro-choices are seen as golden opportunities to make choices that are incompatible with having OCD.

- At the end of the third day, family and friends are invited to a lecture on how they can best support the patient.
- The fourth and last day is allocated to preparing the client for the coming three weeks by integrating behavioral changes into normal living.

Patients express high to very high treatment satisfaction after treatment, and typically describe it as hard and life-changing work. When the B4DT was piloted, the reimbursement system in Norway was based on 45-minute sessions (just like in the U.S.) and the B4DT lost money for the treatment providers. As a consequence of the clinical success of the B4DT, the reimbursement system in Norway has changed — it now covers the concentrated format! We sincerely hope that the same will happen in the US.

The B4DT approach has received tremendous attention around the world. In October 2018, Drs. Gerd Kvale and Bjarne Hansen were selected by Time Magazine as two of "The Health Care 50: Fifty People Transforming Health Care in 2018." They were the only honorees representing psychological treatment, truly a remarkable acknowledgement of recent advancement of OCD treatment. In addition, the B4DT was awarded the "2015 Innovation of the Year" award by the Norwegian Psychological Science Association.

BERGEN 4-DAY TREATMENT OUTCOMES

From the start, Gerd and Bjarne ensured independent outcome assessment, and the results show the following:

The Bergen 4-Day OCD Treatment (continued)

- More than 90% of the patients have reliably improved while 68% have remitted at 12-month follow-up¹.
- Furthermore, 69% are recovered at 4-year follow-up².
- Almost all patients who are offered the 4-day treatment accept it and enroll. There is almost no dropout¹⁻³, which clearly differs from typical psychological treatments for OCD, where approximately 15% of patients decline to enroll and 15% typically drop out of treatment⁴.
- Importantly, neither OCD severity, the number of comorbid disorders, indications of personality disorders or presence of sleep disturbance predict treatment outcome¹⁻³.
- The B4DT is equally helpful for children and adolescents⁵.
- At this time, approximately 1,200 patients have received the B4DT.

In Norway, individuals with OCD are entitled to treatment by one of the 30 specialized OCD teams, and the B4DT is now part of that system. Only if a patient is suicidal, actively abusing drugs, experiencing psychosis, in the manic phase of bipolar disorder, or has an active eating disorder, is treatment postponed until these issues have been stabilized.

The development of the B4DT has created unique opportunities to change mental health treatment delivery as we know it. In early 2017, the B4DT was implemented in Oslo (the capital of Norway) where the Anxiety and OCD Clinic at University of Oslo had about 100 patients on their waiting list. Given the normal staffing practice of the clinic, it would have taken them 18 months to treat all these patients. Thus, Gerd and Biarne suggested that they treat the entire wait list by treating 45 patients during two 4-day interventions. A total of 90 patients with OCD were treated during two 4-day periods, thus effectively eliminating the wait list in a novel and creative way. At the three-month follow-up, 84% of patients had achieved clinically relevant change, and 68% were in remission³. The B₄DT has also been piloted in Iceland with comparable results⁶. The question still remains: will this treatment work in the United States?

DISSEMINATION OF THE B4DT: BRINGING IT TO THE U.S.

Some people have expressed skepticism about this approach. Can this approach really work in 4 days? Maybe it works in Norway, but will it work here? Correctly, we cannot assume it will work in the U.S. without carefully evaluating it first. Thus, we are working on a thoughtful and rigorous dissemination in Houston beginning in June of 2019. The initial dissemination plan involves two pilot studies (about

56 patients in each), one for adults and one for adolescents, with 3-month follow-ups. This work will be made available with generous support:

- The Kavli Trust has provided five-year support to the Bergen group based at Helse Bergen, Haukeland University Hospital to ensure quality international dissemination of the B4DT.
- The Peace of Mind Foundation and Dr. Michael Jenike have pledged their support to sponsor the cost of the two pilot studies in the U.S. that will be conducted at the Houston OCD Program. The team overseeing this dissemination are Drs. Kvale, Hansen, and Björgvinsson in collaboration with McLean Hospital.

Dissemination of effective treatment is a major challenge in mental health care, and even though a clinic might offer evidence-based treatment, there is not a guarantee that patients who can access it will actually receive high-quality care. The Bergen group has developed a model for dissemination that eliminates any discrepancy between what is offered and what is delivered to patients; it ensures that the effectiveness of the B4DT is maintained. It assures that patients will receive competently delivered B4DT regardless of location and/or the composition of the team.

The core features of the model for dissemination are hands-on training and certification of therapist/group leaders, combined with an integrated quality and outcome assessment that allows for benchmarking. It is now possible to establish an "expected outcome" where over 90% the patients reliably improve after the 4 days. If the treatment outcomes with a particular team fail to deliver optimal results, this elicits hands-on supervision and re-certification of the team and/or clinic. This integrated assessment is an essential part of the B4DT, and is an ongoing requirement for any clinic or team that wants to deliver the B4DT.

The Bergen site has also established a "control center" which is responsible for all logistics related to assessment and integrated quality control. OCD-specific symptoms, as well as symptoms of anxiety and depression, are assessed both online and by trained assessors over the phone before, during, and post treatment.

FUTURE DIRECTIONS

The Bergen 4-Day Treatment is practical, evidence-based, focused, and deliberate. It builds on four decades of empirical research and theories about the most effective approach to OCD treatment. The innovation and strength of the work is how it combines the most effective elements of proven treatment into one of the most profound, rapid, and

The Bergen 4-Day OCD Treatment (continued)

robust treatment approaches that we have seen in recent years. Thus, this approach provides for a truly transformative treatment that has the potential to upend how health care is delivered in the U.S. \odot

Gerd Kvale, PhD

Dr. Kvale established and is heading the OCD team at Haukeland University Hospital as well as the Bergen 4-day clinic. Kvale is Professor at the University of Bergen, Norway. Her main professional focus has been to develop and disseminate effective treatments for anxiety disorders and OCD, and she previously ensured the establishment of 35 specialized teams for treating dental fear, covering all Norway. She has published more than 100 scholarly articles, where one-session treatment for dental fear has been essential. At the moment, she is heading a number of national Norwegian research projects in clinical psychology. Kvale will be the director of The Bergen Center for Brain Plasticity.

Bjarne Hansen, PhD

Dr. Hansen's main dedication has been to ensure OCD patients' access to evidence based treatment, and he initiated and headed the Norwegian National Project OCD-project in which 30 OCD teams covering all of Norway were established (2012-2016). He is Associate Professor at the University of Bergen, Norway, and working on the OCD team 4-day clinic at Haukeland University Hospital.

Thröstur Björgvinsson, PhD, ABPP

Dr. Björgvinsson is the founder and director of the Houston OCD Program, a specialized residential OCD program in

Houston, Texas, and the co-director of the OCD & Anxiety Program of Southern California. He is also an associate professor of psychology at the department of psychiatry, Harvard Medical School, the director of the Behavioral Health Partial Hospital Program at McLean Hospital, and co-director of psychology training at McLean Hospital/Harvard Medical School. He is very excited about bringing the B4DT to the USA.

REFERENCES

- Hansen, B., Hagen, K., Öst, L-G., Solem, S., & Kvale G. (2018). The Bergen 4-day OCD treatment delivered in a group setting: 12-month follow-up. Frontiers in Psychology, 9, article 639.
- Hansen, B., Kvale, G., Havnen, A., Hagen, K., & Öst, L-G. (2018). The Bergen 4-day treatment format: Four years follow up of concentrated ERP in a clinical mental health setting. Cognitive Behavioral Therapy, 8, 1-17.
- Kvale, G., Hansen, B., Björgvinsson, T., Børtveit, T., Hagen, K., Haseth, S., Beate Kristensen, U., Launes, G., Ressler, K. J., Solem, S., Strand, A., van den Heuvel, O. A., & Öst, L. G. (in press). Successfully treating 90 patients with Obsessive Compulsive Disorder in eight days: The Bergen 4-day treatment. BMC Psychiatry, 18, 1-9.
- Öst, L-G., Havnen, A., Hansen, B., & Kvale, G. (2015). Cognitive behavioral treatments of obsessive-compulsive disorder. A systematic review and meta-analysis of studies published 1993-2013. Clinical Psychology Review, 40, 156-169.
- Riise, E. N., Kvale, G., Öst, L-G., Skjold, S. H., Hansen, H., & Hansen, B. (2016). Concentrated exposure and response prevention for adolescents with obsessive-compulsive disorder: An effectiveness study. Journal of Obsessive-Compulsive and Related Disorders, 11, 13-21.
- Davíðsdóttir, S. D., Sigurjónsdóttir, Ó., Ludvigsdóttir, S. J., Hansen, B., Laukvik, I. L., Hagen, K., Björgvinsson, T., & Kvale, G. (under review).
 Implementation of the Bergen 4-day treatment for OCD in Iceland.

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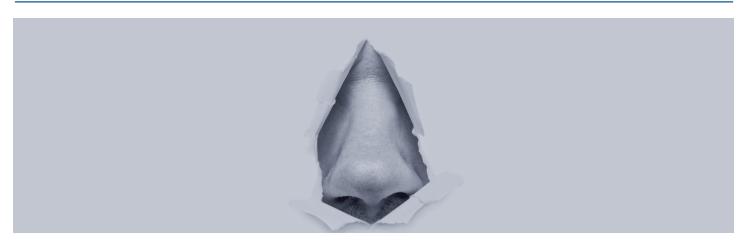
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Olfactory Reference Syndrome: Problematic Preoccupation with Perceived Body Odor

by Katharine A. Phillips, MD



Kyle is a 37-year-old single white male who believes that he has severe halitosis (bad breath) and flatulence, which makes him "stinky and smelly." He states, "I know it's true, because I can smell it, and why would people touch their face, sniff, and move away from me?" To minimize the awful odor that he is certain he emits, Kyle brushes his teeth for about an hour a day, which has damaged his gums and tooth enamel. He gargles with prescription-strength mouthwash about 20 times a day, wears lots of cologne, changes his underwear many times a day, and washes his clothes twice a day. Because he is embarrassed by the "horrible" odor he believes he emits, Kyle avoids most social situations. He does not date and has dropped out of college. Unable to work, he spends most of his time alone in his apartment. He states, "I have to stay alone, because I stink so much, and if I go out people will make fun of me."

Kyle is experiencing olfactory reference syndrome (ORS), an under-recognized disorder characterized by preoccupation with the false belief that one emits a foul, unpleasant, or offensive body odor. This preoccupation causes significant distress or impairment in functioning (for example, avoidance of social situations). Although people with ORS believe that they really do smell bad, other people cannot detect the odor. ORS usually triggers excessive, repetitive behaviors such as repeatedly checking oneself for body odor, or excessive

clothes laundering. As a result of these concerns, social anxiety and social avoidance are usually prominent, and the odor concerns are so distressing and impairing that suicidal thinking and suicide attempts are common¹⁻⁶.

ORS has many similarities to body dysmorphic disorder (BDD), which is characterized by distressing or impairing preoccupation with slight or nonexistent flaws in physical appearance, and obsessive compulsive disorder (OCD)^{2,3,6}. Our understanding of ORS and its relationship to other disorders is limited by a lack of research studies. However, ORS is not a new phenomenon; it has been consistently described around the world since the 1800s as a distressing and often severely impairing disorder^{2,3,7,8}. The largest studies come from Japan, Canada, Nigeria, Saudi Arabia, Brazil, and the United States^{1,6,9-13}.

DIAGNOSTIC STATUS OF ORS

A Google search of ORS yields approximately 590,000 results, reflecting the public's interest in this condition. Efforts were made to add ORS to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)14, but research evidence was considered too limited to include ORS as its own disorder with full diagnostic criteria. Instead, DSM-5 lists ORS as an example of an "Other Specified Obsessive-Compulsive and Related Disorder"14. DSM-5 provides a very brief description of ORS's key clinical features, but does not include full diagnostic criteria or discussion of ORS in the text¹⁴. However, the recently published International Classification of Diseases, 11th Edition (ICD-11), did add ORS as a new, separate disorder in the chapter of Obsessive-Compulsive or Related Disorders, alongside BDD and OCD (see Box)15. It is hoped that inclusion of ORS in ICD-11 will foster much-needed research studies and enhance understanding and recognition of this often severe and under-recognized condition.

Olfactory Reference Syndrome (continued)

CLINICAL PRESENTATION OF ORS

PREOCCUPATION WITH PERCEIVED BODY ODOR

Individuals with ORS are excessively preoccupied with the belief that they emit an unpleasant or foul body odor, most commonly bad breath or sweat (see Table 1). They believe that the foul odor emanates from body areas that correspond to the type of odor — for example, bad breath from the mouth or sweat from the armpits or skin. Occasionally, the perceived odor may smell like non-bodily odors, such as ammonia, detergent, or rotten onions. Most — but not all — people with ORS report actually smelling the odor.

INSIGHT AND REFERENTIAL THINKING

Most people with ORS are completely convinced that they actually smell terrible, despite the fact that other people cannot detect an odor; very few recognize that their belief about the body odor is inaccurate⁶. The likely explanation for this mistaken perception is that most people with ORS report that they actually smell the odor themselves (see Table 1)6. Alternatively, those who do not smell the odor base their belief on a misinterpretation of other people's comments, gestures, or behaviors. For example, if someone opens a window, touches their nose, moves away, or says "It's stuffy in here," people with ORS typically — and mistakenly believe that their unpleasant body odor is the reason for such behavior (see Table 1). This inaccurate belief that other people are taking special notice of them in a negative way because they smell bad is known as referential thinking (or ideas or delusions of reference).

EXCESSIVE REPETITIVE BEHAVIORS

People with ORS experience their preoccupation with body odor as highly distressing, and it triggers upsetting feelings such as depressed mood, anxiety, and self-consciousness. For this reason, nearly everyone with ORS feels compelled to perform repetitive behaviors intended to mitigate, check, mask, or reassure themselves about their perceived odor. The most common behaviors are smelling oneself, excessive showering, and frequent clothes changing (see Table 1).

CAMOUFLAGING THE PERCEIVED ODOR

People with ORS attempt to mask the perceived body odor, most often with excessive perfume or powder, chewing gum, excessive or strong deodorant, or mints (see Table 1). This behavior can occur repeatedly throughout the day.

FUNCTIONAL IMPAIRMENT

ORS typically impairs functioning, which can range from mild to extreme; on average, impairment is severe in clinical

OLFACTORY REFERENCE DISORDER IN THE INTERNATIONAL CLASSIFICATION OF DISEASES, 11TH EDITION (ICD-11) 1,2

Olfactory Reference Disorder is characterized by persistent preoccupation with the belief that one is emitting a perceived foul or offensive body odor or breath that is either unnoticeable or only slightly noticeable to others. Individuals experience excessive self-consciousness about the perceived odor, often with ideas of reference (i.e., the conviction that people are taking notice, judging, or talking about the odor). In response to their preoccupation, individuals engage in repetitive and excessive behaviors such as repeatedly checking for body odor or checking the perceived source of the smell, or repeatedly seeking reassurance, excessive attempts to camouflage, alter, or prevent the perceived odor, or marked avoidance of social situations or triggers that increase distress about the perceived foul or offensive odor. The symptoms are sufficiently severe to result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.

- Reprinted from ICD π: https://icd.who.int/browseπ/l-m/en#/ http://id.who.int/icd/entity/π19008568
- ICD-π uses the term "olfactory reference disorder" rather than the more common term "olfactory reference syndrome."

samples of individuals with ORS⁶. Nearly three quarters of people with ORS report periods during which they avoided most social interactions because of their ORS symptoms, and about 50% report periods during which they avoided most of their important occupational, academic, or life activities because of ORS symptoms⁶ (see Table 1). Some people are completely housebound because they feel too distressed, self-conscious, and embarrassed about the perceived odor to be around other people, or because they fear offending others with their smell.

High rates of psychiatric hospitalization, suicidal thoughts, suicide attempts, and completed suicide have been reported, which many individuals attribute primarily to their ORS symptoms (see Table 1)^{1,6}.

Olfactory Reference Syndrome (continued)

COMORBIDITY

Commonly co-occurring disorders are major depressive disorder, social anxiety disorder, drug or alcohol use disorders, obsessive compulsive disorder, and body dysmorphic disorder⁶.

PREVALENCE AND DEMOGRAPHIC CHARACTERISTICS

In one study, 60% of individuals with ORS were female, and most were single⁶. The prevalence of ORS is not known, but it is certainly more common than generally recognized^{2,3,16}.

WHAT CAUSES ORS?

The cause of ORS has not been studied and thus is not known. Like other psychiatric disorders, its cause likely has many genetic and environmental determinants. ORS has similarities to BDD, OCD, and social anxiety disorder, and thus it may share some etiologic and pathophysiologic characteristics with these disorders. For example, ORS may involve abnormalities in the brain's olfactory system that cause olfactory hallucinations or extreme sensitivity to odors. However, this theory has not been studied, and it likely is not relevant to the minority of those with ORS who do not actually smell the odor.

TREATMENT FOR ORS

MEDICATION

No prospective medication studies have been done (either controlled or open-label studies). Case reports and small case series describe improvement with serotonin reuptake inhibitor (SRI) monotherapy, neuroleptic (antipsychotic) monotherapy, non-SRI antidepressants (such as tricyclic antidepressants), or a combination of a neuroleptic and antidepressant medication²⁻⁴. In the author's clinical experience, SRIs at high doses often effectively treat ORS.

PSYCHOTHERAPY

Reports on psychotherapy are similarly limited to single case reports and small case series, which report improvement with behavioral therapy, cognitive behavioral therapy, and paradoxical intention²⁻⁴. In the author's experience, cognitive behavioral therapy — consisting of cognitive restructuring and advanced cognitive strategies for core beliefs, including self-esteem work and self-compassion; ritual prevention; and exposure-based exercises along with behavioral experiments that are tailored to ORS symptoms — can be effective. ORS's clinical features appear most similar to those of BDD, and an evidence-based CBT treatment manual for BDD can be easily adapted to treat ORS symptoms¹⁷.

NON-MENTAL HEALTH MEDICAL TREATMENT

Nearly half of people with ORS seek non-mental health medical treatment for their perceived body odor⁶, many before seeking mental health care ¹⁸; in one study, one third of people actually received such treatment ⁶. Patients may consult dentists, surgeons, and ear, nose, and throat specialists for supposed halitosis; proctologists, surgeons, and gastroenterologists for supposed anal odors; and other physicians such as dermatologists and gynecologists. Treatments such as a tonsillectomy for perceived bad breath or electrolysis of sweat glands for a perceived sweaty smell may be received. Such treatment does not appear to be effective for ORS symptoms and often leaves patients dissatisfied⁶.

A neurologic workup, which may include an EEG, may sometimes be warranted to rule out a neurologic explanation (such as temporal lobe epilepsy or migraine aura) for perception of an odor that others cannot detect. This kind of evaluation is more relevant when concerns focus on nonbodily odors and occur only intermittently.

RECOMMENDATIONS FOR CLINICAL CARE

Current understanding of ORS is substantially limited by the very small number of published research studies on this condition. Nonetheless, it is important for clinicians and the public to be aware of ORS. Table 2 provides some clinical recommendations, based on current research-based knowledge about ORS and the author's clinical experience. More research studies on all aspects of ORS are greatly needed to advance understanding and treatment of this condition.

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Olfactory Reference Syndrome (continued)

REFERENCES

- Pryse-Phillips W. (1971). An olfactory reference syndrome. Acta Psychiatr Scand, 47:484–509.
- Phillips KA, Gunderson C, Gruber U, Castle DJ. (2006). Delusions of body malodor: the olfactory reference syndrome. In: Brewer W, Castle D, Pantelis C, editors. Olfaction and the Brain. Cambridge: Cambridge University Press; pp. 334–353.
- Feusner JD, Phillips KA, Stein DJ. (2010). Olfactory reference syndrome: issues for DSM-V. Depress Anxiety, 27:592–599.
- Phillips KA, Castle DJ. (2007). How to help patients with olfactory reference syndrome. Curr Psychiatr, 6:49–65.
- Begum M, McKenna PJ. (2010). Olfactory reference syndrome: a systematic review of the world literature. Psychol Med, 1–9.
- Phillips KA, Menard W. (2011). Olfactory reference syndrome: demographic and clinical features of imagined body odor. Gen Hosp Psychiatry, 33:398-406.
- Potts CS. (1891). Two cases of hallucination of smell. U Penn Med Mag, 226.
- Tilley H. (1895). Three cases of parosmia: causes and treatment. Lancet, 907–908.
- Yamada M, Shigemoto T, Kashiwamura KI, Nakamura Y, Ota T. (1977).
 Fear of emitting bad odors. Bull Yam Med School, 24:141–161.
- Prazeres AM, Fontenelle LF, Mendlowicz MV, de Mathis MA, Ferrão YA, de Brito NF, et al. (2010). Olfactory reference syndrome as a subtype of body dysmorphic disorder. J Clin Psychiatry, 77:87–89.
- Iwu CO, Akpata O. (1990). Delusional halitosis. Review of the literature and analysis of 32 cases. Br Dent J, 168:294–296.
- Osman AA. (1991). Monosymptomatic hypochondriacal psychosis in developing countries. Br J Psychiatry, 159:428–431
- Greenberg JL, Shaw AM, Reuman L, Schwartz R, Wilhelm S. (2016). Clinical features of olfactory reference syndrome: an internet-based study. J Psychosom Res, 80:11-6.
- Diagnostic and Statistical Manual for Mental Disorders, 5th Edition. (2013). Arlington, VA; American Psychiatric Association.
- IDC II: url https://icd.who.int/browsen/l-m/en#/http://id.who.int/ icd/entity/m9008568
- Zhou X, Schneider SC, Cepeda SL, Storch EA. (2018). Olfactory reference syndrome symptoms in Chinese university students: Phenomenology, associated impairment, and clinical correlates. Compr Psychiatry, 86:91-95.
- Wilhelm S, Phillips KA, Steketee G. (2013). Cognitive-Behavioral Therapy for Body Dysmorphic Disorder: A Treatment Manual. New York, NY: Guilford Press.
- Greenberg JL, Berman NC, Braddick V, Schwartz R, Mothi SS, Wilhelm S. (2018). Treatment utilization and barriers to treatment among individuals with olfactory reference syndrome (ORS). J Psychosom Res, 105:31-36.
- Eisen JL, Phillips KA, Baer L, Beer DA, Atala KD, Rasmussen SA. (1998). The Brown Assessment of Beliefs Scale: reliability and validity. Am J Psychiatry, 155:102-108.
- Phillips KA, Hart A, Menard W, Eisen JL. (2013). Psychometric evaluation of the Brown Assessment of Beliefs Scale in body dysmorphic disorder. J Nerv Ment Dis, 201:640-643.

TABLE 1: KEY CLINICAL FEATURES OF OLFACTORY REFERENCE SYNDROME

Clinical Feature

% of Patients, or Mean ± Standard Deviation

Source of Odor ²	
Mouth	75.00%
Armpits	60.00%
Genitalia	35.00%
Anus	30.00%
Feet	30.00%
Skin	25.00%
Groin	10.00%
Hands	10.00%
Head/Scalp	10.00%
Under Breasts	5.00%
Total different # of sources	2.9 ± 1.4

Description of Odor²

Bad breath	75.00%
Sweat	65.00%
Other smell ³	65.00%
Flatulence/Fecal	30.00%
Urine	20.00%
Vaginal	10.00%

Other Characteristics of Odor

Olfactory hallucinations	85.00%
Level of insight (Brown Assessment of Beliefs Scale [BABS]) ⁴	20.6 ± 3.7 (delusional/ absent insight range)
Insight (% with delusional/absent insight on BABS) ⁴	84.60%
Referential thinking (ideas or delusions of reference; lifetime)	88.30%

Olfactory Reference Syndrome (continued)

TABLE 1: KEY CLINICAL FEATURES OF OLFACTORY REFERENCE SYNDROME (CONTINUED)

Excessive Compulsive Behaviors²

Smelling self	80.00%
Showering	68.40%
Changing clothes	50.00%
Seeking reassurance	45.00%
Dieting/unusual food intake	45.00%
Brushing teeth	40.00%
Laundering clothes	30.00%
Comparing to other people	30.00%
Other behavior ⁵	30.00%
At least one compulsive behavior	95.00%
Total # of compulsive behaviors	4.2 ± 2.0

Items Used to Mask Odor²

Perfume/Fragrance/Powder	70.00%
Gum	60.00%
Deodorant	55.00%
Mints	55.00%
Mouthwash	50.00%
Toothpaste	30.00%
Clothes	25.00%
Other ⁶	25.00%
At least one item used to mask odor	100.00%
Total # of items used to mask odor	4.0 ± 2.2

Course of Illness

Age of ORS onset	15.6 ± 5.7
ORS onset < 18 years old	65.00%
Course of odor concerns over time	
One set of odor(s) that started at same time and did not change	38.90%
New odors added to ongoing previous odors	44.40%
Complex additions and remissions of odors	16.70%

FOOTNOTES

- Table is adapted from Phillips KA, Menard W. Olfactory reference syndrome: demographic and clinical features of imagined body odor. General Hospital Psychiatry 2011;33:398-406
- Total is greater than 100% because some patients reported multiple odors, odors that emanated from multiple body areas, multiple repetitive behaviors, or multiple masking strategies.

Functional Impairment Attributed to ORS (lifetime)

Avoidance of social interactions	73.70%
Avoidance of occupational/academic/role	47.40%
activities	
Housebound for at least 1 week	40.00%
GAF (Global Assessment of Functioning)	47.5 ± 13.2
(current) ⁷	

Suicidality

History of suicidal ideation	68.40%
History of suicidal ideation attributed primarily to ORS	47.40%
Attempted suicide	31.60%
Attempted suicide primarily due to ORS	15.80%

Violence⁸

History of physical violence	50.00%
History of physical violence attributed primarily	21.40%
to ORS	

Treatment (lifetime)

Psychiatric hospitalization	52.60%
Psychiatric hospitalization attributed primarily	31.60%
to ORS	

- Other smells were (n=1 for each): "like wearing sanitary napkins too long," "unpleasant vaginal odor," ammonia, "bad," "body odor/mucus/post nasal drip," "body odor/rotten odor/morning breath," "hard/unpleasant smell," "like 5 day-old food and cigarette smoke," oily-fishy smell," and "vegetable soup/putrid body (odor)."
- The Brown Assessment of Beliefs Scale (BABS) classifies false beliefs as characterized by excellent, good, fair, poor, or absent insight/ delusional belief (19,20). On the BABS, mean scores for ORS are in the absent insight/delusional range, for BDD are in the poor insight range, and for OCD are in the good insight range.
- Other excessive behaviors were as follows; scrapes tongue/coughs to remove bacteria on tonsils/talks softly/uses feminine wash, scrapes back of tongue/checks tonsils to pull mucous off them, uses spoon to scrape skin on tongue and inside of mouth, checks breath by blowing into nose/drinking water, frequent haircuts/avoids hats, drinks lots of fluids.
- Other items/behaviors used to mask the odor were as follows (n=1 for each); spraying alcohol on self and furniture/wearing heavy underwear, putting cornstarch under feet, putting toilet paper in underwear, crossing legs/putting toilet paper in underwear, using air fresheners.
- The mean GAF score reflects serious symptoms or serious functional impairment.
- Physical violence was defined as motor behavior that physically injured another person or caused significant property damage.

Olfactory Reference Syndrome (continued)

TABLE 2: KEY RECOMMENDATIONS FOR CLINICAL PRACTICE¹

Be familiar with ORS and its clinical features; it is more common than generally recognized.

Do not assume that ORS is simply a symptom of another psychiatric condition, such as depression, a psychotic disorder, BDD, or OCD; focus specifically on ORS when providing treatment.

Screen patients for ORS, especially those with high levels of social anxiety or social avoidance, referential thinking, or performance of the repetitive or camouflaging behaviors in Table 1.

For selected patients, consider a neurologic workup to rule out a neurologic explanation for olfactory hallucinations, such as temporal lobe epilepsy.

Medication is strongly recommended for patients with more severe ORS symptoms, especially those who are very impaired in terms of functioning, are severely depressed, or are more highly suicidal. Medication is also a good option when symptoms are mild or moderate in severity, especially if co-occurring disorders are present that may respond to similar medication (such as BDD, OCD, social anxiety disorder, or depression).

Serotonin-reuptake inhibitors — at high doses if lower doses are not effective — are recommended as the first-line medication for ORS (similar to BDD and OCD).

Atypical neuroleptics (such as aripiprazole or risperidone) may potentially be helpful in combination with an SRI (similar to BDD and OCD). These medications should especially be considered if an adequate trial with an SRI is not sufficiently helpful or if problematic agitation, very severe depression, marked impairment in functioning, worrisome suicidal thinking, or suicidal behavior are present.

Cognitive-behavioral therapy that is tailored to ORS is also recommended, especially for more severe ORS symptoms. It is also a good option when symptoms are mild or moderate in severity. Core components of CBT appear to consist of cognitive therapy, exposure with behavioral experiments, and ritual prevention.

Given the presence of obsessions, repetitive behaviors (rituals), poor or absent ORS-related insight, depressive symptoms (usually present), and often-prominent social anxiety and avoidance, CBT for ORS appears most similar to that for BDD. In the author's experience, an evidence-based treatment manual for BDD can easily be modified to effectively treat ORS¹⁷.

Many individuals with ORS desire non-mental health medical treatment for ORS concerns, such as removal of sweat glands or a tonsillectomy, which does not appear to be effective.

Because ORS-related insight is usually absent (i.e., ORS beliefs are usually delusional in nature), and because many individuals with ORS desire non-mental health medical treatment for ORS concerns, motivational interviewing is often needed to engage and retain patients in mental health treatment.

FOOTNOTES

 Because research evidence on ORS is very limited, these recommendations are also based on the author's clinical experience with ORS and may change as research studies are done.

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**.

AMITA HEALTH CENTER FOR ANXIETY AND OCD AND THE SCHOOL ANXIETY / SCHOOL REFUSAL PROGRAM

ABBHH, 1650 Moon Lake Blvd Hoffman Estates, IL 60169 (847) 755-8566 AHBHHHEAnxiety@amitahealth.org AMITAHealth.org

AMITA HEALTH FOGLIA FAMILY FOUNDATION RESIDENTIAL TREATMENT CENTER

801 Gloucester Dr.
Elk Grove Village, IL 60007
(847) 981-5900
FogligResidentialIntake@an

FogliaResidentialIntake@amitahealth.org AMITAHealth.org

We are excited to announce that we are hiring for all positions at the Foglia Residential Treatment Center. We are looking for anxiety and substance use therapists, nurses, case managers, and residential techs. We are also looking for therapists in our PHP/IOP as well for anxiety and substance abuse. If you are looking for a job where you will get to use CBT and ERP, as well as work with a team that is like minded in their treatment focus, then AMITA Health would love to meet with you and see if a position with us might fit your career needs.

AMITA Health is the largest hospital system in Illinois, and continues to grow. Our services for Anxiety, OCD, Substance Abuse, and Co-Occurring Disorders are all evidence based practices. We continue to work on new ways to engage our patients, such as using Virtual Reality Treatments and medication assisted SUD treatments.

If you would like to come to see our services and locations, we would welcome you to apply for any of our open positions to see if working at AMITA Health might be best for you. Please go and apply at:

amitahealth.org/about-us/careers.

THE ANXIETY AND OCD TREATMENT CENTER

8832 Blakeney Professional Drive Suite 105 Charlotte, NC 28277 (704) 631-3980

kevin@anxietyandocdtreatmentcenter.com anxietyandocdtreatmentcenter.com

The Anxiety and OCD Treatment Center in Charlotte, NC is pleased to welcome Dr. M. William Futtersak, PhD to our growing team of clinicians experienced in treating anxiety and OCD-related disorders.

Dr. Futtersak is a licensed clinical psychologist who has dedicated a career to treating adults, children, and adolescents with a wide variety of individual, family, work, and school related difficulties. As a CBT trained therapist, Dr. Futtersak has focused his attention on delivering creative and effective treatments for OCD, anxiety, panic, and stress related medical conditions. Dr. Futtersak maintains particular interests in treating clients who suffer long-standing obsessive thoughts as well as clients with persistent obsessive and compulsive patterns. He also has special interests in treating social anxiety and agoraphobia, including helping those with driving problems and fears of flying.

We look forward to Dr. Futtersak's contribution to our team and our mission of treating anxiety and OCD-related disorders in children, adolescents and adults.

THE ANXIETY TREATMENT CENTER OF SACRAMENTO, ROSEVILLE, AND EL DORADO HILLS

10419 Old Placerville Road, Suite 258 Sacramento, CA 95826

1899 East Roseville Pkwy Suite 140 Roseville, CA 95661

(916) 366-0647

drrobin@atcsac.net anxietytreatmentexperts.com

The Anxiety Treatment Center of Sacramento is excited to announce that we have moved into our new building (address listed above)! This new location is centrally located next to restaurants, hotels, public transportation, and only 3 minutes from Hwy 50. As we have doubled in size, our new facility offers rooms specifically designated for mindfulness, interoceptive exposures, yoga, art therapy, and an expanded children's program. Our Roseville and El Dorado Hills facilities remain in the same locations.

With our expansion, we have also opened our new Center for Depression and Treatment Resistant Symptoms. We

Institutional Member Updates (continued)

offer a framework based in Recovery-Oriented Systems of care promoting elements of dignity, empowerment and personal growth, values, community involvement, commitment to recovery, and the development of services to support the complex, long-term needs for those struggling with depression. A strong component of Cognitive Behavioral Therapy (CBT) and community exposures will be emphasized in both our Intensive Outpatient Treatment Program (IOP) that is offered five days per week and individual-based therapy. Acceptance and Commitment Therapy (ACT), Equine Assisted Activities (EAA), Self-Compassion, and Mindfulness-based work will be included in our therapeutic treatment modalities.

BEHAVIOR THERAPY CENTER OF GREATER WASHINGTON

11227 Lockwood Drive Silver Spring, MD 20901 (301) 593-4040

info@behaviortherapycenter.com behaviortherapycenter.com

OCD Awareness Week: BTC was present for the OCD Capital Walk and hosted a screening of the movie about children with OCD, "Unstuck" in Silver Spring. We enjoyed meeting OCD sufferers, their friends, and family.

Student becomes master: We welcome our newest addition, Kevin Young, PhD, a prior BTC extern from George Mason University who recently completed his fellowship at University of Kansas Medical Center.

BTC is involved in a research collaboration with American University, in the second phase of validating Comprehensive Behavioral Treatment (ComB) for body-focused repetitive behaviors, comparing a ComB treatment group with a minimal attention control group.

Groups: Drs. Gloria Mathis and Michael Lent are running an exposure group for anxiety disorders/OCD that involves "field trips" for In Vivo exposures.

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

BTC's professionally-assisted GOAL OCD support group still runs strong. Contact Julia Goolsby, PhD, postdoctoral fellow and group coordinator at 301-593-4040, extension 230 for inquiries about our groups or other services.

CBT CENTER OF WESTERN NC, INTENSIVE EXPOSURE PROGRAM FOR ADULTS WITH OCD

1085 Tunnel Rd, Suite 7A
Asheville, NC 28805
828) 350-1177
helder@behaviortherapist.com
behaviortherapist.com/ocd

The CBT Center of WNC currently offers an intensive exposure program (IEP) for adults with OCD. Our program uses the gold standard for the treatment of OCD, or exposure and response prevention (ERP).

The active treatment phase of our IEP (after phone screening, an initial assessment to determine eligibility, and a first individual session with the Program Director Dr. Haley Elder) consists of 3 hours/day, 3 days/week for approximately 3 weeks, with the option of adding additional weeks of treatment depending on each client's progress. The primary bulk of the program involves brief group work with participating clients involving goal-setting, review of homework from the previous treatment day, psychoeducation surrounding symptoms, and didactics with the majority of daily session time being spent engaged in either individual or group ERP with behavioral coaches or the Program Director. There is a biweekly group for loved ones of those currently participating, which will allow opportunities for education and support. Lastly, a medication and nutrition consultation is provided by Dr. Signi Goldman, the Medical Director of our program.

CENTER FOR OCD & ANXIETY-RELATED DISORDERS (COARD)

Saint Louis Behavioral Medicine Institute 1129 Macklind Avenue St. Louis, MO 63110 (314) 534-0200, Ext. 407

sue.mertens@uhs.com slbmi.com

Staff News: One of our staff therapists, Gregory Peebles, MAC, PLPC, recently completed a course of training in Radically Open DBT. He is interested in exploring the application of some elements of the approach to enhance the treatment of OCD-Related Disorders.

[Correction: In the last edition of the OCD Newsletter, we incorrectly listed the academic affiliation of one of our new practicum students, Meghan McDarby, as Southern Illinois University. Her correct affiliation is Washington University.]

Institutional Member Updates (continued)

Clinical Fellowships in OCD & Anxiety-Related Disorders: We are now accepting applications for the 2019-20 academic year. Visit our website for more information.

OCD Awareness Week: COARD was pleased to participate in this important effort to educate the public about OCD and related disorders. Our Center was a co-sponsor of the 4th annual St. Louis OCD Mini-Conference, which included the COARD Director, Dr. Alec Pollard, as a featured speaker.

COARD Joins Efforts to Form a Missouri Affiliate: Dr. Sam Kramer from the COARD clinical staff recently joined the state-wide effort to establish a Missouri affiliate of the IOCDF. The project was initiated by therapists Shanda Curiel, PsyD (Kansas City), Beth Brawley, LPC (St. Louis), and Diane Prost, LPC (St. Louis). The group is reaching out to other areas of the state to solicit participation.

CENTER FOR OCD AND RELATED DISORDERS AT COLUMBIA/ NYSPI

1051 Riverside Drive, Unit 69 New York, NY 10032 (646) 774-8138

marissa.raskin@nyspi.columbia.edu columbiapsychiatry.org/ocd

Our research program is dedicated to improving the lives of people with OCD by conducting cutting edge research to transform how we understand and treat this disorder. For the patients of today, we study how best to deliver current and novel treatments. For the patients of tomorrow, we partner with brain imagers and scientists to examine the causes of OCD.

Our current studies offer treatment for individuals who are on medication, and those who are not. For those currently taking an antidepressant, and still experiencing OCD symptoms, we are exploring the efficacy of a novel medication. For individuals interested in psychotherapy, we are collaborating with nOCD on a mobile application designed to increase accessibility to Exposure and Response/Ritual Prevention therapy.

We have also expanded our mission to the global stage. With collaborators from India, South Africa, the Netherlands, and Brazil, we seek to identify potential brain signatures of OCD that are consistent across cultures. In addition, we have received funding from the Foundation to investigate avoidance behaviors in OCD with our partners, Drs. Liz Phelps and Cate Hartley.

CENTER FOR PSYCHOLOGICAL & BEHAVIORAL SCIENCE

11380 Prosperity Farms Road Suite 209A Palm Beach Gardens, FL 33410 (561) 444-8040

treatment@psychologyandbehavior.com psychologyandbehavior.com

Winter is officially here. Although the bears might be hibernating, it's the perfect opportunity for you to wake up and take your life back! In addition to outpatient therapy, intensive outpatient therapy, and "OCD Boot Camp," we are again offering an 8-week "Introduction to OCD" group.

This group is similar to our social anxiety and panic groups, in that it combines weekly CBT-based psychoeduation modules with opportunities to complete exposures in a group setting. We hope that you'll be a part of it. Adult and child groups are currently forming.

If you're interested in receiving information, visit our sign-up sheet at **recoverfromocd.com**.

We will also continue to offer free support groups for OCD. Our next adult groups will be held on January 8, February 12, and March 12, 2018, at 7pm in our office. As always, these groups provide ample opportunities to connect with other individuals with OCD in a supportive, healthy setting.

Our support groups for children and teens will continue to meet regularly throughout 2018, but these dates are still being determined. See our events calendar for more details.

Happy Holidays! We hope to see you in 2019!

CHILD MIND INSTITUTE

101 East 56th Street New York, NY 10022 (646) 625-4252

jerry.bubrick@childmind.org childmind.org

The Child Mind Institute is excited to announce the launch of our new Parents Guide to OCD. This guide explains the often confusing behaviors that can be associated with OCD in children, and the effective treatments for helping kids who develop it. It also provides parents with strategies for how to work with teachers and administrators to help understand OCD. You can read and download our guide at childmind.org/ocdguide.

We have also had great success with our intensive OCD treatment programs. A recent alumna of our 4-week intensive program showed dramatic gains. Before

Institutional Member Updates (continued)

treatment, she had emetophobia, wouldn't eat or drink all day, and would spend all day in the nurse's office. After 2 weeks in treatment, she transitioned back to school for a week, and the school noted that she was "like a different person." At the end of treatment, she was participating in classes and eating in the lunchroom. We are thrilled to share in her accomplishments.

COGNITIVE BEHAVIOR THERAPY CENTER

16579 Los Gatos Almaden Road Los Gatos, CA 95032 (408) 384-8404

info@cbtsv.com

cognitivebehaviortherapycenter.com

We relocated our Silicon Valley office from Saratoga to Los Gatos. The move allowed us to expand and grow our practice. We hired on an MFT Intern, Jessica Helbush, to join our team. Jessica came to us from the Cupertino Union School District, where she worked with clients and their families in school settings. She provides evidence-based therapy for anxiety and OCD disorders to clients of all ages in our Silicon Valley office.

We hired a new "high energy" Center Assistant, Cindy Tryphonas, to manage our new client intake process and other administrative activities. With Cindy's help, we will continue to grow our center in the Silicon Valley. Cindy graduated magna cum laude with a Bachelor's degree in Psychology.

We are seeking a talented therapist with a strong interest in learning CBT and ERP to join our growing team in Los Gatos. The position is open to LMFT, LPCC, LCSW, PsyD/PhD and Registered Interns. If interested, please visit our website for more information on how to apply: cognitivebehaviortherapycenter.com/jobs.

EAST BAY BEHAVIOR THERAPY CENTER

45 Quail Court, Suite 204 Walnut Creek, CA 94596 (925) 956-4636

drz@eastbaybehaviortherapycenter.com eastbaybehaviortherapycenter.com

We celebrated OCD awareness by offering a free, 2-hour training for clinicians on "Creating Flexible Exposures in Treating OCD and Related Anxiety Disorders using Acceptance and Commitment Therapy (ACT). We were excited to spread the word about how ERP can be delivered within an ACT frame. Bay Area clinicians who participated learned to:

- Describe how ACT capitalizes on the inhibitory learning model to shape exposure-based interventions for OCD;
- **2.** Harness valuing and committed action as processes to shape willingness to engage in exposure-based work;
- Apply ACT components of the hexaflex to augment ERP sessions; and
- 4. Use the "choice point model" as a clinical tool to discriminate values-based behaviors from OCD-driven behaviors when working with clients struggling with OCD.

And, we're preparing exciting news for 2019!

THE GATEWAY INSTITUTE

950 South Coast Dr, Suite 220 Costa Mesa, CA 92626 (714) 549-1030

419 30th Street, Suite 3 Oakland, CA 94609 (510) 444-4810

info@gatewayocd.com gatewayocd.com 18940 N Pima Rd, Suite 165 Scottsdale, AZ 85255 (480) 214-9543

The Gateway Institute in Costa Mesa, CA is pleased to announce our newest team member, Karen Alonso, LMFT. With over 10 years experience working with OCD, Karen will play a vital role in continuing to provide excellent treatment and care to our clients.

The Gateway Institute in Scottsdale, Arizona is pleased to announce our newest team member, Jenny Scheid, LPC. Jenny has joined our team to support clients with our 3-week intensive treatment program. Jenny also has a background in treating all forms of Eating Disorders. We are happy to have her join our team.

The Gateway Institute in Arizona is also proud to announce that we are in the process of creating a weekly OCD Treatment and Support group. This group will be on Wednesdays from 1:00-2:30 pm, and will be therapist-facilitated. If you would like to be a part of this group, please contact us.

The Gateway Institute is committed to providing accessible treatment for OCD and related conditions to as many people as possible and will continue to expand its locations. We will keep you updated as we continue to open new treatment facilities. Visit our website for more information.

Institutional Member Updates (continued)

HOUSTON OCD PROGRAM 708 E. 19th Street Houston, TX 77008 (713) 526-5055 info@houstonocd.org houstonocdprogram.org

OCD AND ANXIETY PROGRAM OF SOUTHERN CALIFORNIA

2656 29th Street, Suite 208 Santa Monica, CA 90405 (310) 488-5850 info@socalocd.org socalocdprogram.org

We are still feeling the excitement from October's OCD Awareness Week events. Our clinical team participated in various events throughout the week, including a Facebook Live Expert Panel Q&A as well as sponsoring and presenting at the 8th Annual OCD Texas Conference.

Houston OCD was especially excited to co-host, along with Peace of Mind, "The Bergen 4-Day OCD Treatment: The USA Journey Begins in Houston," presented by Drs. Gerd Kvale and Bjarne Hansen. Drs. Kvale and Hansen were recently selected as two of TIME Magazine's 50 Most Influential People in Health Care for 2018. This list is curated by TIME's health reporters and editors and recognizes 50 people who changed the state of health care this year, and bear watching for what they do next.

"We both think Houston is a perfect place to launch the Bergen 4-Day Treatment (B4DT) since the infrastructure is there and also a highly competent, caring and dedicated community of therapists who wants to ensure that the patients will have access to treatments that work. The openness and readiness combined with scientific rigor is a perfect starting point."

– Gerd Kvale, Co-Founder B4DT

The B4DT founders were received with enthusiasm in the Houston community and we are looking forward to continued collaboration to bring this innovative approach to Houston in 2019!

MCLEAN HOSPITAL OCD INSTITUTE

115 Mill Street Belmont, MA 01886 (617) 855-2776

ocdiadmissions@partners.org mcleanhospital.org/programs/ocd-institute

We have had several developments at the OCDI's Office of Clinical Assessment and Research (OCAR) since the summer. First, we have published 3 papers over the past few months in Journal of Clinical Psychology, Behavior Therapy, and in Biological Psychiatry: Cognitive Neuroscience and Neuroimaging. We attended the IOCDF's Annual OCD Conference and presented our recent findings in symposia and poster presentations, including a symposium about marginalized identities in OCD treatment and research, chaired by our post-doctoral fellow Lauren Wadsworth, PhD, and speakers from OCAR including Meghan Schreck, PhD, and Sriramya Potluri, BA. We are beginning to use this type of work in considering identities to inform the data we collect from patients at admission. Additionally, Martha Falkenstein, PhD, Administrative Director of OCAR, received a Young Investigator Award from IOCDF for a project titled, "Neural Mechanisms of Avoidance in Exposure and Response Prevention for OCD." This study will investigate whether ERP treatment outcomes can be improved with the addition of a computerized cognitive training.

MOUNTAIN VALLEY TREATMENT CENTER

703 River Road 2274 Mt. Moosilauke Highway Plainfield, NH 03781 Pike, NH 03780

(603) 989-3500

jfullerton@mountainvalleytreatment.org mountainvalleytreatment.org

On Tuesday, October 9th, Mountain Valley was pleased to host the 3rd Seacoast Anxiety and OCD Symposium in Portsmouth, NH. This unique event focused on the latest information for treating Obsessive Compulsive and Anxiety Disorders. Featuring multiple interactive sessions by local experts in the field, focusing on CBT modalities such as DBT, ACT and ERP, clinicians from around the New Hampshire Seacoast Area, and beyond, learned about evidence-based treatment for OCD and anxiety disorders.

The Symposium agenda featured:

I. The "Waves" of CBT: The Movement to Process-Based CBT and Why It Matters, presented by Seoka Salstrom, PhD, Hanover Center for Cognitive Behavioral Therapies, Hanover, NH

Institutional Member Updates (continued)

II. DBT and Exposure & Response Prevention, presented by Ryan Madigan, PsyD., Boston Child Study Center & Boston Child Center Los Angeles

III. Acceptance & Commitment Therapy (ACT) and ERP, presented by Jeanette Nogales, LCMHC, MEd, CAGS, Mountain Valley Treatment Center and Seoka Salstrom, PhD.

IV. Panel Discussion: Barriers for Clinicians Implementing ERP, facilitated by Elizabeth Ellis Ohr, PsyD, Private Practice, Portsmouth, NH and Szu-Hui Lee, PhD., Phillips Exeter Academy and Private Practice, Exeter, NH.

NORTHWELL HEALTH OCD CENTER

Zucker Hillside Hospital 75-59 263rd Street Glen Oaks, NY 11004 (718) 470-8052 apinto1@northwell.edu/

northwell.edu/ocdcenter

The Northwell Health OCD Center offers evidence-based, comprehensive treatment for OCD and related disorders, including body dysmorphic disorder and obsessive compulsive personality disorder. 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. Please call for more information about our Center and to schedule a confidential screening.

We are excited to introduce Christine D'Urso, PhD, licensed clinical psychologist, as the newest member of our OCD Center treatment team. Dr. D'Urso specializes in providing empirically supported treatments for OCD and anxiety disorders. She earned her PhD in clinical psychology from Hofstra University, completed her pre-doctoral internship at the Institute of Living in Hartford, CT, and completed her post-doctoral fellowship at the Center for Cognitive-Behavioral Psychotherapy in NYC. Dr. D'Urso believes in goal-oriented, patient-centered, motivational strategies that seek to strengthen collaboration and to facilitate resiliency and pride in one's progression towards treatment goals. Welcome Dr. D'Urso!

NW ANXIETY INSTITUTE

32 NE 11th Ave Portland, OR 97232 923 NE Couch St Portland, OR 97232

(503) 542-7635 info@nwanxiety.com nwanxiety.com

NW Anxiety Institute and NW Anxiety Pediatrics have some exciting news! In November 2018, NWAI enhanced both IOP programs (adult & pediatric) with two specialized wellness groups. The "sit with it" yoga-based mindfulness group, led by clinical psychologist and yoga instructor, Dr. Andrea Millen, allows individuals the practice of "sitting" with intrusive thoughts while connecting to their present experience. Another creative artist and author, Kathleen Lane, began leading a creative expression & writing group designed to support individuals as they process through anxiety and gain strength through facing their fears.

NWAI also added four pretty rad team members to the clinical team and welcomed their first doctoral student intern. The increase in staff and clinical services allows NWAI to serve more patients from the Pacific NW (and beyond) who struggle with anxiety disorders and OCD.

As the school year kicked off, Kevin Ashworth, clinical director, kept busy and represented NWAI during OCD Awareness week by presenting at three different schools, educating parents and teachers on how to better understand and support students living with anxiety disorders.

PALO ALTO THERAPY

407 Sherman Avenue, Suite C Palo Alto, CA 94306 940 Saratoga Ave. Ste. 240 San Jose, CA 95129

(650) 461-9026

info@paloaltotherapy.com paloaltotherapy.com/ocd

We have lots to celebrate at PAT, we have new additions to the team, as well as our group starting! All of our therapists specialize in CBT 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 pleased to welcome Florina Petcu, LMFT to our Palo Alto location and Michele Hart, LPCC and Rema Nehme, LMFT to our San Jose location. We are excited to have these new therapists with their unique specialties and training.

Institutional Member Updates (continued)

Anxiety to Wellness Class: Our 8-week class will be offered in January and we are open for enrollment. This CBT class consists of teaching and practicing anxiety-reducing techniques and group support to teens and adults.

We Are Hiring! We are actively hiring for new therapists so that we can 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 for us, please send them our way!

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

RENEWED FREEDOM CENTER FOR RAPID ANXIETY RELIEF

Little Thinkers Center 1849 Sawtelle Blvd, Suite 710 Los Angeles, CA 90025 (310) 268-1888

info@RenewedFreedomCenter.com RenewedFreedomCenter.com

Renewed Freedom Center would like to introduce the Little Thinkers Center founded by Dr. Jenny C. Yip, PsyD., ABPP, established on August of 2018. The goal of the Little Thinkers Center is to help children improve their critical and creative thinking skills, and give them specific tools to tackle challenges academically, socially, and emotionally. We do this by giving children specific experiential thinking games that are fun yet challenging enough to build higher order thinking skills. Too many children today are identified with learning challenges and stress that inhibits learning - 2.4 million in U.S. public schools. The positive results of building these thinking skills include: enhanced problem-solving capabilities, stronger academic performance and curiosity, improved social interactions, and most importantly. authentic self-confidence and resiliency. All of this fosters an "I can" attitude that is needed for self-esteem.

ROGERS BEHAVIORAL HEALTH

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

rramsay@rogersbh.org rogersbh.org

Rogers participated in several community OCD Awareness Week events and sponsored screenings of "Unstuck: an OCD Kids Movie" in Chicago, San Francisco, Pewaukee, Appleton, Nashville, and Minneapolis. Outpatient centers also created displays to help people learn about OCD and encouraged themed-dress days, such as wearing mismatched clothes.

Rogers-Hinsdale opened in November, offering partial hospitalization programs for kids and teens, and adults with OCD and Anxiety. Events are being held to introduce the site to referring professionals in the community.

In early 2019, Rogers is opening a new location in Miami, treating child, adolescent, and adult patients in partial hospitalization programs for OCD and Anxiety. Rogers—Miami will be fully bilingual, serving both English- and Spanish-speaking patients. Additionally, existing locations in Appleton, Philadelphia, and Walnut Creek have expanded or are soon expanding their OCD and Anxiety programs.

In early November, Rogers sponsored a continuing education event titled "Obsessive-Compulsive Disorder: From diagnosis to intervention" with OCD Wisconsin, an affiliate of the IOCDF. The event at the Waukesha County Technical College with Rogers also featured clinicians Dr. David Jacobi, PhD; Dr. Brenda Bailey, PhD; and Dr. Keri Brown, PhD.

STANFORD TRANSLATIONAL OCD PROGRAM - RODRIGUEZ LAB

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

ocdresearch@stanford.edu http://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 these studies by calling (650-723-4095) or emailing us (ocdresearch@stanford.edu or clutterhelp@stanford.edu).

The Stanford Translational OCD program, in collaboration with the OCD SF Bay Area IOCDF affiliate and the

Institutional Member Updates (continued)

Department of Psychiatry and Behavioral Sciences of Stanford University, organized a free community event during the OCD Awareness Week: "OCD Update: Advances in Intensive and Online Therapy and Brain Stimulation." The event took place at the Li Ka Shing Learning and Knowledge Center of Stanford University on Saturday October 6th. Faculty from Stanford University and representatives from the private sector and industry spoke on current standard of care, novel treatments, and research advances for OCD. Afterwards, an interactive question and answer session provided the opportunity for panelists and attendees to discuss current OCD treatments and research. A highlight of the event was recognition of our partners: awards were presented to Scott Garnet, Jennifer Park, Stephen Smith, and Nolan Williams in grateful recognition of their outstanding contributions to the OCD community.

STRESS & ANXIETY SERVICES OF NJ, LLC

A-2, Brier Hill Court 195 Columbia Turnpike Suite 120 East Brunswick, NJ 08816 Florham Park, NJ 07932

(908) 705-5659

allen.weg@StressAndAnxiety.com StressAndAnxiety.com

Stress and Anxiety Services of New Jersey is pleased to announce that we have officially instituted telehealth services, available to our clients, old and new. There are numerous guidelines and restrictions about this service, and we encourage those interested to read more about it at our website.

Dr. Zach Infantolino will continue as a clinical staff member at our Center, now that he has recently obtained his NJ Psychology license after completing a one year post-doc fellowship with us. Dr. Stacey Dobrinsky recently joined our staff from OCDI Jr. at McLean Hospital , and has just received her NJ psychology license as well. We welcome Dr. Rivka Halpert to our clinical staff as our newest post-doc fellow.

Dr. Charity Truong has attained a regular position as returning lecturer on CBT treatment for anxiety disorders at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. Dr. Rachel Strohl presented on anxiety treatment for psychiatric fellows at the University of Medicine and Dentistry of New Jersey at Rutgers University on November 11th, and Dr. Allen Weg presented on Treating Anxiety in the Classroom at Joseph Kushner Hebrew Academy in Livingston, NJ on Nov 2nd.

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**.

Why Therapists Don't Use ERP for Youth with OCD and What We Can Do About It: Insights from a National Survey of Private Practice Therapists

by Andrew G. Guzick, MS & Adam M. Reid, PhD

On Increasing Utilization of Evidence-Based Treatment for OCD

I am delighted to introduce Andrew Guzick and Adam Reid's article on the need to promote therapist use of evidence-based treatments. The authors provide a thoughtful summary of the many challenges involved, but also remind us why it is so important to address the problem. Too many people with OCD still do not receive proper treatment, which, of course, was the reason IOCDF initiated the Behavior Therapy Training Institute (BTTI) over two decades ago. We have come a long way since then, but we have more work to do, as this informative article reveals.

C. Alec Pollard, PhD Chair, IOCDF Clinical Training Subcommittee

Most members of the IOCDF community understand how challenging it can be to seek out professional help for OCD or a related disorder. Many people do not know where to look, and if they do, they may not have the resources available to access care. Even when those with OCD overcome these barriers and meet with a mental health professional, they are rarely offered the opportunity to try exposure and response prevention (ERP), the most well-supported therapy for treatment of OCD (e.g., Hipol & Deacon, 2013; Peris et al., 2015). Sadly, this appears to be especially true for kids and teens with OCD (Reid, et al., 2018; Whiteside et al., 2016).

WHY MORE THERAPISTS DON'T USE ERP

In a survey of over 250 private practice therapists across the United States, we recently found that ERP was used just 30% of the time to treat kids with OCD (Reid et al., 2018). Comparatively, breathing retraining and muscle relaxation strategies, two techniques with far less research to support their effective treatment of OCD, were used almost half of the time by private practitioners. Unfortunately, it seems that most therapists perceive ERP to be just one more tool in their toolbox, rather than the core treatment element that so many of us have learned to rely on. This even appears to be true among private practitioners who are often promoted as OCD specialists (Hipol & Deacon, 2013; Reid, et al., 2018; Whiteside et al., 2016).

Why are therapists all across the country using ERP so rarely? It's clearly not due to a lack of evidence, as we have an enormous amount of research that supports the power of this intervention (e.g., Ost, Havnen, Hansen, and Kvale, 2015; Freeman et al., 2018; Peris et al., 2015). While far from perfect, we also know that ERP makes sense and works for people; every year patients and clinicians tell countless stories of overcoming OCD by participating in ERP while at the IOCDF's Annual OCD Conference. During my clinical work in the residential program at McLean Hospital's OCD Institute, I have seen ERP change lives even for those with the most severe cases of treatment refractory OCD.

BARRIERS TO PROFESSIONAL USE OF ERP

TREATMENT BIAS

One major barrier is how practitioners think about ERP. Therapists often hold biases against this treatment. Many believe that patients cannot tolerate the stress of exposures, that they may lose control when directly confronting their fears, and that ERP leads to treatment dropout (Deacon et al., 2013; Reid et al., 2018). I imagine many of you would take issue with these beliefs. We know that individuals with OCD are resilient and can handle the distress ERP brings. Furthermore, a quantitative analysis of 37 ERP studies showed that patients who do ERP drop out of therapy at similar rates to those who participate in other forms of psychotherapy (Ost et al., 2015). Additionally, there is no research to suggest that ERP can lead to worsening of symptoms for people with OCD. Exposure and response prevention has the most research support of any therapeutic intervention. The idea that ERP will hinder the therapeutic bond between therapist and patient is also false (e.g., Kendall et al., 2009). In our clinical experience, it seems to actually strengthen this bond for many cases.

LOGISTICAL BARRIERS

Logistical barriers are an emerging challenge to ERP utilization that warrants more research. In a preliminary study we conducted, this was actually the top self-reported reason that community-based clinicians did not utilize more ERP (Reid et al., 2017a)! This is understandable when you consider that if a clinician lacks the flexibility to do 90-minute sessions, it can be very challenging to review homework, process the week, teach skills, design an exposure, conduct the exposure, process the exposure, and

Why Therapists Don't Use ERP for Youth with OCD (continued)

assign new homework all within one session. This gets even more challenging if it is necessary to perform an off-site ERP. Additional research on how to optimally design and implement ERP in a time-sensitive way would allow more therapists to practice ERP in the community.

LACK OF EDUCATION

Our findings suggest a key reason that clinicians use ERP so infrequently and hold these beliefs is that they simply do not have adequate education. Ninety-two percent of the private practice therapists we surveyed reported that they would benefit from more training in ERP, and unsurprisingly, those with more training used ERP more often. The IOCDF should be applauded for doing their part in addressing this major issue; the IOCDF's Behavior Therapy Training Institute (BTTI) has now trained thousands of clinicians in this treatment with some data to back its effectiveness (Reese et al., 2016).

Beyond the training offered at the IOCDF's Annual OCD Conference, the BTTI offers intensive, three-day workshops aimed at teaching clinicians how to implement ERP. To address the needs of kids and teens with OCD, they have recently developed the Pediatric BTTI, which specifically addresses the unique needs of this group, such as incorporating supportive family members into ERP. To think of the number of people who have benefitted from the thousands of graduates of the BTTI who are now equipped with ERP skills is a truly outstanding achievement.

BUILDING SUCCESSFUL ERP TRAINING MODELS

We now know of a few ingredients in training models that most successfully educate clinicians in a new form of therapy. One important component is the opportunity for continued consultation after training is over; for example, clinicians who trained in the BTTI used ERP more frequently if they consulted with experts or with peers after their training (Reese et al., 2016). One-time workshops or seminars do not seem to do the trick (see Reid & McHugh, 2018 for a review). The research also indicates that any graduate or post-graduate education needs to lean on experiential learning over didactic learning (Reid et al., 2017b, see Reid & McHugh, 2018 for a review). In this vein, another helpful model is a "train-the-trainer" method. This approach involves scaffolding in which skilled therapists train more junior clinicians under the supervision of an even more experienced therapist. This model has the potential to trickle down and reach more clinicians as more therapists become experienced teachers as well.

THE BEHAVIOR THERAPY TRAINING INSTITUTE FOR OCD: A PRELIMINARY REPORT

Published in the Journal of Obsessive Compulsive and Related Disorders, January 2016

By Hannah E. Reese, C. Alec Pollard, Jeff Szymanski, Noah Berman, Katherine Crowe, Elizabeth Rosenfield, and Sabine Wilhelm

The IOCDF organized twelve sessions of the Behavior Therapy Training Institute between 2008 and 2011. During these sessions, 350 therapists were trained to utilize cognitive behavioral therapy (CBT), including ERP, to treat patients with OCD. The BTTI sessions also provide a platform for therapists to consult with experts and peers regarding patient cases. Researchers surveyed training participants and found the following:

- Participants reported that, after the trainings, they were utilizing their ERP skills at a "more than moderate" level in their practice
- Participants who consulted with peers and experts after the BTTI session used their CBT and ERP skills with patients more often
- After attending the BTTI, a majority of participants reported that patients with OCD were being referred to them in greater numbers

Read the complete article: sciencedirect.com/science/article/pii/S2211364915300312

Perhaps the most systemic change that needs to occur, however, is that the education of psychologists, counselors, social workers, etc. needs to more consistently support evidence-based therapy, or therapy that is supported by science, like ERP. Clinicians often do not trust evidence-based forms of psychotherapy, suggesting that they are too rigid to apply to real-world individuals with unique situations; that their clinical intuition is more valuable than scientific evidence; that behavioral therapies like ERP do not adequately address the underlying causes of mental health problems; or that other untested treatments are likely equally effective (e.g., Lillenfeld et al., 2013). Graduate programs that emphasize science in their education will create a culture in which more therapists are eager to use evidence-based approaches like ERP.

Why Therapists Don't Use ERP for Youth with OCD (continued)

TRAINING MORE CLINICIANS IN ERP

The development of ERP is arguably the single greatest contribution to the individuals who suffer with OCD, but even those who have the resources to seek out therapy rarely get to try this treatment. Ensuring that as many young people as possible have access to ERP can set countless individuals with OCD on a positive trajectory for the rest of their lives. Successful dissemination of ERP will require an all-hands-on-deck approach, from individuals advocating for ERP on the ground, to organizations like the IOCDF creating opportunities for successful training, to governing bodies and graduate programs ensuring that early education fosters positive attitudes and opportunities for training in evidence-based forms of therapy like ERP.

Over the past several years, the IOCDF's Training Institute programs, including the BTTI, have provided hundreds of therapists with the opportunity to learn ERP techniques that can be applied in clinical practice. As a result, this program has increased the number of therapists worldwide who are qualified to effectively treat OCD and related disorders. If you are interested in supporting the IOCDF's efforts to train the next generation of therapists and increase access to effective treatment for all, we encourage you to consider donating to the Foundation's end-of-year campaign at iocdf.org/donate. Your gift will help the IOCDF continue to grow its provider training programs and ensure that therapists are able to build the skills they need to help individuals with OCD manage their symptoms and lead full and productive lives. For more information about the IOCDF's Training Institute, visit iocdf.org/training. O

BIOGRAPHIES

Andrew G. Guzick, MS, is a fifth-year doctoral student in Clinical and Health Psychology at the University of Florida (UF). During his graduate training, he has pursued research focused on better understanding ERP at the UF OCD Program, where he has also enjoyed serving as a therapist for individuals affected by OCD, anxiety, and related disorders.

Adam M. Reid, PhD, MSE, completed his doctoral training at the University of Florida in 2016 and subsequently completed an internship and post-doctoral fellowship at McLean Hospital/Harvard Medical School. He currently conducts research at the OCD Institute at McLean Hospital, works in private practice in the Boston area, and serves as a part-time psychologist at Groton School in Groton, MA. He has published over 30 publications and 10 book chapters. His primary research goals are to improve the quality of care, as well as access to this care, for youth with anxiety disorders and obsessive-compulsive and related disorders.

REFERENCES:

Deacon, B. J., Farrell, N. R., Kemp, J. J., Dixon, L. J., Sy, J. T., Zhang, A. R., & McGrath, P. B. (2013). Assessing therapist reservations about exposure therapy for anxiety disorders: The Therapist Beliefs about Exposure Scale. Journal of Anxiety Disorders, 27, 772-780.

Freeman, J., Benito, K., Herren, J., Kemp, J., Sung, J., Georgiadis, C., ... & Garcia, A. (2018). Evidence Base Update of Psychosocial Treatments for Pediatric Obsessive-Compulsive Disorder: Evaluating, Improving, and Transporting What Works. Journal of Clinical Child & Adolescent Psychology, 1-30.

Hipol, L. J., & Deacon, B. J. (2013). Dissemination of evidence-based practices for anxiety disorders in Wyoming: A survey of practicing psychotherapists. Behavior Modification, 37, 170-188.

Kendall, P. C., Comer, J. S., Marker, C. D., Creed, T. A., Puliafico, A. C., Hughes, A. A., ... & Hudson, J. (2009). In-session exposure tasks and therapeutic alliance across the treatment of childhood anxiety disorders. Journal of Consulting and Clinical Psychology, 77, 517.

Lilienfeld, S. O., Ritschel, L. A., Lynn, S. J., Cautin, R. L., & Latzman, R. D. (2013). Why many clinical psychologists are resistant to evidence-based practice: Root causes and constructive remedies. Clinical Psychology Review, 33(7), 883-900.

Öst, L. G., Havnen, A., Hansen, B., & Kvale, G. (2015). Cognitive behavioral treatments of obsessive—compulsive disorder. A systematic review and meta-analysis of studies published 1993—2014. Clinical Psychology Review, 40, 156-169.

Peris, T. S., Compton, S. N., Kendall, P. C., Birmaher, B., Sherrill, J., March, J., ... & Piacentini, J. (2015). Trajectories of change in youth anxiety during cognitive—behavior therapy. Journal of Consulting and Clinical Psychology, 83, 239.

Reese, H. E., Pollard, C. A., Szymanski, J., Berman, N., Crowe, K., Rosenfield, E., & Wilhelm, S. (2016). The Behavior Therapy Training Institute for OCD: A preliminary report. Journal of Obsessive-Compulsive and Related Disorders, 8, 79-85.

Reid, A. M., Bolshakova, M. I., Guzick, A. G., Fernandez, A. G., Striley, C. W., Geffken, G. R., & McNamara, J. P. (2017a). Common Barriers to the Dissemination of Exposure Therapy for Youth with Anxiety Disorders. Community Mental Health Journal, 53(4), 432-437.

Reid, A. M., Guzick, A. G., Fernandez, A. G., Deacon, B., McNamara, J. P., Geffken, G. R., ... & Striley, C. W. (2018). Exposure therapy for youth with anxiety: Utilization rates and predictors of implementation in a sample of practicing clinicians from across the United States. Journal of Anxiety Disorders, 58, 8-17.

Reid, A. M., & McHugh, R. K. (2018). Going beyond didactic trainings: How to increase utilization of cognitive-behavioral therapy in the community. K. S. Dobson & D. J. A. Dozois (Eds.). Handbook of Cognitive-behavioral Therapies (pp. XX), New York: Guilford Press.

Post-mortem Brain Research Holds Potential for Discovery of New OCD Treatments

by Susanne Ahmari, MD, PhD



Editors note: Susanne Ahmari, MD, PhD, is an Assistant Professor of Psychiatry at the University of Pittsburgh. There she leads the Translational OCD Laboratory, where researchers take a multidisciplinary approach to OCD research. She received the 2018 Breakthrough Award from the International OCD Foundation — a \$500,000 research grant — the largest ever provided to a researcher by the IOCDF.

Obsessive compulsive disorder (OCD) is a chronic, severe mental illness that affects 2-3% of people worldwide, and has been identified by the World Health Organization as a leading cause of disability. This severity and high prevalence highlights the need for improved treatments for OCD, particularly with respect to medications. Currently, selective serotonin reuptake inhibitors (SRIs) remain the first-line medication treatment for OCD, but only approximately 10% of patients experience remission with SRI treatment. Currently, we know very little about how the brains of people with OCD are different when compared with the brains of healthy individuals. By gaining a greater understanding of these differences and why they might be occurring, we can potentially open up new pathways to discover improved treatments, including new and more effective medications.

WHAT WE CURRENTLY KNOW ABOUT ABNORMAL BRAIN FUNCTION IN OCD

Brain imaging studies conducted over the past 25 years have consistently revealed hyperactivity in key regions of the brain in people with OCD. Hyperactivity has been observed in brain regions that are involved in making decisions (the orbitofrontal cortex, or OFC), selecting actions (the striatum), and regulating the flow of sensory information to the cortex

(thalamus). This excessive brain activity has been seen in people with OCD both when their OCD symptoms are triggered, and when they are just resting. However, we have almost no knowledge of the molecular and cellular changes that may be contributing to this abnormal brain function.

CHANGES IN GENE EXPRESSION IN THE OCD BRAIN

In order to start to solve this problem, our lab performed one of the first studies to examine gene expression in post-mortem brain tissue samples from people who had OCD during their lives. Specifically, we examined tissue samples from the OFC and striatum. Gene expression is the process through which a cell produces new molecules by using the cell's genes (i.e. DNA) as an instruction manual. Cells can increase or decrease the quantity of new protein molecules that they produce by increasing or decreasing gene expression. Our research found abnormal levels of gene expression when we looked at the OCD brains. Specifically, in the OFC, we found lower levels of a group of genes associated with transmitting electrical communication signals between neurons. This exciting finding led us to a larger question: what is causing these changes in gene expression in people with OCD?

WHAT CAUSES CHANGES IN OFC GENE EXPRESSION IN THE OCD BRAIN?

One possible explanation for our findings is that the thalamus — the brain region that regulates the flow of sensory information to other parts of the brain, including the OFC — is sending signals that are too strong in people with OCD. To try to compensate for this over-activity, the OFC may be trying to "turn down the volume" on the receiving end. Our theory is that the OFC changes the gene expression in the synapses that receive these overly-loud signals from the thalamus. If true, this would shift our way of thinking about the brain

Post-mortem Brain Research Holds Potential for Discovery (continued)

circuits involved in OCD, by placing greater emphasis on the thalamus, which is important for filtering sensory information from the outside world to the decision-making centers of the brain. Testing this theory is the next step in this exciting research that has been funded by the IOCDF Breakthrough Award. We have already begun performing experiments to test this idea.

IOCDF GRANT-FUNDED STUDY ON POST-MORTEM GENE EXPRESSION

In the first part of this project, we will directly examine gene expression in the thalamus of post-mortem brain tissue from people with OCD. We will then compare this to gene expression in people who didn't have OCD and are matched for age, sex, and ethnicity. We are predicting that in people with OCD we will see increases in expression of genes that are important for "rhythmic firing." Abnormalities in rhythmic firing could explain the overly-loud signals that we suspect the OFC may be receiving. By using an approach called RNA-sequencing (RNA-seq) to identify the changes in gene expression, we can directly test this idea while also exploring possibilities that we have not predicted. This will allow us to perform analyses that may uncover the gene expression networks that are most affected in OCD patients.

In the second part of the project, we will perform more precise analysis of the changes in gene expression we observed in the OFC. We will do this by localizing them to specific cell layers and cell types. In addition, we will determine whether, in people with OCD, the networks of neurons in the OFC have a reduced number of contact points — a possible alternative explanation for the decreases in OFC gene expression that we observed in our initial study.

Finally, in the third part of the project, we will assess gene expression in the OFC and striatum of a second group of people with major depressive disorder (MDD). Since OCD co-occurs at a high rate with mood disorders including MDD, it is important to perform this experiment to determine if the observed changes in gene expression are specifically related to OCD, or are instead associated with either depression or medications such as SRIs.

POTENTIAL RESULTS OF THIS STUDY

During the three-year time frame supported by the IOCDF Breakthrough Award, we will gain significant knowledge about molecular changes in the brains of OCD patients that may help us to explain abnormal brain activity patterns that lead to symptoms. These studies will give us new and important information about gene expression in the thalamus and OFC, two key brain regions that have been implicated in the disease process in people with OCD. In addition, this project will allow us to localize these observed molecular

changes to specific cell-types and cell layers within the cortex. In turn, we can use this information to build models for how abnormal activity is generated in the brains of people with OCD. Since it is not possible to directly assess abnormal activity at the level of neurons and brain circuitry in living people (except in very rare circumstances, for example, during surgery for deep brain stimulation), these experiments will provide a crucial window into the functioning of the OCD brain. Importantly, all data generated from this project will be put into a publicly accessible forum after completion of the project, so that other OCD researchers can use the data in their own studies and take advantage of this rare resource for advancement of the entire field.

VISION OF THE IOCDF BREAKTHROUGH AWARD

The vision of the IOCDF Breakthrough Award is to fund studies that may ultimately find a cure or preventive strategy for OCD — in other words, keeping OCD from taking hold, or reducing symptoms as close as possible to zero. As a psychiatrist and neuroscientist who treats people with OCD, I am absolutely committed to this goal of finding real cures for OCD. We have treatments that can be effective for OCD — for example, exposure therapy has been effective in up to 70% of people enrolled in clinical trials, and 50-60% of people have partial responses to SRIs. However, anyone who works with people suffering from OCD knows that these numbers are misleading. A partial medication response may be helpful, but not necessarily transformative. Even though exposure and response prevention (ERP) can be extremely effective, it is often incredibly difficult for patients to complete, and expert treatment providers can be hard to come by. It is therefore clear that we need improved treatments.

Relative to other major psychiatric illnesses such as schizophrenia and major depressive disorder, OCD has not benefited from novel and effective treatments over the past 5–10 years. One potential contributing factor to this discrepancy is our lack of knowledge regarding the molecular pathology of OCD. Post-mortem gene expression studies offer a possible solution to this crucial problem. These studies funded by the IOCDF Breakthrough Award are therefore an important step towards uncovering new information that can help us understand how OCD develops. Through this knowledge, we can ultimately design more specific and effective treatments.

Finally, if you have OCD, you have a unique opportunity to make an incredibly invaluable contribution to this long-term goal by signing up as a brain donor at *braindonorproject.org*.

Thank you to the IOCDF's anonymous donors for funding the Breakthrough Award! \bigcirc

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 Alex Bahrawy at abahrawy@iocdf.org or visit iocdf.org/research.

ONLINE

Starting to take an antidepressant? Participate in important internet-based research!

We are interested in improving OCD and depression treatments by finding out why people respond in different ways to antidepressants.

With your help, we aim to develop a tool that will allow doctors to match the right treatment with the right person – helping people get better, faster.

It is an internet-based study so you can complete participation from your own home. Read more and sign-up here:

https://gillanlab.tchpc.tcd.ie/3300/PIPSinfo

You can also find out more about this study by following us on Twitter: @PrecisionPsych

TEXAS

Are you the parent of a child with OCD?

Are you interested in winning tickets to attend the International OCD Foundation Annual Conference in Austin, TX, July 2019?

The Department of Educational Psychology at the University of Texas at Austin is looking for parents willing to participate in an online dissertation research study that aims to better understand the impact of childhood OCD on parents. As long as you are the biological parent of a child with OCD, proficient in English, and your child is still under the age of 18 with a diagnosis of OCD, you qualify to participate! Participation requires a willing biological parent to complete a brief online questionnaire regarding their child's OCD and will take approximately 1 hour (including screening!). Participation also requires the support of their child's provider through a brief (10-15 minute) online survey about their diagnosis and treatment status.

WIN ENTRIES TO THE GRAND PRIZE RAFFLE!!

All participants will be offered entry into a Grand Prize drawing to win one of two fully-paid FAMILY admissions to

the Annual IOCDF Conference in Austin, Texas in July 2019, valued at over \$500 each!! Additionally, all participants will have the option to win one of several \$50 Visa gift cards for the parent and child OR one of several one-year family memberships to the International OCD Foundation, a \$50 value (your choice!). ** BONUS: Receive 5 bonus entries into the raffle of your choice if BOTH biological parents participate!**

If you are interested in participating, you can get screened now in less than 15 minutes! Just follow this link:

https://utexas.qualtrics.com/jfe/form/SV_bDSSLpQa222ZpfT

If you have questions or concerns, please email the primary researcher directly at **kgushanas@utexas.edu**.

MULTIPLE LOCATIONS

Biohaven OCD Study

Biohaven Pharmaceuticals has commenced enrollment in its potentially pivotal Phase 2/3 clinical trial assessing the efficacy and safety of BHV-4157 in people with obsessivecompulsive disorder. Existing medications for OCD target the neurotransmitters serotonin or dopamine, but increasing evidence suggests that functional disruptions of a different neurotransmitter, glutamate, may be a contributing factor in some cases of OCD. BHV-4157 could be an alternative to current standards of care due to its potential to moderate excessive glutamate. Biohaven expects to enroll approximately 226 participants in this randomized, double-blind, placebo-controlled trial across approximately 35 sites in the United States. Researchers will evaluate acute symptomatic treatment with BHV-4157 as adjunctive treatment in people who are experiencing an inadequate response to their current standard of care medication (an SSRI or clomipramine) for OCD. The primary outcome measure is the change in a person's score on the Yale-Brown Obsessive-Compulsive Scale, a scale designed to assess the severity and type of symptoms in people with OCD. The trial will also assess the safety, tolerability and pharmacokinetics of BHV-4157. Additional details about the trial can be found at clinicaltrials.gov. O

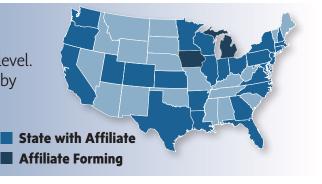
FROM THE AFFILIATES

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 ARKANSAS

An affiliate is forming in Arkansas! To learn more about getting involved in the affiliate's formation, please contact Adam Tinsley at *ocdarkansas@gmail.com*.

OCD MASSACHUSETTS

ocdmassachusetts.org

OCD Massachusetts welcomes new board members Sean Shinnock and Jayme Valdez, LMHC. Sean is an artist and a member of the Creative Expression Ambassador Team for the IOCDF. He also



works as an Advocacy Coordinator and Creative Specialist for McLean Hospital. Jayme Valdez, LMHC, is a licensed therapist who specializes in the treatment of OCD in Central Massachusetts. Jayme also has a special interest in substance abuse and self-injury. Both volunteer their time to the OCD Community and continue to help others by spreading awareness. We are thrilled to have them join us!

During OCD Awareness Week OCDMA partnered with Mountain Valley Treatment Center for their annual Seacoast Anxiety & OCD Symposium. We also had an ocd awareness social media campaign and an event at NU Kitchen in Worcester for the OCD Community.

In December OCDMA will partner with the Arlington Youth Counseling Center and will be having a screening of the documentary Unstuck. Following this will be a panel discussion that will include children and teens who have gone through OCD treatment, their parents and also treatment providers.

Lastly, we continue our fundraiser with Mental Health Mugs. To purchase a mug or tumbler please go to *mentalhealthmugs.com* and use promo code: OCDMASS to get a discount. We thank everyone who has already purchased a mug and has supported OCDMA!

OCD MID-ATLANTIC

ocdmidatlantic.org

We had a great time during OCD Awareness Week with several events! We co-hosted with the IOCDF the Mental Health Advocacy Capital Walk on the National Mall in Washington, DC. This event included other organizations advocating for OCD and related disorders and it was great interacting with representatives from these different organizations. We also had screenings of UNSTUCK: an OCD kids movie at various locations within the Maryland-DC-Virginia in order to increase access and knowledge.

We are currently recruiting for openings on our board and would like to thank outgoing member Ozge Gurel for her time participating as a board member. We are planning for more events in the coming months so please continue to check our website and facebook page for updated information!

OCD NEW HAMPSHIRE

ocdnewhampshire.org

OCD NH and Mountain Valley Treatment Center hosted the 3rd Annual Seacoast Anxiety Symposium on October 9th in Portsmouth, NH. The event attracted clinicians from around the region who want to learn more about evidence-based treatment for OCD and anxiety disorders. This year's event was the largest one yet. OCD NH received a community education grant from IOCDF to help defray some costs of the event and to support the goals of OCD NH to build capacity in the state for ERP trained clinicians — a big need in the area. The date for next year's Symposium is October 8, 2019 and will again be held in Portsmouth, NH. Monthly support groups continue in Concord, NH and Hanover, NH and as part of its annual awareness and outreach goal, OCD NH is developing one-day ERP trainings for clinicians in the area. The first is planned for Spring 2019. Lastly, OCD NH has applied to host a BTTI in collaboration with Mountain Valley Treatment Center in the coming future.

FROM THE AFFILIATES

Affiliate Updates (continued)

OCD NEW JERSEY

ocdnj.org

OCD New Jersey held its Fall Presentation in Cherry Hill, NJ, with Dr. Michael Gotlib of the Center for Emotional Health presenting on using ACT to treat OCD. Our Winter Presentation will be held on December 10th in East Brunswick and will be an Ask the Experts panel, with Board members Drs. Rachel Strohl, Rob Zambrano, and Marla Deibler available to answer any questions about OCD treatment. In September, we hosted yet another of our OCDNJ info tables at the East Brunswick Day Fair, testing fair-goers knowledge about OCD, allowing them the chance to spin for gifts and prizes. (see photo on inside cover)

OCD OREGON

ocdoregon.org

OCD Oregon went through some exciting new changes this fall. Our board of directors reorganized and we welcomed a new board member, Sarah Lemley, MPA, HA. Sarah is also the co-founder and Executive Director of the Northwest PANDAS/PANS Network (NWPPN). During OCD Awareness Week, OCD Oregon partnered with NWPPN, attending multiple professional conferences together. Both organizations presented at tabling events for the Pacific Northwest Pediatric Symposium and the Oregon Counselor Association Conference. Responses from conference attendees were extremely positive with many attendees requesting presentations from both OCD Oregon and NWPPN in the coming year. OCD Oregon was also proud to support and promote local author Ryan Bernstein and his recently published book, OCD to Me; An Anthology of Anxieties during OCD Awareness Week. Two readings were scheduled at locally-owned, independent bookstores in the Portland area. In keeping with the #RealOCD theme this year, Ryan's book presents narratives from OCD sufferers, detailing their personal experience with OCD. It's currently available on Amazon and is the perfect holiday gift for spreading OCD awareness!

OCD SACRAMENTO

ocdsacramento.org

OCD Sacramento embraced another year of support for of OCD Awareness Week by hosting our free monthly lecture series and a therapist networking event. Dmitri Primavera presented on how to compliment exposure and response prevention (ERP) treatment utilizing acceptance and commitment therapy (ACT) with a standing room only group of attendees.

Our Annual Therapist Networking Event was also a big success bringing over 50 providers from the area interested in learning more about how to treat anxiety disorders with a comorbid depressive condition. This event is always an instrumental avenue to let providers know about the proper treatment for anxiety disorders, the IOCDF, how they can become more involved in advocating for frontline, evidenced-based treatment modalities, as well the mission of OCD Sacramento and our resources.

On November 12, 2018, the board met to discuss plans and events for 2018 which includes Valerie Andrews taking on the role of Vice-President. Our 2019 line up is as follows: January 15 - Robin Zasio, PsyD, LCSW will present on Distinguishing Anxiety Disorders and How Treatment Differs; February 12 - Kathy Ventry, LMFT will present OCD in Children and Adolescents; March 12 - Susan Armstrong, LMFT will present OCD is a Family Disease: How to Navigate with a Loved One Struggling with OCD.

OCD SF BAY AREA

ocdsfbayarea.org

OCD SF Bay Area sponsored four programs during what turned out to be OCD Awareness Month in the Bay Area. Thanks to these wonderful people and organizations for co-sponsoring and presenting excellent programs that were attended by about 200 people:

- "OCD Update: Advances in Intensive and Online Therapy and Brain Stimulation" presented by the Rodriguez Lab at Stanford University and the Department of Psychiatry and Behavioral Sciences at Stanford University
- "Educational talks and discussions for adults with OCD and their loved ones and for families with children or teens with OCD" presented by Rogers Behavioral Health and the San Francisco Bay Area Center for Cognitive Therapy (SFBACCT)
- "Treatment Enhancing Options" presented by choicetherapy, TMS Health Solutions, and the San Francisco Bay Area chapter for Acceptance and Commitment Therapy
- "Creating Flexible Exposures in Treating OCD and Related Anxiety Disorders using Acceptance and Commitment Therapy" presented by East Bay Behavior Therapy Center

It was inspirational to see therapists, MDs, researchers, and people with OCD gathering together to give so much of themselves to the community — their time, knowledge, and shared stories.

FROM THE AFFILIATES

Affiliate Updates (continued)

OCD SOUTHERN CALIFORNIA ocdsocal.org

On Sunday, October 7th, OCD Southern California held major events in Los Angeles, Orange County, and San Diego to kick off

tattoos, a raffle, and more!



OCD Awareness Week. The focus of these events was not only to educate attendees on the disorder but also to create a sense of community and support as well.

In Los Angeles, OCD SoCal held a day of fun in the park!
Attendees participated in OCD-themed face painting, pumpkin decorating, and games, such as confront-your-fears hopscotch.
Attendees also had the pleasure of listening to some live music!
In Orange County, participants had a fun day outdoors in the sun where they heard OCD success stories, enjoyed lunch, and participated in games such as a watermelon eating contest!

in addition the even included a DJ, OCD Jeopardy, airbrushed

San Diego held an OCD Awareness and Resource Carnival which took place at a local middle school. San Diegans came out for a day of fun, games, and activities that encompassed OCD exposures. Attendees participated in OCD Jeopardy, as well as a community art project where participants wrote their hopes and dreams on leaves and put them on a tree to symbolize how their life could flourish after working through their fears!

OCD Southern California also participated in OCD Awareness Week was by hosting resource tables at relevant events like the CAHM (Community Alliance for Healthy Minds) conference. Finally, our vice president Chris Trondsen shared his story of recovery and initiated a call-to-action for others to do the same as part of the IOCDF's #RealOCD campaign!

SAVE THE DATE! OCD Southern California will be holding our 4th annual OCD conference on Saturday, March 30th, 2019. The conference will once again be held in Irvine, California at 5001 Newport Coast Dr, Irvine, CA 92603 starting at 10:30AM. Please save the date and we look forward to seeing you there! For information on anything mentioned in this newsletter, or to learn more about OCD Southern California, please visit our website: **OCDSoCal.org** and join us on social media at **Facebook.com/OCDSoCal!**

OCD TEXAS

ocdtexas.org

OCD Texas would like to express our sincere gratitude for all presenters, panel members, and attendees that were able to join us at OCD is Not An Adjective: Breaking Free From Stereotypes event. This year, we were lucky to have two

keynote speakers, Sheree Cruz and teen Hannah Smith, both avid mental OCD advocates, shared their own personal stories of incredible hope, growth, and recovery and lead the charge against stereotyping individuals with OCD.

This year, OCD Texas started a Peer Mentoring Program which offers brief, experience-based support to individuals and families who are new to the OCD therapy journey or in a place of transition in treatment. To seek enrollment as a peer mentor with OCD Texas, please contact mentor@ocdtexas.org to learn more.

Save the date for Saturday, June 1, 2019 to join us for OCD Texas' fourth year participating in IOCDF's 1 Million Steps 4 OCD Walk. Walks are scheduled to be held in Houston, Austin, and Dallas! If you or your organization is interested in chairing a walk in the state of Texas, please reach out to <code>info@ocdtexas.org</code>.

Find out more about volunteer offered by OCD Texas on our website and social media pages: Instagram and Facebook (@ OCD_Texas).

OCD WASHINGTON

ocdwashington.org

In support of OCD Awareness week, OCD Washington was part of three diverse events this year! Board members participated in community outreach at the St. James Cathedral's Annual Mental Health and Wellness



Fair, and met many people in the community who were interested in learning more about OCD and OCD resources. Joining with the Bellevue networking meeting of WAMFT, the Washington Association of Marriage and Family Therapy, we held a screening of UNSTUCK: an OCD kids movie. A discussion led by OCD Washington followed. We also hosted our second annual Improv for OCD with ComedySportz Seattle, with an enthusiastic 20+ attendees! CSz Seattle continues to offer Improv for Anxiety workshops, with advisement from OCD Washington. For more information, visit seattlecomedygroup.com/classes.

We are also pleased to announce our new board for 2018-2020: We now have Kate Reeves as President, Erjing Cui as Vice President, Shereen Morse has moved from her role as founding president to be a board member at large, and Chelsea Clark is joining us as assistant secretary; Several positions stayed the same as the previous term: Stacey Nagle, treasurer; John del Rossi, Secretary; and Sachin Girdhar, Tech Lead.