

# International OCD News etter

FROM THE FOUNDATION

Summer 2013

# **A SUMMER TO** REMEMBER

From our first-ever walk for OCD Awareness, to one of our best Annual OCD Conferences, to introducing a new look for the Foundation, it has been an action-filled summer for the IOCDF and the OCD Community.

In this issue, we bring you the highlights from this amazing summer, including the winners of the 2013 Research Grant Awards presented at our Annual OCD Conference, as well as a number of important resources, including: a research update on new medications for OCD as well as herbal-supplement, aka "nutraceutical," alternatives, new evidence about treating co-occuring eating disorders and OCD, and, as always, your submissions from life "on the front lines" of living with the disorder. We are also excited to announce details about this year's International OCD Awareness Week, happening on October 14-20. We hope you will get involved!



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

President, IOCDF Board of Directors: Denise Egan Stack, LMHC

Chairman, IOCDF Scientific & Clinical **Advisory Board:** Michael Jenike, MD **Executive Director & Newsletter** Editor-in-Chief: Jeff Szymanski, PhD **Communications Director & Newsletter Managing Editor:** Carly

Bourne, MA

Health Literacy Reviewer: Stephanie Cogen, MPH, MSW

Copy Editor: Marissa Keegan Layout Design: Fran Harrington

The mission of the International OCD Foundation (IOCDF) is to help individuals with 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.

#### Contact the IOCDF

Phone: (617) 973-5801 Fax: (617) 973-5803 Email: info@iocdf.org Website: www.iocdf.org Facebook.com/IOCDF

#### Mailing Address:

International OCD Foundation P.O. Box 961029 Boston, MA 02196

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

#### **Notice Something New about the IOCDF?**

We are excited to introduce a new logo for the Foundation! Since 1986, the IOCDF has served the OCD community, and we are excited to unveil a new look to represent the Foundation for years to come.





INTERNATIONAL

2008-2009 - the Foundation moves to Boston, MA and officially

changes name to the International

**1986** - the Obsessive Compulsive

Foundation is founded in

individuals with OCD

OCD Foundation.

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International Foundation

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2013 - the International OCD Foundation reveals a new logo and mission statement to better reflect the Foundation's goals for serving the OCD & related disorders community. To learn more about the new face of the Foundation, watch our new video on the IOCDF homepage at **iocdf.org**.



#### Letter from the President

Dear Friends,

Living with OCD or loving someone with OCD is often very lonely, despite the fact that 1 in 100 adults — that's 2 to 3 million adults in the United States, alone — are currently living with OCD. There are also at least 1 in 200 kids and teens living with the disorder. That is half a million children in the US — about the same number of kids who have juvenile diabetes. That means four to five children with OCD are likely to be enrolled in any average size elementary school. In a medium to large high school, there could be 20 students struggling with the challenges caused by OCD. Even so, people affected by OCD often feel they are suffering in isolation. They fear that they are the only ones who have violent or sexual intrusive thoughts; are solely responsible for their loves ones well-being; or have to count, tap, check, pray, or touch things in a certain order. Loved ones may find themselves sworn to secrecy, isolated by someone else's OCD rules, or worn down with worry and shame.

Countless times in my clinical work and when meeting people through the IOCDF and OCD Massachusetts, I hear the heartbreaking story of how an already devastating situation was made worse by the feeling that no one else would possibly understand or ever be able to help. People report having struggled alone and in silence for years and are tremendously relieved when I tell them they are not alone, there is effective help, and they can have real hope that things will get better.

Since 1986, the IOCDF has been committed to and passionate about creating an OCD community — a place where everyone affected by OCD can access accurate and up-to-date information about the disorders and effective treatments, meet others like them who truly understand, get guidance and support from internationally recognized experts, collectively join forces to give OCD a voice, and give back to the community through volunteer work. There are, in fact, many ways to be a part of the OCD community.

Earlier this year, the IOCDF hosted the 1 Million+ Steps for OCD Awareness Walk in Boston and online. There were opportunities to participate big and small. Did you take part in one of those opportunities? In July, 1,140 people attended the IOCDF's 20th Annual OCD Conference in Atlanta, a wonderful opportunity to be a part of the IOCDF community in an intimate and powerful way. A comment from one of our conference goers sums up this experience for me:

"Being allowed and willing and able to help volunteer at the Annual OCD Conference is a way for me to feel I am giving back to the OCD Community, as I have OCD myself and am trying to help others with it as well. Thank you for the opportunity!" If you haven't found your way into the OCD and related disorders community so far, ask yourself: what is getting in the way?

I have proudly been involved in the OCD Massachusetts IOCDF affiliate (formerly the OCF of Greater Boston) for over 15 years. Many of the IOCDF affiliates sponsor lecture series, workshops, conferences, social events, and fundraising activities. They offer support for how to work with schools, point you in the direction of your nearest support group, give talks to community groups, and are always looking for volunteers! OCD Awareness Week is coming up on October 14–20th and each affiliate will have activities planned in their local communities. If you haven't participated yet then this may be the perfect opportunity to get involved.

Are you on social media? The IOCDF has over 7,000 Facebook fans, over 4,000 Twitter followers, and a YouTube channel. You can join monthly chats on OCD related topics, read stories from guest bloggers, watch IOCDF-produced videos, or simply stay up to date on all IOCDF initiatives and OCD news.

There are many ways to reduce the isolation that numerous individuals with OCD and related disorders feel. Maybe this year is the year that you take steps towards finding a community. As stated by another one of our conference goers this year: "My favorite part of the conference was meeting other parents going through what my husband and I have been going through, and completely understanding." Because, ultimately, support and understanding are what the IOCDF community is all about.

Sincerely,

Denise Egan Stack, LMHC President, IOCDF Board of Directors

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#### Pediatric Campaign for Hope: Double your Gift to the IOCDF

What if there were a way for you to double your income that wasn't complicated or time-consuming — you'd do it, right? Who doesn't want a "bigger bang for their buck?"

One of the IOCDF's most dedicated supporters has presented the Foundation with a tremendous opportunity to do just that. This individual has volunteered to match your gift on a dollar-for-dollar basis if we receive it before October 31st — up to a total of \$25,000! This matching gifts campaign will go directly to the IOCDF's Pediatric Campaign for Hope.

We often cite the statistic that it takes 14–17 years, on average, from the onset of symptoms for people with OCD to gain access to effective treatment. Perhaps you or one of your family members are one of the people who had to wait that long, going through undiagnosed or misdiagnosed OCD, ineffective treatments, and years of frustration.

Jackie Lea Sommers is also one of those individuals. Jackie is the newest guest blogger to the IOCDF blog, and you may have read her recent post about the process of starting cognitive behavioral therapy (CBT) for her OCD after 20+ years of struggling with her OCD.

Jackie writes: "You'd be shocked to hear just how similar my Minnesota hometown was to Mayberry, that sweet fictional town of Andy Griffith Show fame. We didn't lock our homes or cars, everyone knew everyone else, and the whole town showed up each Friday night for high school football. My parents are the funniest, most generous people I know, and I grew up on a farm just outside of town. I should have been the happiest girl on planet earth.

But I wasn't. I had undiagnosed obsessive compulsive disorder from strep throat gone awry (PANDAS), and it stole joy from my would-be charming life like the worst kind of bandit—one without a name. Childhood should have been an enchanting time of growth, exploration, and discovery—and instead, I spent it in fear, anxiety, and outright terror. I had a period of three years where I cried nearly every single night. My parents didn't know what was wrong or how to help, nor was the internet yet available with its wide access to helpful resources. Even if it had been, what would they have searched: "our child thinks bad thoughts?"

Jackie's story, like so many others, underscores the need for early diagnosis and treatment of OCD and related disorders in kids and young adults. Untold years of suffering could be avoided if intervention happened earlier.

The IOCDF has made pediatric OCD a priority in our current initiatives. Your support of our Pediatric Campaign for Hope will provide the much needed funding to support the pediatric-focused programs planned for the next year. For example, this fall, the IOCDF is launching both a Pediatrician Outreach Program and our inaugural Pediatric Behavioral Therapy Training Institute (BTTI) to train pediatricians, family physicians, and mental health professionals on how to effectively recognize and treat OCD in children, including those with PANS (Pediatric Acuteonset Neuropsychiatric Syndrome)/PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections).

To ensure that these two new programs have an immediate and lasting impact, we need support from people like you. If you are a parent of a child living with OCD and have been a victim of the all too complicated healthcare system, then you know what Jackie and thousands of others have faced in their lives. What would it have meant to you if your pediatrician or family physician had been able to effectively diagnose and treat your child? I suspect it would have meant the world. Please help the IOCDF to help other children and parents avoid these heartbreaks.

Don't miss this opportunity to DOUBLE your gift to the IOCDF. A gift of \$100 can now mean \$200, or a gift of \$500 can mean \$1,000! Have you been meaning to make a gift to the IOCDF but haven't gotten around to it? Now is the ideal time. And, if your company has a matching gift program, then you have the potential to triple your gift's ability to help people living with OCD!

Your gift to our Pediatric Campaign of Hope can help other families cope successfully with the suffering, confusion, doubt, and fear that surround those living with or caring for someone with OCD or a related disorder.

Remember, your gift will be matched dollar-for-dollar — but only if we receive your check by October 31st! You can make your gift easily online at: www.iocdf.org/donate. O



Please take advantage of this opportunity to have your gift to the IOCDF DOUBLED. And be the first to receive a special lapel pin with the new IOCDF logo by making a gift of \$250 or more before October 31st!

#### Help Us Celebrate International OCD Awareness Week this October!

International OCD Awareness Week is almost here! We are busy working with affiliates and partners around the world to make this OCD Awareness Week the biggest yet. This year's events include Ping Pong 4 OCD, a Book Festival, conferences, fundraisers, and a number of other activities. In addition to the community events around the country and globe, we are also planning a number of online events that you can access no matter where you live.

Here is a look at some of the highlights and ways that you can get involved:

## ENTER THE 2013 INTERNATIONAL OCD AWARENESS WEEK CREATIVE EXPRESSION CONTEST

Open to submissions in creative writing (fiction, non-fiction, and poetry), songs/music, photography, paintings, drawings, videos, and other media. Two winners will be selected by votes from the IOCDF community, and will win a trip to the 21st Annual OCD Conference in Los Angeles in 2014, including airfare from anywhere in the continental US\* and a 3-night hotel stay at the Hyatt Regency Century Plaza. To enter, visit <code>iocdf.org/2013contest</code>

#### JOIN OUR #OCDCHAT SERIES

This daily chat series is back for #OCDweek and will feature a different topic and guest expert every day. The chats will take place at 12 noon ET. Have ideas for chat topics or experts you would like to see participate? Email your ideas to <code>info@iocdf.org</code>, or look for our poll on the IOCDF Facebook page at <code>www.Facebook.com/IOCDF</code>.



#### USE THE #OCDWEEK SOCIAL MEDIA CAMPAIGN TO TELL YOUR PERSONAL NETWORK ABOUT OCD

"I really am so OCD. Are you?" Building on the placard idea that we used last year (thank you to OCD-UK for the inspiration), we are creating signs for our social media users to print

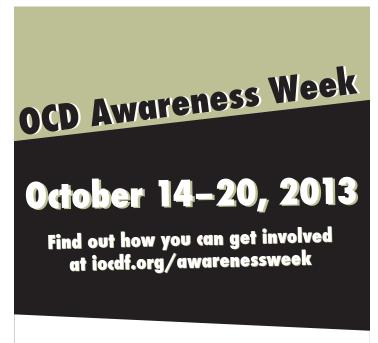
out at home and take a self-portrait with to share on social media and use as your profile picture online. The "I really am so OCD," theme builds on the discussions we have been having with the IOCDF community for the last year to break down societal misperceptions and stigma around OCD. Go to *iocdf.org/awarenessweek* to download your own sign to print out at home!

#### FIND AN OCD AWARENESS WEEK ACTIVITY NEAR YOU

Check the International OCD Awareness Week Google Calendar for up-to-the-minute information about activities and events taking place in communities across the globe. Don't see an event near you? Start one! Host an open mic night, organize a pizza fundraiser, arrange to speak at a local school or university, or even just make it your mission to be a social media advocate for the week. We want to you to be a part of this!

Visit www.iocdf.org/awarenessweek for all of the details. •

\*Up to a \$500 value. Contest participants from outside the continental US are eligible to enter, and will receive a \$500 credit towards airfare to Los Angeles for the 21st Annual OCD Conference, but will be responsible for raising funds to cover the remainder of the airfare.





#### FROM THE FRONT LINES

#### Confession #681

by Corey Harrilal

When I opened my acceptance email from MIT (Massachusetts Institute of Technology, one of the most competitive universities in the world) and saw that I got in, I ran to my mom and hugged her with the biggest smile. Before the school year officially started, I did a summer program at MIT and met the best friends anyone could ever ask for. When it was time to start my freshman year, I walked through the Infinite Corridor on campus with more confidence than, well, a pre-frosh who was just accepted into one of the best schools in the world. I did well my first semester — with the help and support of my friends, of course. Soon after, it was time for my first IAP (winter break).

During the month of January, I went home. I remember the terrible drive home... I couldn't stop thinking of equations and concepts that I just finished talking about with my peers. On the surface, this seems common and normal, but the extent that these thoughts took over my time was definitely not normal. When I arrived home, my thoughts became even worse. They were magnified tenfold. I knew something was wrong when I could not sleep, eat, or shower. I was avoiding everyone. I felt like I was there physically, but not mentally. I could not finish what I wanted to do during my break, which was to prepare for classes for the upcoming semester. When I could not take thinking about the same concepts over and over and over again for hours and even days straight, I finally broke down. I cried in front of my father and told him what was wrong. I knew what I had. It was an evil, monstrous imp in my mind, which would not give up. It was a malignant tumor in my head that would not stop growing. It was a soul-sucking fiend that was never satisfied. It was OCD.

I diagnosed myself and saw a psychiatrist, who at first did not believe me. Oh, how wrong he was. After giving me some Zoloft, it was already time for me to head back to campus for the next semester.

I could not keep up with the classes I was taking. I emailed my professors with page-long emails asking them deep questions that were not relevant. I had the biggest urge to derive, prove and question everything I was taught. When I couldn't handle it anymore, I sought help from MIT medical. Thinking I was suicidal, they sent me to Cambridge Hospital. I spent the night there, scared and worried. I sent a text out to all my friends talking about where I was. They became extremely worried and visited me at the place where I went to next. After my brief stay at Cambridge Hospital, I was

sent to what I now feel is the best hospital in the world. But, sadly they first sent me to a psychiatric ward, where they took away my cell phone, laptop, and any other electronic devices I had. I couldn't even tell my parents where I was. They just kept me there with no definite time of leave. I wasn't allowed to go outside on my own and there were mandatory check ups every 10 minutes. This was one of the most horrible experiences in my life. I felt so alone, so isolated, and just plain violated. Then I heard of an institute, an institute that was the best of its kind, just like MIT. An institute to make me better. An institute just for OCD. I was lucky enough to attend that institute for about 13 weeks. I met the best of friends there. People who were dealing with the same problems I was dealing with. There were definitely many ups and downs, but I survived. I did exposure and response prevention (ERP) therapy along with cognitive therapy and classes for healing. When it was time for my departure, MIT informed me that I would have to complete some steps before returning. I would need to take classes "somewhere else" before coming back so they could tell I was ready for MIT's intense course load. So I did exactly that. I took classes at Columbia University. Then I took classes at another university and I received all A's.

And here I am today. With the help of constant psychotherapy and medicines, and the unforgettable support of my friends, I was able to overcome OCD. Here I am today, writing this message. I am on summer vacation working as a teacher and a private tutor, with a whole bunch of experience points on my back.

Now what was the point of me telling you my deepest, darkest secret? I need your help. I need your prayers for me. I am applying to attend MIT again this fall. I am nervous and anxious about the whole thing. But I am also confident and I feel strong. Please, pray or hope or just have faith in me. I don't need sympathy, but I need closure. This disorder is something that I have conquered not by myself, but with the help of others. I wanted to let the MIT community know that OCD is not just a quirk or a little problem where people wash their hands too much or organize things too much. NO. It is much more than that. It is a crippling mental disorder than is unbearable without help. But thank God that is over for me. I am ready for MIT.

I love MIT so much. I cannot express in words how much I have missed the MIT community.

#### FROM THE FRONT LINES

#### Confession #681 (continued)

Don't take anything for granted. I know I will not anymore. Thank you for reading. I hope to see you soon. Live strong and forever MIT!

**EPILOGUE:** Thank you for reading this. I originally posted this anonymously on a "Confessions" Facebook page for the MIT community. I did not expect this post to receive all of the attention it received (over 650 likes and 40 comments). The MIT community was very comforting and supportive toward me in this time of suspense and struggle. I spent my

treatment time at the OCD Institute at McLean Hospital in Belmont, Massachusetts. And now I am doing aftercare in NYC. I am 99% better now because of my dedication and all of the help that I received.

**And an update:** Yes, I am heading back to MIT! My journey definitely ended on an awesome note. Well, it's not ending just yet. I still need to win a Nobel Prize. I am starting this fall as a second semester freshman, and my major will most likely be chemical engineering and a minor in mathematics.

#### **Dear Support Group**

by Rebecca Felser, Pittsburgh, PA

In the immortal (obviously) words of The Rolling Stones:

You can't always get what you want But if you try sometimes, well you just might find You get what you need

When I first joined this support group many years ago, I felt some people were brash and heartless. I found a complete lack of empathy and support in some members. However, over time (it took me far too long to grasp this but at least it happened eventually) it occurred to me that my definition of support was certainly not getting me anywhere. I wanted support from this group in the form of acceptance of my rituals and suggestions of how to perform them. I wanted support from my friends and family in the act of helping perform rituals. I wanted support from my therapist, whom I saw at least once a week for three years, in the form of coddling me. I wanted support from my psychiatrist in the form of the magical pill that would cure me.

When I woke up to the reality of the dire situation, I realized that there was no outside fix for OCD. Certainly help was available in the form of CBT/ERP from therapy, medications such as SSRIs from the psychiatrist, encouragement and hope that people have regained control of their lives with pure determination, and love and acceptance that this isn't going to happen overnight or be easy from friends and family. The key factor was that the fix had to come from within myself. I had to choose to live in the driver's seat or continue on as a passenger and let the OCD decide everything for me. So, after many therapists, psychiatrists, medications, miracle cures, etc., I decided it was time for me to dive into the one treatment that has been talked about consistently here and has proven to work for so many with varying degrees of OCD — CBT/ERP. I started slow and had successes and setbacks, but I was determined. It took over a year and a half but I finally was able to leave my house alone and participate in a partial hospitalization program that focused on CBT. It was left up to me when to be discharged, and I went four days a week from 8 AM until 2 PM for three months. My medications were finally stabilized there as well. I left the program a completely different person. When I was getting prepared to leave, I noticed the people seeking the same type of support I had first sought. I knew then how far I had come.

I am happy to say I now only see my therapist every other week and my psychiatrist every three months. I'm ecstatic to be living in the here and now and have faced some extremely turbulent life situations and have managed to keep my head above water. I constantly amaze myself at the new things I am trying. I no longer live in a world dominated by fear. I never thought I would actually be able to feel happiness again. I thank each and every member for the HONEST SUPPORT you've given me over the years. I can only pay it forward by writing posts like this and trying to help others see that the light at the end of the tunnel is not an oncoming train.

Many thanks and wishes of living a happy life to all of you,

Rebecca O

#### Treatment of Obsessive Compulsive Disorder with Comorbid Eating Disorders

by Rachel C. Leonard, PhD, & Bradley C. Riemann, PhD Rogers Memorial Hospital

Obsessive compulsive disorder (OCD) and eating disorders often co-occur, and while well-established treatments exist for each of these disorders on their own, there is little research to suggest what clinicians should do when faced with an individual who has both OCD and an eating disorder. Evidence-based treatments are typically examined using randomized controlled trials, which often include participants with only one disorder, follow disorder-specific treatment protocols, and have stringent guidelines regarding medication use throughout the research study. For OCD, evidencebased treatments include cognitive behavioral therapy (CBT) emphasizing exposure and response prevention (ERP), the use of serotonin reuptake inhibitors (SRIs; specifically clomipramine and selective SRIs), or a combination of these therapies. For eating disorders, evidence-based treatments include CBT emphasizing eating monitoring and cognitive restructuring (for both anorexia nervosa [AN] and bulimia nervosa [BN]), the use of fluoxetine (for BN), and weight restoration (for AN).

ERP is highly effective for OCD, either alone or in combination with SRIs,<sup>2</sup> and has been used with some success to treat BN.<sup>3</sup> Pilot studies also suggest that exposure techniques may be helpful for patients with AN.<sup>4</sup> Emerging research now suggests that ERP may also be an option when simultaneously treating co-occuring OCD and eating disorders, supplemented with additional evidence-based interventions, such as medication management and weight restoration (for AN).

In a recently published article, Simpson et al. 5 described the application of ERP techniques to both OCD and eating disorder symptoms and presented the outcomes from patients treated with this approach in a residential treatment program. Participants were 56 adults with OCD and a co-occurring eating disorder who were admitted to the program between June 2006 and July 2011, and who completed all measures of interest at admission and discharge. These included self-report assessments of OCD symptom severity (Yale-Brown Obsessive-Compulsive Scale — Self Report [Y-BOCS-SR]), eating disorder symptom severity (Eating Disorder Examination Questionnaire [EDE-Q]), and depression symptom severity (Beck Depression Inventory-II [BDI-II]). In addition, body mass index (BMI; kg/ m<sup>2</sup>) was calculated at admission and discharge. The average duration of treatment was 57 days. Of the 56 participants, 23 were diagnosed with AN, 14 were diagnosed with BN, and 19

were diagnosed with eating disorder not otherwise specified (ED-NOS).

Patients received 15-20 hours per week of ERP for their OCD and eating disorder symptoms (see below for a description). Additional treatment elements included cognitive restructuring techniques, regular meetings with a dietician (to monitor adherence to the meal plan and monitor weight), psychiatric medications and meetings with a psychiatrist to monitor the use of medications, experiential therapy, and social work support. Social workers met with patients individually twice per week to provide supportive psychotherapy and discharge planning. They also conducted weekly family sessions for psycho-educational purposes and provided a weekly process group.

## HOW IS ERP IMPLEMENTED FOR OCD AND FOR EATING DISORDERS?

For OCD symptoms, a detailed exposure hierarchy tailored to each patient's symptoms is created. Each exposure is designed to evoke an obsessive thought, impulse, or image that will cause a challenging but manageable level of anxiety that the patient is asked to experience without engaging in any corresponding compulsions (i.e., rituals). The goal of exposure therapy is for the patient to experience habituation, which is a decrease in anxiety experienced due to the passage of time. Therefore, through repeated exposure trials, patients learn that their anxiety will decrease without the need to engage in avoidance behaviors or rituals. The exposure hierarchy contains a detailed list of exposures across a wide range of anticipated anxiety levels. Patients start with less challenging exposures and work up to more challenging exposures. For example, a patient with fears about contracting HIV through touching surfaces may start by working on an exposure to touch a table in her home that only her spouse has touched without then washing her hands and, over the course of treatment, work up to an exposure to shake hands with individuals at an HIV resource center without washing. In addition to specific exposure exercises, patients are asked to resist engaging in their rituals, especially when their anxiety is at a manageable level.

ERP procedures are used in a similar manner to address eating disorder symptoms. A hierarchy of feared foods is created, and as part of the patient's meal plan, feared foods are incorporated gradually, starting with less feared foods and working up to more challenging foods. While this is similar to challenge foods incorporated into many treatment plans for

individuals with eating disorders, exposures for those with both eating disorders and OCD are done in a very detailed and graduated manner consistent with an exposure hierarchy. In addition, exposures are included to address anxiety regarding eating situations, such as eating in public. Exposures may also be used to address concerns with body shape, such as viewing disliked body parts in a mirror, wearing normally fitting rather than loose clothing, or trying on swim suits at a local mall. Similar to ritual prevention for OCD, patients are expected to complete exposures without any compensatory behaviors related to their eating disorder, such as vomiting, restricting at a future meal, excessively exercising, overeating when faced with negative emotions, comparing their body to others' bodies, covering up with a blanket, counting calories or other food quantities (e.g., grams of fat), or cutting their food into very small pieces. In addition to specific exposure exercises, patients are asked to resist engaging in their identified compensatory behaviors, especially when their anxiety is at a manageable level.

#### **HOW WELL DOES THIS APPROACH WORK?**

Simpson and colleagues<sup>6</sup> found that participants entered treatment in the severe range on the measures of OCD symptom severity and depression symptom severity, and had scores indicative of significant eating disorder pathology. Participants experienced statistically significant and clinically meaningful reductions in OCD severity, eating disorder severity, and depression severity after receiving treatment.

Regarding improvement in OCD symptoms, 80% of participants responded to treatment (indicated by a reduction of 25% on the Y-BOCS-SR) and 50% of participants had only mild or minimal OCD symptoms at discharge (indicated by a Y-BOCS-SR score of 12 or less). These rates of improvement are similar to those reported in studies of ERP that recruited patients with OCD and no comorbid eating disorder and with similar OCD severity at baseline. Participants with each of the three eating disorders experienced significant improvement in OCD symptoms; however, those with BN experienced significantly more improvement than did participants with AN. Participants with ED-NOS did not significantly differ from those with AN or BN, with change scores falling in between these two groups.

Participants also experienced significant decreases in eating disorder severity. This was the case for all three eating disorder diagnoses, although, as with OCD symptoms, participants with BN experienced significantly greater improvement in eating disorder severity than did those with AN. Those with ED-NOS improved more than those with

AN and less than those with BN, but this difference was not significant in either comparison. Further, participants experienced significant improvements in depression severity, despite the severe level of depression symptoms at admission and the fact that depression was not an area of significant focus in treatment.

#### **CONCLUSIONS AND IMPLICATIONS**

Due to the numerous treatment elements and naturalistic design, we cannot definitively conclude that the observed improvements were due to the ERP component rather than other aspects of treatment (e.g., structured eating, residential setting, social support, medication changes, etc.). However, it is unlikely that the results are due to medication, since the majority of participants (89%) were taking medication upon admission, with only a few participants beginning new classes of medications throughout the course of their treatment. In addition, there is a very low response rate in OCD to nonspecific interventions, suggesting that the improvement was due specifically to ERP. It is likely that some of the improvement in eating disorder symptoms was due to non-ERP treatment components.

These results suggest that the incorporation of ERP techniques as part of a multimodal treatment approach can be highly effective in improving symptoms of both OCD and eating disorders. 

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#### THANK YOU DR. REID WILSON!

Since 2010, our Annual OCD Conference has kicked off with an intensive 2-day treatment program run by Dr. Reid Wilson, co-author of *Stop Obsessing!*, and author of *Don't Panic!* This allows individuals with OCD — who might not otherwise have had the opportunity — to access specialized and intensive treatment. This also served as a training vehicle for therapists who were able to observe the 2-day program. Dr. Reid now runs a second 2-day treatment group/training after the conference as well. These always sell out and the evaluations are extremely positive.

The IOCDF would like to give a big thank you to Dr. Wilson both for offering this treatment and training opportunity for the OCD community and for generously donating all of the registration funds back to the IOCDF!

#### **Institutional Member Updates**

Institutional Members of the International OCD Foundation are programs or clinics who provide intensive treatment and/or specialty outpatient treatment options for OCD and related disorders. These institutions are committed to providing evidence-based treatment for OCD and related disorders, and have staff members who dedicate time to advancing OCD treatment and research. For a full list of these Institutional Members, click "Find Help" on the IOCDF website, and select either "Specialty Outpatient Clinics" or "Intensive Treatment."

THE ANXIETY TREATMENT CENTER OF SACRAMENTO 9300 Tech Center Drive, Suite 250 Sacramento, CA 95827 Phone: (916) 366-0647 Email: drrobin@atcsac.net www.AnxietyTreatmentExperts.com

The Anxiety Treatment Center of Sacramento has moved and expanded to cover the growing needs of individuals suffering from OCD, anxiety disorders, and related conditions (including skin picking and hair pulling). The ATC is the only treatment facility in Northern California offering the following:

- Intensive Outpatient Treatment Program five days per week, four hours per day;
- Compulsive Hoarding track;
- Individualized treatment (rather than primarily group based), which allows therapists to customize treatment plans and provide exposure in the community including home visits; and
- Housing for those traveling from out of town, located within walking distance to the facility at an affordable cost.

The ATC offers Exposure and Response Prevention as the first-line treatment modality and also specializes in Cognitive Behavior Therapy, Habit Reversal Training, and Mindfulness-Based Techniques. Additional services include individual, group, and family education tracks. We treat all ages and work with most insurance companies. For those insurance panels in which we are not contracted, often times a Single Case Contract (SCA) or Letter of Agreement (LOA) can be obtained to cover the costs of treatment.

#### **Institutional Member Updates** (continued)

#### THE AUSTIN CENTER FOR THE TREATMENT OF OCD

6633 Highway 290 East, Suite 300 **Austin, TX 78723** Phone: (512) 327-9494

Email: mansbridge@austinocd.com

www.austinocd.com

The Austin Center for the Treatment of OCD is pleased to announce that it has extended its special 4-day intensive treatment program for children and families in order to minimize children's absence from school and parents' absence from work. Sessions are now available from Thursday-Sunday, Friday-Monday, and/or Saturday-Tuesday. For information, call AustinOCD at (512) 327-9494 or email info@austinocd.com.

AustinOCD's director, Bruce Mansbridge, PhD, will also be helping the North Texas OCD Association to kick off OCD Awareness Week at their "Handling Your OCD" conference in Dallas on Saturday, October 12. Dr. Mansbridge will speak on "Understanding the OCD Experience" and join Kim Rockwell-Evans, PhD, Peggy McMahon, PhD, and John Hart, PhD in a panel answering questions about OCD and OCD treatment. The 1-day conference, including lunch, is free. To learn more, call (214) 368-6999 or email handlingyourocd@gmail.com.

#### **BEHAVIORAL SCIENCES OF ALABAMA**

810 Shoney Drive, Suite 120 Huntsville, AL 35801 Phone: (256) 883-3231

Email: david.barnhart@trinitycounseling.com www.behavioralsciencesofalabama.com

Behavioral Sciences of Alabama continues to offer a high quality, uniquely specialized intensive treatment program for those battling OCD and related disorders. Our intensive ERP program, along with our OCD support group L.O.C.K. (Learning Obsessive Compulsive Knockout), continually show positive results. Our participants have shared their thoughts stating, "It was a relief to meet others who have similar struggles as mine," "I feel like the members are my friends," and "the support group is a very good way of not being alone in your struggles in life, and sharing with others brings great comfort, you leave having a good feeling about yourself." Our treatment program works within a 100-mile radius when needed so we are able to take treatment into the home or community of our participants. We have added an office in Birmingham, AL to branch out to prospective patients living

in the area. Please contact us for more information about our practice.

#### **BIO BEHAVIORAL INSTITUTE**

935 Northern Boulevard, Suite 102 **Great Neck, New York 11021** Phone: 516) 487-7116

Email: info@biobehavioralinstitute.com www.biobehavioralinstitute.com

Bio Behavioral Institute is offering a weekly adolescent socialization group open to teens who suffer from depression, anxiety, or OCD and related conditions. We are recruiting participants aged 18 and over with BDD or OCD for a new study investigating the role of shame, disgust, and self-consciousness. Participants can log on to www. **surveymonkey.com/s/5DNXWWR** to complete study questionnaires. Our staff run free monthly OCD support group meetings on the last Wednesday of every month from 7:30-9:00pm. Please check our website for details.

#### **CAPE & ISLANDS COGNITIVE BEHAVIORAL INSTITUTE**

704 Main Street, Falmouth, MA 02540 Phone: (508) 457-0440 www.capecbi.com

Cape CBI offers specialized treatment for individuals struggling with OCD and related disorders; anxiety disorders including panic disorder, social anxiety, and phobias; and depression. We provide evidence-based treatment approaches including Cognitive Behavioral Therapy (CBT), specifically Exposure and Response Prevention (ERP), and Acceptance and Commitment Therapy (ACT). These structured, goal oriented approaches enable our clients to achieve maximum treatment gains in the most timely and cost effective manner. Treatment programs are customized to meet the needs of all of our adult, adolescent, and child clients as well as their family members. We provide individual, group, family, home-based, and intensive therapy. Contact us for more information on our fall group schedule, which includes: Face Your Fears for children, Emotion Regulation and Mindfulness for teens and adults, and Buried in Treasures for people with hoarding disorder.

#### **Institutional Member Updates** (continued)

## CENTER FOR OCD & ANXIETY-RELATED DISORDERS AT ST. LOUIS BEHAVIORAL MEDICINE INSTITUTE

1129 Macklind Avenue, Saint Louis, MO 63110

Phone: (314) 534-0200, ext 407 Email: info@slbmi.com www.slbmi.com

For the first time in 30 years, the Anxiety Disorders Center at SLBMI has a new name. We are now the Center for OCD & Anxiety-Related Disorders (COARD). The change was initiated to more accurately reflect the range of disorders treated at the Center as defined by the new diagnostic manual (DSM-5). The name change was timed to coincide with the launch of our new website in July of 2013. Feel free to visit the site at **www.slbmi.com** and view the many new informative features.

We are pleased to announce two new additions to the COARD clinical staff. Celeste Herleth, MD, is now the COARD Medical Director. Dr. Herleth, who completed her residency at Washington University in St. Louis, has a strong interest in OCD and anxiety disorders. Dorothy Toran, LCSW, is a highly experienced therapist who comes to us with a dual specialty in anxiety and eating disorders. Dr. Herleth and Ms. Toran have already made significant contributions to our clinical service.

Training is an important part of the Center's mission and September marks the beginning of the 2013–14 training year. We welcome our 3 new postdoctoral fellows — Drs. Ashleigh Golden, Jenessa Sprague, and Will Haynes, who are developing clinical specialties in OCD and anxiety while at the Institute. The graduate practicum students also start in September. We look forward to having Myra Altman, Hannah King, and Jon Gooblar from Washington University and Ashley Hemrich from Southern Illinois University as the new student members of our clinical team.

#### KANSAS CITY CENTER FOR ANXIETY TREATMENT (KCCAT)

10555 Marty St., Ste. 100 Overland Park, KS 66212 Phone: (913) 649-8820 Email: info@kcanxiety.com www.kcanxiety.com

KCCAT is excited to introduce our newest team members!

Angela Cathey, MA, joins KCCAT as an Advanced Assistantship trainee in clinical care and research. She is currently a doctoral candidate in Clinical Psychology at Wichita State University, and holds a Master's degree from the University of Houston–Clear Lake. Her prior training emphasis has been in Acceptance and Commitment Therapy and the treatment of anxiety disorders, with a research focus on OC spectrum, panic disorder and treatment process factors. Angela is also Founder and President of Kansas' local IOCDF affiliate, OCD Kansas.

William Oakley, PsyD, joins KCCAT as an Advanced Postdoctoral Fellow in ERP specialty training. He completed a post-doctoral year with Cognitive & Behavioral Consultants of Westchester and Manhattan, NY, focused on individual and group CBT and DBT services. He holds a Doctorate in Clinical Psychology from Midwestern University in Illinois, where he received training at the Center for Anxiety and Obsessive Compulsive Disorders at Alexian Brothers Hospital, and completed a predoctoral internship at the Carson Center for Adults and Families in Westfield, MA. In addition to his work with OCD and anxiety disorders, Dr. Oakley holds experience in addiction treatment, behavioral management, parenting, and relationship problems. He is particularly interested in enhancing motivation for behavioral change, and is a qualified Motivational Interviewing Network Trainer (MINT).

## MOUNT SINAI DIVISION OF TICS, OCD, AND RELATED DISORDERS (DTOR)

1240 Park Avenue (enter on 96th Street)

New York, NY 10029 Phone: (212) 659–1660 Email: DTOR@mssm.edu

www.mountsinai.org/patient-care/service-areas/ psychiatry/areas-of-care/division-of-tics-ocd-and-relateddisorders

The Icahn School of Medicine at Mount Sinai recently established the Division of Tics, OCD and related disorders (DTOR), which houses two programs with a common mission to enhance care and understanding of related neuropsychiatric disorders that onset in childhood or young adult life. DTOR is headed by Wayne Goodman, MD, co-founder of the IOCDF and principal developer of the Y-BOCS. The Tics and Tourette's Clinical and Research Program, directed by Barbara Coffey, MD, MS, focuses on the evaluation and treatment of children, adolescents, and adults with tics, Tourette's Disorder (TD), and co-occurring disorders, such as Attention Deficit Hyperactivity Disorder (ADHD). The Obsessive-Compulsive Disorders Program, directed by Dorothy Grice, MD, specializes in OCD and related disorders,

#### **Institutional Member Updates** (continued)

such as tics, BDD, hoarding, skin picking, and trichotillomania. Both programs provide comprehensive evaluations and state-of-the-art treatment for patients, including psychopharmacology and intensive outpatient ERP, as well as opportunities to benefit from novel therapies through participation in research studies. Deep Brain Stimulation (DBS) is available for certain patients with intractable OCD.

With pediatric and adult psychiatrists, psychologists and other behavioral health specialists assembled into one division, DTOR offers seamless care throughout a patient's lifetime, as well as simultaneous or coordinated treatment for child, adolescent or adult members of the same family who may be experiencing related conditions.

SAGE ANXIETY TREATMENT PROGRAM

601 University Avenue, Suite 225 Sacramento, CA 95825 Phone: (916) 614–9200 Email: robin@sagepsychotherapy.org

Email: robin@sagepsychotherapy.org www.SagePsychotherapy.org

Sage Anxiety Treatment Program has two events planned for OCD Awareness Week. On Tuesday evening, October 15, 2013, we will host a screening of films on OCD as well as a panel discussion about treatment options that will include a Q&A session. The panel will be comprised of clinicians specializing in treating OCD in private practice, in an Intensive Outpatient Program (IOP) setting, and clients who have successfully completed treatment for OCD. This event is geared toward the general public, but clinicians are also welcome.

In order to provide outreach and education for clinicians in the community during OCD Awareness Week, we are excited to announce that Mike Twohig, PhD will present the current research on mindfulness-based treatments and OCD. Dr. Twohig is an Associate Professor in the Department of Psychology at Utah State University, an engaging speaker, and a leading researcher on Acceptance and Commitment Therapy. This presentation will take place on Friday, October 18, 2013.

Sage is also pleased to announce the expansion of the Intensive Outpatient Program for Anxiety Disorders. In order to allow clients to continue to function and participate in as many areas of their lives as possible, treatment will now be available Monday through Friday 10am–1pm and in the evening track on Monday/Wednesday/Thursday 5pm–8pm.

Sage is also looking forward to the opening in October 2013 of our facility expansion, which will allow us to meet the increasing demand for treatment in Northern California.

Treatment in the IOP includes both group and individual therapy as well as a weekly Family Support Group. Individuals in the IOP are first given a foundation in the core concepts of ACT, which allows for a different way to experience the thoughts and sensations associated with OCD; then, clients begin exposure therapy one-on-one with a therapist who helps them to integrate the concepts of ACT while experiencing different degrees of anxiety. Please visit our website to read comments from graduates of the program.

#### YALE OCD RESEARCH CLINIC

34 Park Street, 3rd Floor CNRU, New Haven, CT 06519 Phone: (203) 974-7523 Email: ocd.research@yale.edu www.ocd.yale.edu

The Yale OCD Research Clinic is currently recruiting participants for both treatment and non-treatment studies. Recent evidence suggests that the neurotransmitter, glutamate, may be out of balance in some patients with OCD. A major focus of the Yale OCD Research Clinic's work is to better understand this imbalance and to explore whether medications that target glutamate can help some patients whose symptoms do not respond to established OCD treatments. Through this focus on the development of new medications, as well as new non-pharmacological treatments, we aim to provide new hope for patients whose symptoms do not respond completely to the currently available therapies.

Participants may be eligible for our treatment study if they are between the ages of 18 and 65, live in the Northeastern US, and are taking an SSRI medication for OCD that is not helping.

Our non-treatment studies use neuroimaging, genetics, and other approaches to investigate the changes in the brain that may lead to OCD. Those who may be eligible for our non-treatment studies are between the ages of 18 and 65 and live in the Northeastern US.

Please contact the Yale OCD Research Clinic at (203) 974–7523 for more information.

#### WHAT'S NEXT FOR OCD MEDICATION?

"First line" treatments for OCD (treatments that multiple research studies have shown to be effective in reducing symptoms for a significant number of patients) include medication and cognitive behaviorial therapy, specifically Exposure and Response Prevention. For many people, one of these treatments, or a combination of the two, have been extremely effective in reducing OCD symptoms. And for those individuals who have found relief via those treatments, there is no need to change course.

However, one of the most common phone calls or emails we receive at the International OCD Foundation concerns medication treatment options for OCD, and how to treat OCD that has not responded to the treatment options mentioned above. Though there are a handful of "first line" medications a psychiatrist may use to treat OCD symptoms (mostly serotonin-targeting medications), as you will see in the two articles below, as many as 1 in 4 individuals do not respond to these first-line treatments or have intolerable side effects.

**So, what do you do if you are someone who has not responded to the "first line" treatments?** For this issue of the *OCD Newsletter*, we reached out to some of the leading researchers in the area of "what's next" for OCD medications. The first article takes a look at a new family of medications that target glutamate levels in the brain rather than serotonin.

We also often receive questions from members about using "herbal supplements" or "neutraceuticals" as possible options for individuals who have had a minimal or poor response to serotonin-based drugs. The second article examines research about these alternative treatment options, to determine if there really is benefit to be had from supplements.

As you will see in both articles, more research needs to be done. We encourage individuals in the OCD and related disorders community to help advance our understanding of effective treatments for OCD by participating in these studies. You can find a list of recent studies currently recruiting participants on page 21 of this newsletter, and a more extensive list of OCD and related disorders research projects on our website at: <a href="https://www.iocdf.org/Participants.aspx">www.iocdf.org/Participants.aspx</a>. In some cases, these research studies offer an opportunity to receive free treatment as well.

- Jeff Szymanski, PhD, Executive Director, International OCD Foundation

#### **Towards New Medications for Refractory OCD**

by Christopher Pittenger, MD, PhD<sup>1,2</sup> & Wayne Goodman, MD<sup>3</sup>

- 1. Yale OCD Research Clinic, Department of Psychiatry
- 2. Department of Psychology, Child Study Center, and Interdepartmental Neuroscience Program, Yale University School of Medicine
- 3. Mount Sinai School of Medicine, New York, NY

Current psychotherapy and medication treatments for OCD can be of help to many who suffer from the disorder. Unfortunately, as many as a quarter of patients do not experience much benefit from these standard treatments, such as selective serotonin reuptake inhibitors (SSRIs) or Exposure and Response Prevention (ERP), even when they are used well. The development of new treatment options for these individuals is an urgent clinical and research need. This article looks at up-and-coming research on medications that affect the brain's glutamate system as a strategy for treating refractory OCD (also known as "treatment-resistant" OCD).

The SSRI antidepressants — fluoxetine (Prozac), fluvoxamine (Luvox), sertraline (Zoloft), paroxetine (Paxil), citalopram

(Celexa), and escitalopram (Lexapro) — are the standard "first line" medications used for OCD pharmacotherapy. (The first four of these have been approved by the FDA for the treatment of OCD; the last two have not, but research shows them to be just as effective, and they are often prescribed "off label.") Many patients find that their OCD symptoms get a lot better within 8–12 weeks of taking one of these medications. (For more information about these medications, please visit the IOCDF website at <a href="https://www.iocdf.org/MedSummary.aspx.">www.iocdf.org/MedSummary.aspx.</a>) However, some patients do not respond to or tolerate the first medication they are prescribed, and thus may be prescribed a different SSRI or the older antidepressant clomipramine. If this fails, a "second-line" medication may be recommended, such as a low dose "antipsychotic" medication like risperidone.

These first- and second-line medications target the neurotransmitters serotonin and dopamine, and they provide some benefit in a majority of OCD cases. Unfortunately, many

#### Towards New Medications for Refractory OCD (continued)

patients — up to 30–40% — do not get much benefit. And many of those who are considered 'responders' still have significant symptoms, or have difficulty with side effects, especially with the second-line medications.

Because of the clear need to develop treatment options for the many people who do not benefit much from these standard treatments, there has been great interest recently in the use of medications that target other neurotransmitter systems in the brain. In particular, there has been a lot of interest in the neurotransmitter glutamate, an important part of the central nervous system. If glutamate imbalance contributes to OCD, then medications that target the glutamate neurotransmitter system in a variety of ways may hold promise for individuals with otherwise treatment-resistant OCD. This is a major focus of current research, both in academic settings and in the pharmaceutical industry.

Several lines of evidence suggest that changes in glutamate contribute to OCD, in at least some cases. First, genetic abnormalities in a brain protein responsible for maintaining normal glutamate levels have been associated with OCD in numerous studies. While this association has not been proven beyond a doubt and is likely to explain only a minority of OCD cases, it is still the most repeated, and therefore most accepted, genetic finding in OCD to date.<sup>2</sup> Second, examination of cerebrospinal fluid from individuals with OCD has revealed increased levels of glutamate in some of them.<sup>3,4</sup> Third, some studies using magnetic resonance spectroscopy (MRS), a brain imaging method that makes it possible to measure certain molecules in the brain, have shown changes in normal glutamate levels, with the nature of the change depending on the brain region studied. 5 Less direct evidence for glutamate changes come from findings in animal studies, changes in brain electrical response that are similar to an altered glutamate state, and other research.1

The theory that glutamate imbalance contributes to OCD has led to studies of a number of drugs and over-the-counter (OTC) supplements that are already widely available, either with or without a prescription. Small studies, most of which have not had a placebo control group, have provided interesting preliminary evidence of benefit from riluzole, memantine, N-acetylcysteine, and topiramate, all of which have an effect on glutamate. In none of these cases is the data strong enough for any of these drugs to be considered part of standard treatment; certainly they are not appropriate in place of a trial of one of the better-proven SSRIs. But in individuals who do not respond to

first- and second-line treatments, these other medications are becoming reasonable options. For more information about over-the-counter alternative treatments, please see the article "Over-the-Counter Supplements in the Treatment of Obsessive Compulsive Disorder" on page 17 of this newsletter.

The way glutamate works in the brain is by attaching to several different receptor proteins, which are essentially the "On/Off" switches for neurons. Thus, glutamate affects electrical communication (or "signaling") in the brain. One specific receptor, the NMDA receptor, has become a major focus of attention in OCD and other neuropsychiatric conditions, including major depressive disorder. The NMDA receptor is the target of the drug memantine, which is being used by some psychiatrists in treatment-resistant cases of OCD. It is also the target of the drug ketamine, which has been shown in recent studies to have a remarkable, rapid antidepressant effect.<sup>6</sup> The effect of ketamine in treatmentresistant OCD remains unclear, with one study suggesting that it is not effective (though it can benefit depression in patients who suffer from both conditions), and a more recent one suggesting that it is.<sup>7,8</sup> This is an interesting and important area of ongoing work.

There are other, more indirect ways to affect the NMDA receptor, which is a receptor for both glutamate and the related small molecule glycine. Changing brain levels of glycine indirectly adjusts the effects of glutamate; this is an exciting area of recent focus in OCD research. A placebocontrolled trial of glycine itself suggested that it can be of benefit in treatment-resistant OCD. Unfortunately, the very large doses of glycine needed in order to have an effect in the brain resulted in unpleasant side effects, especially nausea.<sup>9</sup>

The indirect effect of glycine using sarcosine, which is an amino acid that comes from glycine and is available over the counter, showed some evidence of benefit in an uncontrolled trial. Sarcosine works in the brain by blocking the reuptake of glycine, much as SSRI antidepressants block the reuptake of serotonin, and therefore increasing its levels without the problems associated with taking large amounts of glycine itself. This has led to the idea that a more powerful and specific blocker of glycine reuptake may represent a new frontier in OCD treatment. Such drugs are not yet approved by the FDA or widely available by prescription, but they have been developed by several different pharmaceutical companies for a variety of uses.

(continued next page)

#### **Towards New Medications for Refractory OCD** (continued)

An investigation of one of these drugs for individuals with refractory OCD, sponsored by the pharmaceutical company F. Hoffman La Roche, Ltd., is currently underway at research sites across the country. The drug, called bitopertin, was originally developed as a new treatment for schizophrenia, especially for "negative symptoms" such as reduced motivation<sup>11</sup>; it is completely distinct from traditional antipsychotics like risperidone and haloperidol. While bitopertin is not yet clinically available, it has been used in hundreds of people in earlier studies. This trial is important for the field of OCD research for two reasons. First, it should provide us with important information about a completely new type of medication that may be of benefit to refractory patients. Second, it is the first time since the 1980s that a major trial of a new medication for OCD has been undertaken by the pharmaceutical industry. Collaborations of this sort are very important for turning our growing understanding of the neurobiology underlying OCD symptoms into innovative new treatments.

This trial, which goes by the name of Skylyte, is currently looking for individuals with OCD symptoms that have not responded to SSRI treatment to participate. More information can be found at <a href="https://www.skylytestudy.com">www.skylytestudy.com</a>.

The needs of OCD sufferers whose symptoms are refractory to the best psychotherapy and pharmacotherapy that we have to offer are great. However, we are in an exciting time for OCD research, and new hope may be on the horizon. The idea that chemicals that have an effect on glutamate can benefit some patients has driven a great deal of research in recent years. And a major treatment trial of a new medication, Skylyte, may indicate new interest by the pharmaceutical industry in the development of new treatment strategies — an interest that has been unfortunately lacking for many years. We are hopeful that these research efforts will lead to new hope in the coming years.

#### **ACKNOWLEDGEMENTS & DISCLOSURES**

Dr. Pittenger is the Associate Professor of Psychiatry, Psychology, and in the Child Study Center and Director of the OCD Research Clinic at Yale University in New Haven, Connecticut. His work is funded by the NIMH, the Doris Duke Charitable Foundation, and the State of Connecticut through its support of the Ribicoff Research Facilities at the Connecticut Mental Health Center. Dr. Goodman is Chair of Psychiatry at the Mount Sinai School of Medicine in New York City and is co-founder of the IOCDF. His work is funded by National

Institute of Mental Health. Both authors are recruiting patients for the SkyLyte study, funded by F. Hoffman La Roche, Ltd., at their research sites, and have received compensation (< \$5000) from Roche for consultative input during the design phases of this trial.

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## Over-the-Counter Supplements in the Treatment of Obsessive Compulsive Disorder: Practical Considerations and Evidence

by Stephen A. Kichuk, BA1, Richard M. Carlton, MD,3 and Christopher Pittenger, MD, PhD 1,2

- 1. Yale OCD Research Clinic, Department of Psychiatry
- 2. Department of Psychology, Child Study Center, and Interdepartmental Neuroscience Program, Yale University School of Medicine
- 3. Bio-Behavioral Institute, Great Neck, NY

The effective treatment of obsessive compulsive disorder (OCD) can be challenging. Standard treatments include exposure-based therapy and prescription medications such as selective serotonin reuptake inhibitors (SSRIs). These can produce significant relief for many who suffer from OCD, but not all. When standard treatments do not produce enough improvement, or when they are unavailable or are unacceptable due to side effects or some other reason, trying less well-proven treatments may be appropriate. A number of over-the-counter (OTC) nutritional supplements, sometimes called "nutraceuticals," have been used for OCD. 1.2 In this article we discuss several of these, review the research evidence that supports their use, and try to provide some general guidance for patients and practitioners interested in trying them.

There are several factors that limit our ability to make clear judgments about how well these OTC remedies work. First, because they are much less regulated than prescription medicines, the make-up, amount of active ingredients, and strength of different supplements can vary quite a bit between brands or suppliers, or over time from a single supplier, though certification by the US Pharmacopeial Convention, a non-governmental group, provides some reassurance about the contents of OTC supplements and herbs.3 Second, we do not have many strong scientific studies evaluating the benefit from these supplements in OCD; that is partly because of a lack of research funding, and partly because of the difficulty of ensuring that the supply is consistent, which impedes careful study. In some cases there is more evidence for benefit in other disorders, such as depression, than in OCD.

On the other hand, when used in moderation, many of these herbs and supplements are by and large fairly safe, with limited side effects — that is why they are available without a prescription. Therefore, even when the evidence for benefit in OCD is fairly limited, there may be little harm in trying them in particular cases.

Although these chemicals are available OTC, it is always best to use them in consultation with a doctor. Sometimes they are perceived as "natural," and therefore as harmless. However, if they can affect brain chemistry in such a

way as to influence OCD,
mood, anxiety, or other
symptoms, then they can
certainly affect the brain
and body in other ways,
too. They may also
interact with prescribed
medications that you are
taking. It is important to always
discuss these supplements with
your prescribing doctor, just as you
would any other medication. An additional useful source
for information on some OTC supplements and herbs is the
National Library of Medicine.<sup>4</sup>

#### **N-ACETYLCYSTEINE (N-AC)**

N-AC is an antioxidant that comes from the amino acid cysteine. It is commonly used to counteract acetaminophen (Tylenol) poisoning and in the treatment of some lung ailments; the brand name typically used in hospitals is Mucomyst®. In the brain, N-AC acts both as an antioxidant and as a chemical that affects the neurotransmitter glutamate. Because glutamate imbalance may contribute to OCD,<sup>5</sup> there has been significant interest in using N-AC as a treatment. The evidence for its usefulness remains fairly thin, however. In 2006, we published an early case report documenting the rapid reduction of OCD symptoms after a high dose of N-AC.<sup>6</sup> And a recent controlled study from Iran seems to support benefit from N-AC treatment<sup>7</sup>; however, methodological issues limit this study's usefulness, and more research is clearly needed.

There has also been some interesting evidence that N-AC may be of help in individuals with trichotillomania, pathological skin picking ('excoriation'), and related grooming disorders. A carefully controlled study showed substantial benefit in adults with trichotillomania<sup>8</sup>; unfortunately, a similar study in children failed to show any similar benefit.<sup>9</sup> Here, too, more research is needed.

N-AC has a sulfurous smell that can be unpleasant; some recently developed versions minimize this. The optimal dose for OCD has not been established; the studies noted above have used 2.4–3.0 grams per day, split into morning and evening doses. Unpublished clinical evidence suggests benefit at lower doses in some cases of skin picking and trichotillomania. Common side effects include a mild rash.

#### Over-The-Counter Supplements in the Treatment of OCD (continued)

mild nausea, constipation, and flatulence, but these are generally not a major difficulty.

**Bottom line:** More research is needed, but N-AC may prove helpful at low doses for some people with skin-picking, trichotillomania, and possibly OCD.

#### **GLYCINE**

Glycine is a naturally occurring amino acid found in dietary protein, and is an essential part of all cells in the body. In the brain, it can effect glutamate's action, though in a different way than N-AC.<sup>5</sup> A case report of long-term treatment<sup>10</sup> and a small placebo-controlled study<sup>11</sup> suggest that it may be of benefit in OCD.

The doses of glycine used in these investigations have been large — up to 60 grams per day — and many patients have difficulty taking it. Glycine has a chalky taste and can cause nausea. These characteristics limit its use.

Another interesting study looked at sarcosine (also called N-methylglycine), which is derived from glycine. Sarcosine blocks the cellular reuptake of glycine, in much the same way that SSRI antidepressants block the reuptake of serotonin. In an uncontrolled study, sarcosine at doses of up to 2 grams per day was of modest but statistically significant benefit in a group of OCD patients. <sup>12</sup> New supplements with the same mechanism of action have been developed by several pharmaceutical companies; a clinical trial in patients with OCD is currently underway with one such supplement — bitopertin. <sup>13</sup> (See the article, "Towards New Medications for Refractory OCD," on page 14 of this newsletter to learn more about bitopertin and other glutamate-targeting pharmaceutical treatments for OCD.)

**Bottom line:** While glycine's side effects likely outweigh any benefit, sarcosine at a low dosage is a promising, though still unproven, alternative.

#### **TRYPTOPHAN AND 5-HTP**

Tryptophan (also called 5-hydroxytryptamine, or 5-HT) is also a naturally occurring amino acid, and is a precursor of the neurotransmitter serotonin. In principle, increasing dietary tryptophan might increase serotonin levels in the brain. No careful studies have examined the benefit of tryptophan supplementation in OCD. High doses of dietary tryptophan can have significant side effects, including drowsiness, headache, and nausea. Taking tryptophan together with an SSRI carries the risk of serotonin syndrome, an uncommon condition in which the body produces too much serotonin. Symptoms can include confusion, agitation, vomiting, and

restlessness. This syndrome can become dangerous if severe and requires medical attention. Another serotonin precursor, 5-hydroxytryptophan (5-HTP), has been used in patients with depression and anxiety for similar reasons to tryptophan; it has similar side effects.

**Bottom line:** Given the lack of evidence for benefit and the risk of side effects, there is not enough evidence to recommend tryptophan or 5-HTP as treatments for OCD.

#### **MYO-INOSITOL (MI)**

MI is a small molecule that is involved in communication (or "signaling") within neurons and other cells; it interacts with serotonin, glutamate, and other signaling systems in the brain. There have been several studies investigating MI treatment in OCD. A placebo-controlled study of MI alone, without any other medications, suggested that it can be beneficial in OCD. If In contrast, when MI has been added to SSRI pharmacotherapy there has not been clear benefit. These studies are small and should not be considered definitive; but they suggest that MI may provide some of the same benefits as SSRIs, but no additional benefit when added on top of established SSRI treatment.

MI doses in these studies were high — 18 grams/day. The most prominent side effects were gastrointestinal symptoms, such as nausea, bloating, flatulence, and diarrhea; however, these were typically mild and tended to diminish with time.

**Bottom line:** MI may prove helpful when taken without an SSRI, though more research is needed.

#### **BORAGE AND MILK THISTLE**

Borage is an herb, sometimes called "starflower," that has been used in Europe as a remedy for a variety of gastrointestinal, respiratory, and cardiac conditions. It has been used by some individuals to reduce anxiety; chemicals in the plant may interact with the serotonin transporter, which is also the target of the SSRI antidepressants. One study has examined using a borage extract alone as treatment for patients with OCD; benefit was reported after 4–6 weeks both in OCD and in anxiety symptoms. Reported side effects included headaches. Check labels and avoid any borage formulations containing "pyrrolizidine alkaloids," which are carcinogenic (potentially cancercausing).

Milk thistle (MT) is a purple flowering thistle. It has been used traditionally for gastrointestinal and liver ailments, and for cancer. A single study has compared it to fluoxetine

(Prozac®) in OCD and reported comparable benefits from the two treatments. Is Side effects in this study were similar to those of Prozac and included sexual dysfunction, nausea, heart palpitations, and insomnia.

Both of these studies were done by a single group in Iran, and methodological issues limit confidence in the ability of their results to be repeated.

**Bottom line:** It is best to consider these two alternative treatments — borage and MT — to be unproven for the time being.

#### ST. JOHN'S WORT (SJW)

SJW is a flowering herb that may have antidepressant properties; it is commonly used in Europe, particularly in Germany. A large number of studies — more than exist for any of the other 'alternative' remedies discussed here — have given mixed results, but by and large they indicate that SJW can be of benefit for depression.<sup>19</sup> The mechanisms underlying this effect remain unclear.

Two studies have examined SJW in OCD. An uncontrolled study of SJW as the sole treatment used found a rapid reduction in OCD symptoms.<sup>20</sup> However, a subsequent high-quality placebo-controlled study by the same group found no benefit from SJW.<sup>21</sup> Side effects of SJW are typically mild when they occur. Reported side effects include erectile difficulties, nausea, headache, insomnia, and diarrhea. However, SJW can interact with other medications. It can lower the level of certain drugs in the body, including anticoagulants and birth control pills. It may also interact with SSRIs, making side effects more likely when the two are used together. It is therefore particularly important to discuss the use of SJW with your doctor.

**Bottom line:** While more studies would be helpful, it seems that St. John's Wort is not effective against OCD, though it may be of benefit for comorbid depressive symptoms. As with all of the nutraceuticals discussed here, be sure to discuss SJW with your doctor before using.

#### **EICOSAPENTAENOIC ACID (EPA)**

EPA is an omega-3 fatty acid. Fish are a common dietary source of EPA; it can also be taken in the form of fish oil and omega-3 supplements. EPA has been investigated in several psychiatric conditions. As in the case of St. John's Wort, the largest number of studies have investigated EPA's potential benefit in depression; some studies have suggested benefit, though overall the results have been mixed. The relevant mechanisms of action of EPA, and of omega-3 fatty acids more generally, are unclear; they may effect neuronal signaling or inflammation.

To date, a single study has examined EPA in OCD. Two grams of EPA or a placebo were added to stable SSRI pharmacotherapy. EPA and placebo groups improved similarly in this study, indicating no specific benefit from EPA treatment.<sup>24</sup> However, this single study was quite small (11 patients); more research is needed to reach strong conclusions. Side effects of EPA are generally mild and can include heartburn, nausea, and diarrhea.

**Bottom line:** There is no evidence of specific benefit from EPA in OCD. There is some evidence of benefit in major depressive disorder, and its use may be appropriate in individuals with both conditions.

#### **KAVA**

Kava is a green, leafy member of the pepper family that is native to the South Pacific, where it has been used to treat anxiety and insomnia. A number of careful studies have investigated the use of kava in generalized anxiety disorder and similar conditions, and there is significant evidence for benefit.<sup>25</sup> The mechanisms of this effect are unclear; specific alkaloids in the kava plant may interact with neuronal calcium channels, receptors for the neurotransmitter GABA, and the reuptake transporter for the neurotransmitter noradrenaline, all of which are targets for many of the current psychiatric medications.

There have been no studies examining the benefits of kava in OCD. Its ability to moderate anxiety in other conditions suggests that it may be helpful in some cases. However, side effects are of concern.<sup>25</sup> There have been multiple reports of potentially severe liver toxicity in kava users. It can also cause movement abnormalities, skin discoloration, and drowsiness.

**Bottom line:** While short-term use may be beneficial, potential side effects mean that longer-term and high-dose usage is probably to be avoided, unless done carefully with the input of a physician and with periodic monitoring of liver function.

#### **CONCLUSION**

Information to guide the use of over-the-counter remedies to treat OCD remains sparse; we do not have sufficient evidence to provide specific guidance or to estimate the likelihood of response, as we do with the SSRI antidepressants and CBT. There have been more studies in other disorders; in particular, SJW and EPA appear to be of benefit in major depression and kava in the treatment of anxiety (although with caveats due to the potential side effects).

However, with the few exceptions discussed above, these compounds are generally quite well tolerated, and many

(continued next page)

#### Over-The-Counter Supplements in the Treatment of OCD (continued from page 19)

patients find them more acceptable than prescription medications. They also tend to be relatively affordable. This being the case, it may often be reasonable to use one of them, alone or together with more standard treatment, in particular cases. This is always best done in consultation with a psychiatrist, and it is important to keep your medical doctors informed as to what OTC remedies or supplements you may be using, so that they can be mindful of potential interactions between different prescribed or non-prescribed compounds.  $\bigcirc$ 

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#### **Research Participants Sought**

The IOCDF is not affiliated with any of the following studies, but we provide this information as a service to our members. The studies are listed by alphabetically by state, with online studies and those open to multiple areas at the end.

If you are a researcher who would like to include your research listing in the OCD Newsletter, please contact Stephanie Cogen, Assistant Program Director at scogen@iocdf.org.

#### **CALIFORNIA**

#### Do you have a fear of vomiting?

This fear can be chronic and debilitating, affecting work and academic performance, social functioning, and family life. This fear is known as Emetophobia, and as Specific Phobia of Vomiting.

The research study, based at Argosy University San Diego, will measure the effectiveness of cognitive behavioral therapy in reducing fear of vomiting. Eligible San Diego and Riverside County, California residents are invited to participate at no cost. The study will take approximately 14 weeks, with weekly visits lasting between one and two hours.

You may be eligible if:

- You are 18 or older.
- You have a fear of yourself vomiting both alone and in front of others.
- You are willing to complete various assessments and tests over the course of the study. This involves answering demographic questions, questions about past or current symptoms that you may be experiencing, and details about your fear of vomiting.
- You are willing to travel to a clinic to participate in assessments and 12 weekly sessions of cognitive behavioral therapy, or be assigned to a waiting list and be given the option to participate in the therapy sessions after the waiting period.

For more information or to sign up, call Lori Riddle-Walker at (760) 715–7273 or go to **Vphobia.com** 

#### CONNECTICUT

#### **Bitopertin Medication Study for Treatment-Refractory OCD**

BACKGROUND: Several recent studies suggest a glutamate imbalance in some OCD patients. Medications that modulate glutamate, directly or indirectly, represent a potential new avenue to treat OCD symptoms. The Yale OCD Research Clinic at the Connecticut Mental Health Center has been a leader in these investigations over the past decade.

The study (HIC#1206010424) will investigate the efficacy of adding bitopertin to a stable dose of a selective serotonin reuptake inhibitor (SSRI), such as fluoxetine (Prozac), sertraline (Zoloft), or escitalopram (Lexapro). Bitopertin selectively inhibits glycine reuptake, which increases the amount of glycine in the space outside neurons in the brain. A small controlled study of glycine itself showed encouraging results in patients with OCD (Greenberg, et al., 2009). The Yale OCD Research Clinic, in partnership with F. Hoffman- La Roche Ltd., hopes to expand on these early findings through this large scale, multi-site, double-blinded study.

PARTICIPATION: The Yale OCD Research Clinic is currently recruiting participants (age 18–65 with no currently significant alcohol or substance abuse issues) whose Obsessive-Compulsive Disorder symptoms have not responded well to first-line medications to participate in a clinical trial of a new investigational medication treatment. This new medication, bitopertin, increases the brain's level of glycine, an amino acid that modulates the activity of the neurotransmitter glutamate. This study is a doubleblind, placebo-controlled 16-week trial of bitopertin, added to a participant's current SSRI medication. (Yale HIC#: 1206010424).

ClinicalTrials.gov Identifier: NCT01674361

FOR MORE INFORMATION, PLEASE CONTACT:

Suzanne Wasylink, RN-BC

Nurse Manager

Yale OCD Research Clinic Local: (203) 974–7523

Toll-Free: 1–855–OCD–YALE

ocd.yale.edu

Mac Kelly Research Assistant Yale OCD Research Clinic (203) 974–7534

Or visit the participation section of our website: www.ocd.yale.edu/participate/participate.aspx

#### Research Participants Sought (continued from page 21)

#### **MULTIPLE SITES**

## The Sertraline Pediatric Registry for The Evaluation of Safety (SPRITES)

Has your child received a new prescription of sertraline or recently started psychotherapy to treat their psychiatric condition?

If you answered YES to this question, your child may be eligible to participate in a long-term research study to learn about how sertraline or psychotherapy affect aspects of the cognitive, emotional, and physical development in children/adolescents ages 6 to 14.

For qualified participants, the SPRITES study will include 8 study visits over the course of 3 years. Each study visit will take approximately 30 minutes to complete, however the first study visit may take longer (e.g., 45 to 60 minutes). Based on their clinical judgment, the study doctor will decide if your child will receive a new sertraline prescription or start psychotherapy to treat their psychiatric condition. This may mean that if your child is currently taking another medication for their psychiatric condition, the study doctor may adjust the medication dose, or discontinue the medication entirely, if necessary, without affecting your child's participation in the SPRITES study.

During the study period, patients must agree to follow all the study requirements, including keeping all study visit appointments, and following the directions of their study doctor. Patients/ parents will receive compensation for their transportation/ time for SPRITES study visits. The study is also seeking interested study centers to participate in the study. If you are a mental health care provider who treats pediatric patients that are currently treated with or could benefit from treatment with sertraline, contact us for more information.

FOR MORE INFORMATION about the SPRITES study, PLEASE CONTACT:

Elisa Sgherza at elisa.sgherza@duke.edu or (919) 668-8876

Or visit the clinicaltrials.gov posting for this study: <a href="http://clinicaltrials.gov/ct2/show/NCT01302080">http://clinicaltrials.gov/ct2/show/NCT01302080</a>

#### **ONLINE STUDIES**

#### A Study of Sexual Worries and Cognitions

Researchers at the University of Louisville, University of Houston Clear Lake, and Nova Southeastern University are conducting research on Sexual Orientation OCD (SO-OCD / HOCD). They are interested in volunteers who want to participate in the research study. The reason for the study is to create a new tool for therapists and researchers to use so they can easily identify and recognize Sexual Orientation OCD in the people they treat. Other psychological measures will also be given to help understand some of the concerns and traits of individuals with Sexual Orientation OCD problems. The current study will be conducted entirely online and individuals may be eligible to receive compensation of a \$15 gift card.

If you are interested, please carefully read the qualifications for study eligibility below:

- You must have previously been diagnosed with OCD and be willing to provide documentation that will allow researchers to confirm your OCD diagnosis.
- **2.** You must be willing to participate in an initial phone screening.
- **3.** We are interested in individuals who experience a variety of OCD symptoms (contamination concerns, order, symmetry, harming obsessions, checking, and sexual orientation OCD).
- 4. You must 18 years or older.
- **5.** Be willing to complete a battery of questionnaires that will take approximately one hour to complete.

If you meet the criteria above and you are interesting you should contact <code>so-ocd@mentalhealthdisparities.org</code> or phone (502) 852–7413 or complete the online form at <code>www.mentalhealthdisparities.org/so-ocd.php</code>. Importantly, your name and interest in the study will be kept confidential during the initial screening process and throughout the study if you decide to participate. We would also be happy to answer any questions you might have about the study or the screening process.

The principal investigator of this study is Monnica Williams, PhD, of The University of Louisville. She can be reached at (502) 852–2521. •

#### 2013 IOCDF Research Grant Awards

The International OCD Foundation is committed to finding and promoting the most effective treatment methods for all individuals with OCD and related disorders. Research is vital to our goals of better understanding OCD and related disorders, and improving treatment.

To help achieve these goals, each year the IOCDF awards research grants to promising studies thanks to generous donors from within the IOCDF community. In the past year, a total of over \$150,000 was raised for the IOCDF Research Grant Program. Thank you to all who contributed!

The IOCDF received over 40 proposals for our 2013 Research Grants, which were reviewed by the Grant Review Committee led by Sabine Wilhelm, PhD, Vice Chair of the IOCDF Scientific and Clinical Advisory Board. Recommendations by this committee were submitted to the IOCDF Board of Directors who made the final selection of projects to be funded. Congratulations to the 2013 Research Grant Winners listed below!

#### STEPPED CARE CBT FOR PEDIATRIC OCD

Adam Lewin, PhD

**Assistant Professor** University of Southern Florida Award Amount: \$43,838

We are proposing a pilot study to develop and assess the feasibility and preliminary efficacy of Stepped Care cognitivebehavioral therapy for the treatment of pediatric obsessive compulsive disorder. This study represents an innovative approach to tailoring treatment to each child and family's needs by developing a less costly, lower intensity intervention as a first step of treatment and "stepping-up" care for those patients requiring more intensive, personalized care. Without accessible and effective treatment, youth with OCD are at risk for a developmental trajectory of impairment and chronic distress that places undue burden on the child and family, and imposes significant societal costs. In line with the NIMH strategic plan that recognizes that "we are increasingly challenged by the costs and complexities of health care" and with the NIMH mission "to support research that optimizes services," this project has the potential to empirically support the use of an innovative treatment that could be delivered with less therapist time, thereby reducing the cost of treatment for both patients and providers; improving treatment access; and reducing the societal impact and morbidity of childhood OCD.

#### **COGNITIVE BIASES IN OCD: MECHANISMS OF GENERATIONAL TRANSMISSION**

Noah C. Berman, MA **Doctoral Student** 

Massachusetts General Hospital Award Amount: \$29,661

Cognitive biases (i.e., ways in which threatening information is processed) are recognized as distinct psychological diatheses for OCD. Thus, identifying the factors that contribute to OC-related cognitive biases will help tailor prevention and intervention programs to meet the individual needs of those who carry specific and measurable risk factors. No research, however, has empirically investigated the risk factors that predict attention and interpretation cognitive biases in youth at risk of developing OCD. The current study, therefore, will administer validated and age-appropriate self-report and idiographic behavioral measures to a well-characterized (i.e., diagnostically assessed) sample that is vulnerable to the development of OC-related cognitive biases — the offspring of a parent with OCD. We aim to better understand the complex interactional processes associated with offspring's cognitive biases in order to improve the early detection and prevention of OC symptoms.

#### REPLICATION OF GENOME-WIDE ASSOCIATION **FINDINGS OF OCD**

James A. Knowles, MD, PhD

**Professor of Psychiatry** University of Southern California Award Amount: \$43,629

The International OCD Foundation Genetics Collaborative, a multi-national group established to discover genetic variation predisposing to OCD, has conducted the most extensive genetic study of OCD to date (half a million chromosomal locations in 1,465 affected individuals, 5,557 ancestry-matched controls, and 400 trios). Genome-wide significant evidence of association was found in the trios on chromosome 20 (rs6131295) near the gene encoding transcription factor BTBD3,

(continued next page)

#### 2013 Research Grant Awards (continued from page 23)

but this finding was not significant when combined with the case-control data. Interestingly, the best results from this combined analysis were in genes (FAIM2 and ADCY8) with human brain expression patterns that are highly correlated with genes regulated by rs6131295 (BTBD3, DHRS11 and ISM1). This suggests an interrelated set of genes that may predispose individuals to OCD. We want to extend these initial GWAS findings by adding at least 1,348 OCD-affected individuals and 1,349 ancestry-matched controls to unequivocally identify a genetic locus (gene) for OCD and to provide a set of molecular targets for rational development of small molecule therapeutics for OCD.

## THE ROLE OF DEEP BRAIN STIMULATION ON EXCESSIVE AVOIDANCE IN RATS: A MECHANISTIC WINDOW TO THERAPEUTIC ACTION IN OCD

Tomek (Tomasz) Banasikowski, PhD Post-Doctoral Fellow University of Pittsburg Award Amount: \$40,000

Research using animal models of avoidance learning and extinction is changing the way we think about the etiology and treatment of anxiety disorders such as obsessive compulsive disorder (OCD). OCD is characterized by inflexible, repetitive behavior that is elicited by environmental stimuli to which the action has become strongly tied. According to the DSM-IV-TR, repetitive behaviors in OCD are perceived as

"reducing distress or preventing some dreaded event" and are disruptive to a person's social relationships and general everyday functioning. Recently, deep brain stimulation (DBS), a neurosurgical technique where high-frequency electrical impulses are applied to a specific brain region called the ventral striatum, has been shown to have potential therapeutic effect in treating refractory OCD symptoms in humans. However, little is known about DBS and how it affects the brain and its impact on behavior, emphasizing the need for translational animal studies. The proposed studies will examine the role of DBS, using a novel animal model of acquired avoidance. We will test an overarching hypothesis that DBS gradually disrupts excessive avoidance behavior by reducing the value and salience of anxiety-triggering stimuli i.e., environmental stimuli previously associated with aversive footshock. Concurrently, by recording electrical activity from brain regions implicated in compulsive behavior we will be able to examine DBS effects on a brain circuit-level in freely-behaving animals. The results from our studies will have a significant impact on understanding i) the neuronal mechanisms involved in compulsivity and its extinction. especially related to anxiety and avoidance reported in OCD, ii) system-level changes in response to DBS and iii) how such activation leads to adaptive behavior.

#### THANK YOU TO OUR GRANT REVIEW COMMITTEE

Jonathan Abramowitz, PhD
Thilo Deckersbach, PhD
Martin Franklin, PhD
Randy Frost, PhD
Wayne Goodman, MD
Jessica Grisham, PhD
Dean McKay, PhD
John Piacentini, PhD
Katharine Phillips, MD
Bradley Riemann, PhD
Carey Savage, PhD
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Eric Storch, PhD

Maureen Whittal, PhD

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Dan Geller, MD
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MaryKay Lobo, PhD
Tanya Murphy, MD
Christopher Pittenger, MD, PhD
Steven Rasmussen, MD
Barbara Rothbaum, PhD
Jeremiah Scharf, MD, PhD
S. Evelyn Stewart, MD
David Tolin, PhD

#### FROM THE AFFILIATES

#### **Affiliate Updates**

Our affiliates carry out the mission of the International OCD Foundation through programs at the local, community level. Each of our affiliates are non-profit organizations that are run entirely by dedicated volunteers. If you would like to find help in your community or would like to volunteer in grassroots efforts to raise awareness and funds locally, please contact one of our affiliates. For more information, visit: www.iocdf.org/affiliates

#### **OCD JACKSONVILLE**

www.ocfjax.org

OCD Jacksonville will host its first-ever OCD Symposium at the Fine Arts Center of the University of North Florida (UNF) in Jacksonville on Friday, October 18th from 9:00 am to 4:00 pm. The theme is "Best Evidence Treatment for OCD." Be on the lookout for the video clip promo on YouTube. Registration should begin about mid-September. Five hundred tickets are available for mental health professionals (\$20), nurses (\$20), clergy (\$20), the general public (\$10), and college students (free). Continuing education credits will also be offered. Audience participation is welcome!

The panel features four mental health professionals:

- Eric Storch, PhD: Child/Adolescent OCD & DSM 5 Revisions
- Emanuel Martinez, MD: Psychiatric Management of OCD
- Frank Morelli, MA, LMHC: Adult OCD
- Brian Fisak, PhD: Emerging Trends in the Treatment of OCD

OCD Jacksonville is also proud to announce that the UNF chapter of Active Minds, a student-led mental health advocacy organization, will sponsor an OCD Fundraiser. Details TBA.

If you are interested in attending or volunteering for the symposium, please visit our new and improved website for details and registration information at <a href="https://www.ocfjax.org">www.ocfjax.org</a>. See you there!

#### **OCD KANSAS**

www.facebook.com/OCDKansas

OCD Kansas is one of the newer affiliates of the International OCD Foundation based out of Wichita, Kansas. During the last year we have further developed our organization and have reached out to like-minded organizations around the nation about how best to develop our affiliate. We have presented to local professional organizations and hosted public presentations on anxiety disorders and the use of exposure therapy in the treatment of anxiety. We also obtained an interview on the local news to discuss OCD and appropriate treatment of OCD.

For details about monthly local and online support groups, OCD Awareness Week activities planned for Wichita and Kansas City, and other information, please "Like" our Facebook page at <a href="https://www.facebook.com/OCDKansas">www.facebook.com/OCDKansas</a>. You may also reach OCD Kansas at (316) 347-7561 or OCDKansas@gmail.com.

We would also like to thank: the Wichita State University Clinical Psychology faculty; Lisa Hale, PhD, and her staff (Ashley Smith, PhD, Amy Jacobsen, PhD, Lindsey Murray, MA-LMLP, and Ryan Hale) at the Kansas City Center for Anxiety Treatment; and Patrick McGrath, PhD, at OCD Midwest for their support and continued involvement in the development of OCD Kansas.

#### **OCD MASSACHUSETTS**

www.ocdmassachusetts.org

OCD Massachusetts is planning a "Ping Pong for OCD" fundraiser during OCD Awareness Week. For more information, please Like us on Facebook (www.facebook.com/OCDMassachusetts) or visit ocdmassachusetts.org.

#### OCD MA Lecture Series\* at McLean Hospital, Belmont, MA

- October 1: "The Basics of Exposure & Response Prevention," by James Vermilyea, PhD, Cognitive Behavior Therapy Associates
- November 5: "Neurotherapeutic Interventions for OCD," by Darin Dougherty, MD, McLean Hospital OCD Institute
- December 3: "Acceptance and Mindfulness and OCD," by Lisa W. Coyne, PhD, New England ACT Institute, Suffolk University

#### OCD MA Lecture Series\* at UMass Medical Center, Worcester, MA

- October 10: "Hoarding Recovery: Sharing My Personal Journey," by Lorraine Gilmore
- November 14: "Medication for OCD," by Dr. Paul Cannistraro, MD, Massachusetts General Hospital
- December 12: "Acceptance & Commitment Therapy (ACT) for OCD," by Jennifer Cullen, PhD, McLean Hospital

\*Two support groups run after each lecture

#### Cape Cod Support Groups

- Falmouth: 1st Thursday of each month at 7pm. Call for more information: (508) 457-0440
- Hyannis: 3rd Wednesday of each month at 6:30pm. Hyannis Youth and Community Center, 141 Bassett Lane, Hyannis, MA

For more information about any of these events, please contact Denise Egan Stack at deganstack@gmail.com or Carla Kenney at carla@ocd-therapy.net, or visit www.ocdmassachusetts.org.

#### **OCD MIDWEST**

www.ocd-midwest.org

We will be promoting OCD Awareness Week in several ways:

OHIO: please join us on October 15th at the Lindner Center of Hope for "Anxious Kids in School: Rethinking Response Strategies." Dr. Patrick B. McGrath will be the keynote speaker discussing how school attendance can be affected by anxiety and OCD. Other panel members will include Dr. Charles Brady, Dr. Leah Casuto, Jennifer Wells, and Liz Lindley. OCD Midwest, along with NAMI and Lindner Center of Hope, will be sponsoring this event.

ILLINOIS: Please support OCD Midwest at "Ping Pong for OCD" at the Whole Foods store in Schaumburg from 5:00–9:00pm. Join us to play ping pong, enjoy some food and drinks, and meet other OCD Midwest members. The store is located at 750 N. Martingale Road, Schaumburg, IL 60173. We will have food, entertainment, and ping pong. Donations will be accepted at the door. So, come on out and join us as we have some fun and continue to raise money to help fund OCD research and prevention.

#### FROM THE AFFILIATES

#### Affiliate Updates (continued)

Please check our OCD Midwest Facebook page (www.facebook.com/ OCDMidwestAffiliate) in order to see the most updated information about our programs as well as local support groups.

#### **OCD NEW HAMPSHIRE**

www.ocdnh.org

OCD New Hampshire will be doing a lecture on October 17th at the Portsmouth Public Library from 6:30-7:30pm. We'll post info on our website soon. The lecture will be on "OCD Diagnosis and Treatment." Like us on Facebook to stay up-to-date on what's happening in New Hampshire: www.facebook.com/OCDNH

#### **OCD NEW JERSEY**

#### www.ocdnj.org

OCD New Jersey will hold it's quarterly meeting/presentation in South Jersey for the first time ever. Our presenter, Diana Antinoro, Psy.D., Clinical Director of the Child & Adolescent OCD, Tic, Trich & Anxiety Group (COTTAGe) at the University of Pennsylvania, will be presenting on the treatment of pediatric OCD. The presentation will be held at the Cherry Hill Public Library on Monday, September 9th, at 7:30 PM, is open and free to the public, and is geared towards both the general public and professionals. Go to www.OCDNJ.org for details.

With OCD Awareness Week in mind, OCD New Jersey will host information tables at two events in October.

- October 7th: University Behavioral Health Care and NAMI Middlesex County — Intensive Family Support Services Fall Speaker Series "You Can Beat OCD"
- October 20th: East Brunswick Multi-Cultural Fair.

And save the date for OCD New Jersery's 14th annual conference on March 9th, 2014. For details, visit www.OCDNJ.org.

#### **OCD NEW YORK**

www.ocdny.org

OCD New York is excited to announce our plans for OCD Awareness Week 2013. We are planning a state wide OCD Screening and Information Day to be held in various clinics and universities throughout the state of New York. It will give the public an opportunity to receive a free screening for OCD and related conditions, receive information and referrals as well as see a video or lecture. Locations and event details will be announced soon on <a href="https://www.ocdny.org">www.ocdny.org</a>.

#### **OCD TEXAS**

www.ocdtexas.org

To celebrate OCD Awareness Week 2013, OCD Texas will be hosting a 2-day conference in San Antonio on October 19–20, with the theme, "Everything You Always Wanted To Know About OCD (But Were Afraid To Ask)." It's our first-ever conference in this city; we will be reaching out especially to the Latino population and to others who have not yet connected with us. Our keynote, Allen Weg, PhD, author of "OCD Treatment Through Storytelling", will host a family-friendly "OCD Bedtime Stories" session Saturday evening for parents and kids of all ages; OCD-themed stories read by Dr. Weg act as metaphors for the experiences and

struggles of OCD. Attendees will then get a chance to express themselves at "Open Mic." People with OCD and family members will also tell their stories on Sunday, during our always-popular "OCD Success Stories" panel. Authors of books about OCD will speak at the conference, read excerpts, and sign copies of their books. Exhibiting sponsors will offer information on resources for OCD and related disorders. We will also offer a CEU session for professionals.

Online, we will be hosting a OCD Book Festival for everyone in the OCD community. Selected books will include personal accounts of OCD, stories from family members, and books for treatment professionals. Authors will participate in online Q&A discussions, and we will post book summaries and questions to kick-start online group discussions. We will also be encouraging people throughout the world to host their own "OCD book club" meetings in their communities, as well as to participate online.

#### **OCD WESTERN PENNSYLVANIA**

www.ocfwpa.org

We will be presenting "Understanding and Treating Obsessive Compulsive Disorder in the Pediatric Community" on Friday, October 18 from 9am—1:30pm. Karen Cassiday, PhD, will be the keynote speaker. The conference will be held at the Clarion Lake Erie Bel-Aire Conference Center, 2800 West 8th Street, Erie, PA. Qualified health professionals will earn 4 CE credits. We also invite parents, adult family members, and interested individuals to attend with the understanding that the material may be technical in nature. Online registration is available at <a href="https://www.ocfwpa.org/OCDConf-who.html">www.ocfwpa.org/OCDConf-who.html</a>. Scholarships are available to graduate students in mental health related fields, medical students and psychiatric residents as well as individuals with financial limitations. General questions and scholarship applications should be directed to <a href="https://www.ocfwpa.org">info@ocfwpa.org</a>.

The 7th Annual Dirt Monster 5 Mile Trail Race and 1 Mile Trail Walk will be held Saturday, November 2 at Grant Pavilion in North Park at 9:30am. The challenging cross country style race is the major fundraising event for the OCFWPA. Online registration is available at <a href="https://www.ocfwpa.org">www.ocfwpa.org</a>. Individuals interested in volunteering for the race should contact Hilary Zurbuch at <a href="https://hilary.com/hilary/burbuch@ocfwpa.org">hilary.com/

#### **OCD WISCONSIN**

www.ocdwisconsin.org

OCDWI is up and running! OCD Awareness Week activities we are planning for October include:

- We are creating a poster to promote OCD Wisconsin, which we plan to have available at the end of September for distribution.
- We are planning to hold lectures and talks for professionals and consumers during OCD Awareness Week. Dates and topics will be in the Upcoming Events section of our website at the end of September.
- Our Executive Director, Megan Welsh will moderate a webinar by Rogers Memorial Hospital on Tuesday, Oct. 15th at 6:00 p.m. during Awareness week. This will include Dr. Brad Riemann and 3 other panelists. You can also find information about this on our website or on Rogers website at the end of September.

If you are interested in learning more or would like to get involved in one of our committees, contact <code>info@ocdwisconsin.org</code>.

#### **SUMMER 2013 HIGHLIGHTS**

# Highlights from the 1 Million+ Steps 4 OCD Awareness Walk June 8, 2013

The inaugural OCD Awareness Walk was a huge success! What we thought would be a modest community walk that would gradually grow over time was just the opposite: The response from the OCD and related disorder community to the 1 Million+ Steps 4 OCD Awareness Walk has been overwhelming!

To date, the Walk has raised \$70,000 in online and onsite donations (smashing our original goal of \$25,000)! There were 200 walkers present at our walk at Jamaica Pond in Boston on June 8th, with over 100 "virtual walkers" walking in their own communities all over the country. And over 1,000 people donated to walkers participating in the event.

Thank you to everyone who participated, and to our event sponsors: Brooks Running, the OCD and Related Disorders Program at MGH, and the BDD Program at Rhode Island Hospital!

And, to help launch walks like this around the country next summer, we are hosting a free Webinar during OCD Awareness Week on Thursday, October 17th for ANYONE interested in hosting an OCD Walk in their own community. Visit www.iocdf.org/OCDwalk or contact Jeff Smith, IOCDF Director of Development, at jsmith@iocdf.org or (617) 973-5801 for more details. •























Photos by Kelly Davidson Photography

#### **SUMMER 2013 HIGHLIGHTS**

1. Clockwise from top left: Board Member Shannon Shy served as one of our Conference Ambassadors, helping people find their way at the conference. IOCDF Spokesperson Jeff Bell (right) and Keynote Speaker Shala Nicely at the Q&A after the Keynote Presentation. Ina and Julian Spero were presented with the IOCDF Patricia Perkins Service Award in absentia. Dr. Wayne Goodman presents the IOCDF Career Achievement Award to Dr. Randy Frost and Dr. Gail Steketee. Jeff Bell also acted at the Emcee for the Saturday Morning Awards & Keynote Presentation.

























- 2. Clockwise from left: Ping Pong 4 OCD was a popular evening activity for kids and adults, alike. Dr. Allen Weg hosts OCD Storytelling for families, complete with hot cocoa! An attendee browses the OCD Bookstore. Research poster presenter Robert Selles talks to IOCDF Board Member Chris Vertullo at the Research Reception. Dr. Christiana Bratiotis presenter of the Pre-Conference Training for Hoarding Professionals, chats will fellow presenter Jesse Edsell-Vetter at the Speakers' Reception. Dr. Renae Reinardy, with a "ribbon-happy" attendee at her "Courage for Kids" talk. IOCDF Web Developer, Fran Harrington, serves as trivia-master for the 1st-ever OCD Pub Trivia icebreaker.
- 3. Bottom row (from left): IOCDF Spokesperson Liz McIngvale enjoys OCD Pub Trivia. Two young artists get creative in the Kids & Teens Art Therapy Rooms. Conference Speaker Kevin Putman checks out the Research Posters in the exhibit hall.