

### International OCD Foundation and McLean Hospital Host "A Night to Believe"



(Winners L to R) Kendra Mattozzi (film), Megan Holden (short story), Mystery Almond (poetry), Kevin <u>Putman (music)</u>

Four individuals each suffering from OCD were honored on Saturday, October 15 for their winning forms of expression about living with OCD during the International OCD Foundation's "A Night to Believe" event.

Held at McLean Hospital just outside of Boston, the winners of the Foundation's first ever Dare to Believe contest shared their original work in front of a live audience of about 175 people, as well as thousands watching live online.

The celebration and fundraiser for the International OCD Foundation was held in conjunction with OCD Awareness Week, which took place from October 10-16.

International OCD Foundation national spokesman Jeff Bell emceed the event and also read some of the "Messages of Hope" that were posted on the Foundation's website prior to the event. Dr. Michael Jenike, Medical Director of the OCD Institute at McLean, Diane Davey, Program Director of the OCD Institute at McLean, Dr. Jeff Szymanski, IOCDF Executive Director, and IOCDF board member Joy Kant all talked about their own Dare to Believe experiences and introduced the awardees from each category.

The winning works fell into four categories: poetry, short story, film and music.

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#### **Letter From The President**



Dear Friends,

I hope that you were able to participate in one of the many OCD Awareness events around the country in October. I believe that this year's Awareness Week, our third, was our best yet. Programs were held in more than a dozen states across the United States,

as well as in Canada and the UK. Here in Boston, I was delighted to be a part of our signature event, A Night to Believe. The works of our four artists were so inspiring and it was amazing to hear about the unique experiences that led to the creation of each story, poem, film, and song. If you did not get a chance to see the live stream, you can view it via a link on our web site and I encourage you to do so. It is a great reminder of what a terrific, diverse community the IOCDF is, and how all of us, whether OCD sufferer, family member, or treatment provider, can work together to build awareness and overcome adversity.

Also, building on last year's campaign, I hope that each of you have had a chance to review our latest "No Show Ball" invitation sent out as our Annual Appeal. We count on your year-end help to support the IOCDF's continued success in providing high quality programming and education about OCD. I hope you have been impressed by all of the new initiatives coming from the National office. Not only was OCD Awareness Week an overwhelming success, but our newest website, OCD in Kids (**www.ocdinkids.org**) has been met with national praise and media attention. The site provides information for kids, teens, young adults, parents, school personnel, and professionals.

#### **OCD Newsletter**

The OCD Newsletter is published by the International OCD Foundation, Inc. President, IOCDF Board of Directors: Diane Davey, R.N. Chairman, IOCDF Scientific Advisory Board: Michael Jenike, M.D. Executive Director: Jeff Szymanski, PhD Newsletter Editor-in-Chief: Jeff Szymanski, PhD Newsletter Editor: Marissa Keegan Newsletter Editor: Pamela Lowy Newsletter Layout/Design: Fran Harrington

The International OCD Foundation (IOCDF) is a not-for-profit organization whose mission is to educate the public and professionals about OCD in order to raise awareness and improve the quality of treatment provided; support research into the causes of, and effective treatments for, OCD and related disorders; improve access to resources for those with OCD and their families; and advocate and lobby for the OCD community.

Next year, we will also be expanding the number of our BTTI trainings for professionals from three to five! The interest and need for these trainings is apparent as all of last year's trainings sold out in less than 48 hours. The expansion and success of this program is due to help from generous donors who have kept registration costs low by underwriting them. In order to do more trainings without raising the fees exponentially, we require more funding. You can help us make this happen!

Additionally, you will be receiving our annual Research Appeal, a copy of which is also reprinted in this newsletter edition, in the near future as well. Again, the IOCDF is dedicated to funding research so that we can continue to find cutting edge treatments, and hopefully a cure, for OCD. Continuing our excellent stewardship of your donations, 100% of every dollar donated will go to fund our research grants. While I know that receiving all of these requests for donations can be challenging during the holidays, even the smallest of donations are very much appreciated and can make a huge difference. We appreciate whatever support you can provide.

Dran Davey

President, IOCDF Board of Directors

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#### **DISCLAIMER:**

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

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### Dear Friends,

We need your help. Every day I see the suffering inflicted upon OCD patients as well as their family members. For over 30 years I have been involved in research and treatment of OCD. Recently, I have become more interested in the increasing evidence that infectious causes of OCD are very important, and and we see more young children everyday who develop OCD suddenly after an infection (now referred to as Pediatric Acute-Onset Neuropsychiatric Syndrome or PANS). These children are routinely misdiagnosed and mistreated when correct treatment could prevent a lifetime of unnecessary suffering. Hundreds of children with OCD are stuck in their illness and missing their lives despite the efforts of very dedicated parents. We need to know more about this and research is the key.

PANS is one example, but I know that many of you have a particular area of interest in research as well. Many of you support IOCDF's mission to devise new and more effective treatments for OCD and related disorders through creative research. As a result, this year you can indicate a priority preference for your gift that you feel is important, including: hoarding, spectrum disorders (Body Dysmorphic Disorder, Trichotillomania, skin picking, Tics/Tourette's), genetics, pediatric OCD, and PANS/PANDAS specific research. Should the IOCDF not receive a qualified grant proposal for the area you have indicated, I will actively recruit proposals from outstanding researchers. If you don't have a specific area of interest, then it is most helpful to give to the general research fund so we can fund the most impressive grants.

There are a finite number of talented researchers working on neuropsychiatric disorders such as OCD. Providing funding allows them to continue this crucial research. We now have researchers who want to further study the genetics and molecular biology of OCD. The more we understand what actually is going on in the brain, the better we will be able to help OCD patients.

Each year the IOCDF receives research proposals such as these, submitted by investigators from all over the world. Members of the Foundation's Scientific Advisory Board then rank the proposals to be sure that only the most promising of these projects are funded. The only thing holding us back from progress in understanding these devastating disorders is a lack of research funding.

We all know how important research is in helping find the causes of OCD and related disorders and in helping to develop new and more effective treatments. On behalf of myself and the many individuals and families who will ultimately benefit from your generosity, thank you. Since there are so many new clues that can lead to innovative diagnostic and treatment options, we need your help now more than ever. If you'd like to donate to this fund please go to **www.ocfoundation.org/donate** or call the IOCDF office at 617-973-5801

Sincerely,

M. Jenke, MD

Michael A. Jenike, MD Chair, Scientific Advisory Board International OCD Foundation

Professor of Psychiatry, Harvard Medical School

### Call for Presentations for the 19th Annual IOCDF Conference July 27-29, 2012 - Marriott Chicago Downtown Magnificent Mile - Chicago, IL

### What is the Annual IOCDF Conference?

The Annual IOCDF Conference is the only national meeting where people from all parts of the OCD Community come together to share knowledge, experience and expertise. The OCD Community is comprised of people with OCD or an OC Related Disorder, their families and friends, and the mental health professionals who treat OCD or are conducting research in this field.

### **Topics of Interest**

After reviewing the evaluation forms from our 18th Annual Conference in 2011, we have compiled the following list of topic suggestions that may help you to develop your proposal. This list is not exclusive or exhaustive, so please feel free to submit a proposal on any topic that you feel would contribute to our 2012 Conference. Also, consider who the audience of your talk will be. This year we will again be asking our presenters to tell us who their programs are intended for: adult patients, children, teens, family members, professionals, or researchers. In addition, you'll be asked to tell us if your talk will be for those new to the disorder, with some experience, or with an advanced level of experience. To help our attendees choose which session to attend, we'll also be asking for three learning objectives for your session.

We also have a limited number of openings for evening support groups.

#### **Tips for Being Selected**

- Choose your audience wisely. Last year, we were particularly light on proposals for children and teens as well as those intended for researchers. Any proposals in these three categories will improve your chances of being selected.
- Slots for personal stories are limited. Personal stories are inspiring and motivational, but with room for only a handful of these talks, we often have to turn away many more than we can accept. If submitting a personal story, consider doing so as part of a small panel.
- Make sure your proposal is complete. As the conference grows, the timeframe for setting the program has narrowed. Please make sure that you have all of your presenters' contact information and biographies before submitting.

A partial list of suggested workshop topics includes: General Issues about OCD

- In-depth examination of specific OCD symptoms/ subtypes
  - Contamination/cleaning
  - Emotional contamination
  - Checking
  - "Just right" obsessions
  - Perfectionism
  - Scrupulosity
  - · Intrusive violent/sexual thoughts
  - Hoarding
- OC Related Disorders
  - Trichotillomania
  - Body Dysmorphic Disorder (BDD)
  - Compulsive Skin Picking
  - Tourette's/Tic Disorders
  - Hypochondria
- Obsessive Compulsive Personality Disorder (OCPD)
- · Co-occurring impulse control problems
- Other diagnostic issues
- · OCD in different populations
  - Children and adolescents
  - Adults
  - Older Adults
  - Minorities
  - Individuals with a co-occurring physical disability
- OCD in the classroom/issues with collaborating with schools
- · Recovery and reentry into life, work, and school
- Relapse prevention
- Addressing treatment resistance
- Treatment refractory OCD
- · Issues surrounding access to treatment
- Accessing private insurance, Medicare and Medicaid for coverage possibilities
- Legal issues and OCD
- Interactive sessions for children (younger than 13 years old)
- Interactive sessions for teens (13 years old and older)

### Family Issues

- · Coping strategies for family members
- Family accommodation
- · Parenting issues for individuals with OCD
- · Dealing with adult children struggling with OCD
- · Information on treatment modalities for parents
- · Couples and intimacy issues

### Treatment

- General Cognitive Behavioral Therapy (CBT) issues
  - Exposure and Response Prevention
  - Cognitive Therapy
  - · Skills training
  - · Acceptance and Commitment Therapy
  - · Dialectical Behavior Therapy adaptations
  - · Motivational interviewing
- CBT protocols for specific OCD symptoms/ subtypes
- · CBT in non-traditional settings (e.g., home based)
- CBT in different levels of care and modalities (residential, day program, group therapy, etc.)
- · Educating the support system (friends, family, etc.)
- Medications for OCD and OC Spectrum Disorders
- · Medication augmentation strategies
- Co-morbid conditions and their impact on treating OCD
- Neurosurgery options (e.g., deep brain stimulation)

#### Research

- OCD and genetics
- · OCD and neurobiology
- Research updates on treatment for different OCD symptoms/subtypes
- Reviews of recent treatment modality research (e.g., group therapy effectiveness for treating hoarders)
- PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep)

Only electronic submissions will be accepted. The proposal submission system will open on Tuesday, January 3, 2012. To learn more about our conference or to submit a proposal, visit: www.ocfoundation.org/Conference.aspx. Only electronic submissions will be accepted.

## **Annual Conference 2012**

Chicago Marriott Downtown Magnificent Mile | July 27-29

- Hear the latest in OCD research
- Interact with the country's top OCD experts
- Participate in therapeutic workshops
- Find support groups and treatment

### Who should attend?

- Individuals of all ages
- Relatives and caregivers of OCD sufferers
- Professionals who provide therapy, support and information to those affected by OCD
- OCD Researchers



More info at: www.ocfoundation.org

### A Night to Believe (Continued from front page)

Kendra Mattozzi, 23, of Massachusetts, shared her winning animated film "OCD + Me = 5," which she created as her senior project at Mass College of Art and Design. Ten-year-old Mystery Almond traveled from Louisiana to read her winning poem, "Special and Proud."

Philadelphia college student Megan Holden was honored for her short story, "Gaining Control," which illustrated the struggle of a middle school girl battling OCD, a story inspired by her own battle with the disorder.



Pictured L-R: Jeff Szymanski PhD, Kendra Mattozzi, Megan Holden, Mystery Almond, Kevin Putman, and Jeff Bell

Closing the show was Kevin Putman from Michigan who performed "Breakin' the Symmetry," his winning rap about how the OCD inpatient treatment program at the Houston OCD Program saved his life. His band, Boyne River Remedy, also provided live music throughout the event.

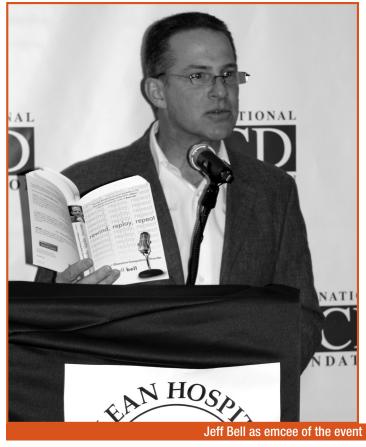
"People suffering from OCD often hide the disorder from friends and family," said Jeff Szymanski, Executive Director of the International OCD Foundation. "Through our Dare to Believe campaign and our 'Night to Believe' event, we want OCD sufferers know there is hope and a larger community supporting them."

Winners were selected from dozens of entries through a public voting contest on the International OCD Foundation website. Winners received a free trip to Boston to participate in the event.

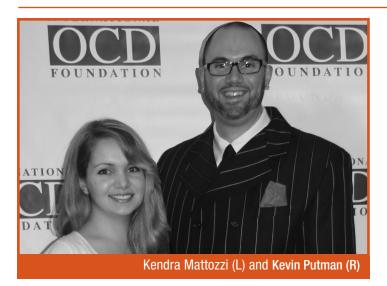
The recorded broadcast of "A Night to Believe" can be viewed online at **www.ocfoundation.org/ awareness2011**. Interviews with each of the four winners can also be found on the following page in our special "OCD Awareness Week" edition of the From the Front Lines section of the newsletter.



OCD ring worn by Kevin Putman



### **Exclusive Interviews with our Dare to Believe Contest Winners**



### **Kevin Putman**

Winner of this year's music contest, Kevin Putman has suffered from OCD since he was 10 years old. After completing 2 months of treatment for his debilitating OCD at the Houston OCD Program, Kevin wrote "Breakin' the Symmetry", a rap song about OCD as his creative way of thanking the staff who he truly believed saved his life. Kevin has also created a ping pong tournament, called Ping Pong 4 OCD, to raise awareness and funds for OCD in his community in Northern Michigan. The "4" in Ping Pong 4 OCD represents the four words that have put Kevin on the road to recovery and guide him each and every day: resist reassurance and sacrifice comfort. You can find out more about Kevin and Ping Pong 4 OCD by going to www.pingpong4ocd.com.

### Kendra Mattozzi

Winner of this year's film contest, Kendra Mattozzi earned her BFA in Animation at the Massachusetts College of Art and Design in Boston, MA where she currently lives. At age 23, she has been battling OCD since her childhood and wanted to tell her story through her animation. Currently, she is an Associate Producer at CloudKid, a local animation studio.

### Tell us about your own personal experience with OCD (about when you were diagnosed, what was it like telling your friends, your experiences with treatment, what you would tell someone else who has just learned they had OCD, etc.)

*Kevin-* OCD is something that I have had my entire life but I didn't realize I had it until I was in college in a Psych 101 class. During a lecture on OCD, I self-diagnosed. As far as telling my family and friends, I didn't have a choice. Two years ago my OCD became so debilitating that I went away to treatment for two months at the Houston OCD program, so they eventually became aware of my OCD due to my

absence. To someone who has just learned that they have OCD I would tell them that there is hope. There are a lot of organizations and people out there to help, you just have to be willing to do the work. OCD is something that you will always have but you can learn to manage.

Kendra- I think the first people to "diagnose" me would be my parents. They noticed as I was growing up that I had obsessive tendencies, and that they were beginning to escalate. When it got to a point where I was emotional and unable to get through normal tasks, they insisted I seek help. I was very hesitant to talk to a therapist or doctor about my issue, though. It wasn't until high school that I spoke up to my doctor and began medication. It was hard telling my friends at first because I thought they wouldn't believe me. I was worried they would think I was just looking for attention. Luckily I had a great core group of friends throughout high school and in college that helped me and were very supportive of me. I think that the reason why I am able to cope with my obsessive tendencies is from the support of my friends and family. I would tell anyone else who struggles with OCD to not only seek help medically and through therapy if it works for them, but also to turn to the people closest to them for guidance.

# Why did you decide to enter our Dare to Believe contest for OCD Awareness Week?

*Kevin*- It just seemed like the thing to do, it was a song contest for OCD and I had an OCD song. I want it to be known that "Breakin the Symmetry" was not written for the contest. I wrote it a year and a half ago as a thank you to the Houston OCD program for saving my life.

*Kendra*- When I made my animation in college, I had assumed that only the people in my class, and at the most my school, would see it. There was always a thought in the back of my head that I would love to have it seen by either the medical community, professionals and even others with OCD. To have the opportunity to enter my animation into the Dare to Believe contest was really perfect, actually. I'm really excited to have been involved with this event.

# Kevin, how did you get involved in singing and writing music? How do you think having a hobby that you love has helped you in your fight against OCD?

*Kevin-* This is the first song that I have ever written. When I was in treatment my friend knew I liked rap music and he made a beat and sent it to me. When I got home I listened to the beat again and it was like the song was inside of me. All I had to do was sit down at the computer and let it out. I am also very fortunate to be surrounded by talented musicians - the song was a collaborative effort with all the members of my band "Boyne River Remedy." Music is (Continued on page 8)

### Exclusive Interviews with our Dare to Believe Contest Winners (Continued from page 7)

therapy. It is just such a mindful activity, you can really lose yourself in it.

### Kendra, how did you get involved in creating short films? How do you think having a hobby/career that you love has helped you in your fight against OCD?

*Kendra*- I earned my BFA in Animation at Massachusetts College of Art and Design. I have always loved drawing as well as animated shorts and films, so I wanted to learn how they were made. Looking back, animation was probably one of the best art choices for me because of the repetitive process of drawing frames. I now am an Associate Producer at a local animation studio, and find my organization skills and attention to detail actually help me with my job.

#### Tell us about the day you found out you were one of the winners of the Dare to Believe Contest. How did you react?

*Kevin*- First of all, all of the songs in the finals were excellent. I felt proud to be one of the five finalists. When Mike Spigler, Program Director at the IOCDF, called me on the phone, I was super excited, I had no idea. The first thing I did was text my band "Boyne River Remedy" and told them we were headed to boston. That night we had a gig and on a break we started to make our travel plans.

*Kendra*- When I received the call that my animation had won, I was really shocked and then immediately nervous. I wasn't sure what this truly entailed. I felt that the other two animations were far better than my own, so I was uncertain how mine could have won. But now I'm really happy that I entered and have been able to tell my story.

#### What is the best piece of advice you could give someone who is going through their own struggles with OCD and/or a related disorder?

*Kevin-* Keep your head up. Commit yourself to getting better. Do your CBT and ERP everyday. RRSC: resist reassurance and sacrifice comfort.

Kendra- To others who are going through a difficult disorder, I would say if it is hindering your day to day activities and you are really unhappy, talk to someone. If that person is a family member, friend, teacher or doctor, then fine. Find someone who you are comfortable talking to and who you can confide in. That's what I did and I found that talking about it made it easier to deal with. Harboring your feelings and thoughts for too long can just make things worse. The other piece of advice I have is to find a sense of humor. I tend to deal with many things in life by making light of the situation, or at least trying to find humor in them. This isn't making fun of or laughing at people and their hardships, it's a coping mechanism. Maybe it will work for you and maybe it won't. But it can't hurt to try to laugh. Kevin, You are not from the area and had to travel to Boston for the OCDAW event. Have you been to Boston before? What did you do while you were here and what was your favorite thing that you saw?

*Kevin*- This was my first time to Boston. Five of us drove 21 hours straight in a minivan with all of our instruments to attend the event. We were in Boston for less than 24 hours but had some great lobster bisque at the Barking Crab.

#### Kendra, since you live in the Boston area, you didn't have to travel far to the event. Is there somewhere else that you'd like to travel to at some point?

*Kendra*- I would love to go to Europe - however I hate flying so that might cause a hindrance. I do love Boston though. I have lived here for about 6 years and am really happy here. There is so much to do and so many places to explore.

#### In honor of OCDAW and our Dare to Believe campaign, what do you want OCD Newsletter readers to Dare to Believe?

*Kevin*- I want OCD Newsletter readers to dare to believe that change is possible.

Kendra- People need to dare to believe in a hope that it won't always be difficult. I have had many days where I couldn't get out of my bedroom in the morning because of my rituals and obsessive tendencies. Now, I am able to handle it a lot better. I still have my days where it isn't easy, but I have grown to accept it. I accept that OCD is a part of my life and is also a part of who I am. Accepting and finding a way to work through it is something each person must do. Everyone is different and deals with things differently. So, find what works for you and makes you happy.



### **Exclusive Interviews with our Dare to Believe Contest Winners**



### **Mystery Almond**

Winner of this year's poetry contest, Mystery Almond is a 10-year-old from Louisiana. She was diagnosed with OCD at age 5 and Asperger's Syndrome at age 10. She loves horseback riding, drawing, reading, writing, and performing for an audience. She also loves animals and has lots of pets including 4 cats, a dog, a rabbit, a guinea pig, a rat, and fish. Mystery's poetry gives her a chance to express her feelings and to cope with her OCD. She hopes to continue making progress in understanding her feelings and working toward being able to function more easily in a world that is made better and brighter by unique individuals like her.

### Megan Holden

Winner of this year's short story contest, Megan Holden is a 19-year-old college student from Pennsylvania. She is currently studying in Philadelphia where she aims to graduate with a BFA in Graphic Design in 2014. She has been battling OCD as long as she can remember. She entered this contest to educate others about the disorder that has played such a huge role in her life.

### Tell us about your own personal experience with OCD (about when you were diagnosed, what was it like telling your friends, your experiences with treatment, what you would tell someone else who has just learned they had OCD, etc.)

*Mystery*- I was diagnosed with OCD at age 5. It was hard to tell my friends because I thought they might not like me anymore. Some didn't but the ones who stayed are my

best friends. When I first started going to therapy, I was scared. Now I'm used to it and it helps me a lot. To those who have been diagnosed, don't think you have changed – you are still you. Find someone to help you like I did and you'll come a long way.

Megan- I have had OCD as long as I can remember, but I was officially diagnosed in the sixth grade. I remember my symptoms becoming worse until I reached the point where I couldn't handle it on my own anymore. I was scared and incredibly nervous. I didn't even know what OCD really was- I had no idea what was making me do what I did but I knew I needed help. That is when I found the courage to talk to my parents. I started treatment and went to several doctors who didn't use CBT. My Mom then went to the International OCD Foundation's website and called every doctor listed within 200 miles. It was hard to find one who would treat a kid. Eventually, when I was in the eighth grade, we found a therapist near Philadelphia- it was a two-hour drive to get to her office, an hour in her office and two hours back. I saw her every week in the beginning of treatment, and this was during the school year, but it was worth it. Five years later, that same therapist suggested taking the next step and going to a weeklong intensive CBT program in Hartford, Connecticut. It was really challenging, the most challenging week of my life, but the results were amazing. I went from being ranked as "moderately severe" to only having "mild OCD." I still struggle to maintain my ability to control my obsessions and compulsions and it is definitely a challenge to practice CBT while studying in college but I never want to go back to being that burdened by OCD. I have my set backs, but I know what I have to do to be free from my OCD. It can be hard telling my friends I have OCD. It doesn't always come out easily in everyday conversations and can be hard to bring up. It can be scary because I don't know how my friends will take it. Some people know very little about OCD so then I tell myself to just be able to explain what it is like if they want to know and be able to answer their questions if they have any to ask. My words to someone who was just diagnosed with OCD is that it isn't easy. It is a long, sometimes exhausting, road to getting better, but in the end it is all worth that feeling of being free from your OCD. Trust me, I've been there.

# Why did you decide to enter our Dare to Believe contest for OCD Awareness Week?

*Mystery*- My dad entered my poem without me knowing. But I'm glad he did because I met a lot of wonderful people and it helped me understand I'm not alone in the world.

### Exclusive Interviews with our Dare to Believe Contest Winners (Continued from page 9)

*Megan-* I entered the Dare to Believe contest in hopes to educate others about the distress OCD brings to those who have it and even to their family members. I wanted others to be able to relate to my story and maybe even help them feel better. I have always been adamant about letting others know about my OCD and what it is like to have it. I believe that the more people understand about OCD, whether they have it or not, the better our society will be at accepting and respecting those struggling with the disorder.

### Mystery, how did you get involved writing poetry? How do you think having a hobby that you love has helped you in your fight against OCD?

*Mystery*- I started writing poetry to express my feelings – sometimes sad, sometimes happy. My Nana says even when I was a little girl, I would like to make things rhyme. Poetry can be a good way to talk about having OCD.

# Megan, how did you get involved writing? How do you think having a hobby that you love has helped you in your fight against OCD?

*Megan-* Writing has always been something I found I excel at but I never really pursued writing until high school. I was the kind of person with a lot of ideas but I never finished a story completely. I took a creative writing class in high school where I was pushed to follow through with my ideas and it was around then when I wrote the first version of my winning story. I have always found it very helpful to have a way to express my struggles with OCD. I have multiple projects that I completed in my art classes in high school that deal with OCD or mental health and I plan to continue that trend in my work as I study at a visual arts college. It makes me feel like I am doing something about having OCD as well as making me feel better about what I am going through.

#### Tell us about the day you found out you were one of the winners of the Dare to Believe Contest. How did you react?

*Mystery*- When I found out about being one of the winners, I was so excited. I was jumping up and down and running around the house because I could not believe it.

*Megan*- When I found out I was the winner of the short story category, I was super excited, surprised and a little nervous. I was also really happy and told everyone who had supported me that I had won, but it didn't really hit me that I won until much later. I remember sitting at the Dare to Believe event and everything was being set up and I just

looked around and thought "Wow, I did it!"

### What is the best piece of advice you could give someone who is going through their own struggles with OCD and/or a related disorder?

*Mystery*- My advice is to try to make friends who can help you and to just be yourself. If you fall down along the way, just get back up and keep going. Talk to your friends, family and therapists.

*Megan*-I would tell that person to just keep pushing forward. It really is a hard thing to do at times but it is what will put you on the road to where you want to be. Don't let yourself slip backwards, and if you do, don't let it discourage you just get back up and start making your way forward again.

### You are not from the area and had to travel to Boston for the OCDAW event. Have you been to Boston before? What did you do while you were here and what was your favorite thing that you saw?

*Mystery*- I had not been to Boston before. My favorite thing I saw was the aquarium. I got to touch a shark and a manta ray.

*Megan*- No one in my family had ever been to Boston so we took a trolley tour. We saw a lot of historical sights like Old North Church, Paul Revere's grave and the U.S.S. Constitution as well as more modern attractions such as the duckling statues from the book "Make Way for Ducklings" in Boston Common, and Quincy Market. My favorite stop was Boston Common because I got my picture taken with the duckling statues. I read that book as a child and knew of the statues in Boston but never thought I would actually see them someday.

#### In honor of OCDAW and our Dare to Believe campaign, what do you want OCD Newsletter readers to Dare to Believe?

*Mystery-* I would like the readers to Dare to Believe that if they try, anything is possible.

*Megan*- I want OCD newsletter readers to dare to believe that there is hope. Whether you know someone with OCD, or you have OCD yourself, keep pushing forward, and little by little, life will get better.

### Obsessions Related to Homosexuality -- What They Are and How to Cope With Them By Paul Greene, PhD

Paul Greene, Ph.D. is a clinical psychologist and the director of the Manhattan Center for Cognitive-Behavioral Therapy. He also serves as an Instructor at the Mount Sinai School of Medicine.

Obsessive thoughts can come in several varieties. Among the most popular themes for these thoughts are blasphemy, violence, and sex. One thing all obsessions have in common is that they consist of a thought (e.g., "I want to pick up that knife and stab myself") followed by intense anxiety at having had that thought. Another thing obsessions have in common is that it is difficult to completely disprove the fear they describe. For example, if someone has an obsessive thought about harming themselves, how can they definitively prove that it's not true? If someone has an obsessive thought like "I hate God," how can they then convince themselves that they don't? If someone has an obsessive thought about wanting to sexually molest their dog, how can they prove to themselves, beyond doubt, that they will never do it? For people trying to cope with obsessions, the uncertainty that accompanies these situations can be very distressing.

This is the paradox of obsessive thinking: we become anxious about the possibility of something that we cannot prove or disprove, and the search for such proof only leads to more anxiety. One example of this process can be seen in obsessive thoughts about being gay. This is not an uncommon type of obsessive thought to have, typically for heterosexual people suffering from OCD (someone who identifies as gay, on the other hand, might be vulnerable to obsessive thoughts about being straight). For the person with this type of obsession, finding immediate proof that one is not gay can be difficult. After all, how do people "know" whether they are straight or gay?

Take, for example, the case of Rob (all names have been changed), a straight man in his late 30's. Robert had struggled with OCD since his late teens, and had dealt with symptoms as diverse as excessive handwashing, having to get up and sit down "just right," and obsessions about harming others. For Robert, the obsessions about being gay started suddenly. When in an airport terminal with some time to kill, he wandered into a bookstore and was looking at the various magazines. One of the magazines, Men's Vogue, featured a picture of an attractive male actor on the cover. Rob noticed that

he had a hard time taking his eyes off the picture, and thought, "I like the way he looks." This was followed by the thought, "Does this mean I'm gay?" Rob immediately became very anxious. He had never even wondered before whether he was gay or straight. He had been in several heterosexual relationships, and had never been involved with another man. In Rob's very alarmed state of mind, he wracked his brain to reassure himself that he was straight. He looked at the magazines with attractive women on the cover to gauge his reaction. He then looked for an attractive woman in the terminal, and finding one, looked at her to see if she "did it" for him. After a while, he was able to reassure himself that he was not, in fact, gay. However, Rob was not able to prevent this thought from coming back, and was troubled by this fear that he might be gay for years following the incident in the airport.

How can one cope with these troubling thoughts? There are two strategies often used - one good, one bad. We'll start with the bad: Seeking reassurance about one's sexuality is perhaps the most commonly used strategy for people with OCD who have sexual obsessions. Seeking reassurance can be mental or it can be behavioral. For a straight male, mental efforts at reassurance could involve remembering all of the women or girls that he had previously been attracted to or been involved with. Similarly, the man might imagine an attractive female and mentally "check" whether he finds the girl/woman attractive. It may be more common, however, for the OCD sufferer to engage in behavioral reassurance seeking. This is the strategy that Rob used in the airport. Examples of behavioral reassurance seeking can be seeking out members of the opposite sex, either to interact with or to look at, in the hopes of feeling an attraction. Some people with these types of obsessions will begin or continue romantic relationships partially for the purpose of achieving this kind of reassurance. Sharon was a heterosexual 22-year-old woman when she began to have obsessive thoughts that she was gay. She had been in three romantic relationships, all with men, and had never entertained the idea that she might be gay. Her best friend at the time was a gay woman. One evening, Sharon thought that her friend was acting flirtatiously with her. She thought nothing of it, and was not particularly bothered by it. However, days later, the (Continued on page 12)

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thought occurred to her that if she didn't mind her friend's flirting, she must be gay too. Why else would she have reacted the way she did? The thought sent Sharon into a panic. She felt that a rug had been pulled out from under her, as she had never had reason to question her sexuality before. She thought back to her experience in high school and college, thinking about whether she had missed any hints of attraction to gay women she had known in the past. She mentally reviewed some romantic and sexual experiences she'd had with men to "decide" whether she had really enjoyed them, or whether part of her just suffered through them. The more she tried to reassure herself that she was straight, the more unsettled and panicky she became. Eventually, she decided that she needed to become involved with a new boyfriend to feel sure about her sexual identity. However, Sharon was unable to free herself of these troubling thoughts despite her new relationship and all her best efforts.

This brings us to a more helpful strategy – learning to better tolerate anxiety can lead to long term reductions in anxiety and obsessive thoughts. When Sharon first came in to our practice for cognitive-behavioral therapy, she was unable to seriously entertain the notion that it might be helpful to experience the anxiety that followed her obsessive thoughts. She had become so accustomed to seeking reassurance that she was straight that it was difficult to imagine doing anything else. When she began exposure and response prevention therapy (ERP), she tried hard to learn to bear the anxiety that followed thoughts about being gay. With the help of her therapist, she trained herself to respond to that anxiety by talking back to it. She would say, "maybe enjoying flirty interactions with my friend means I am gay, or maybe not. It's hard to tell," and would then try her best to resist the temptation to figure out whether she was gay or not. This was difficult for her, but after working hard at her exposure exercises, she was able to change her response to these thoughts. Sharon noticed a decrease in the anxiety that such thoughts caused her. Eventually, the thoughts became less frequent, as well as less distressing. Her therapist explained that through her hard work, she had taught herself to tolerate the anxiety associated with her obsessions instead of giving into her compulsive urge to reassure herself. Sharon left feeling much better prepared to deal with obsessive

thoughts about her sexual identity. Her symptoms had all but disappeared.

Sharon was lucky to have found a therapist that correctly understood her symptoms as a type of obsessive-compulsive pattern. Many people who have come to our practice describe talking to many friends, therapists, and other well-meaning people who have told them that "it's okay to be gay," "we still accept you for who you are, gay or not," or even, "I went through a similar tough time when I realized that I was gay." As well intentioned as these sentiments may be, they are unhelpful to the person with sexual obsessions, who often comes away from these conversations feeling more misunderstood than before. Therapy, in particular, can be dangerous for people with sexual obsessions if the therapist does not have expertise with OCD and sexual obsessions. Unfortunately, these patients are sometimes told that their confusion is due to denial or to repression of their true identity, and that the sooner they face up to that, the better. Mike, a heterosexual man, was 21 when he came in for OCD treatment. He had seen two prior therapists who apparently misunderstood his sexual obsessions as a part of the coming out process. Mike suspected he had OCD, and was aware of research suggesting that cognitivebehavioral therapy can be helpful. In college, Mike was told by some friends that he was likely "fighting a losing battle" against realizing that he was gay. After having struggled with obsessive thoughts about being gay all through high school and college, he decided to have a sexual encounter with another man, in order to gain some certainty about his sexuality. While he came away from the experience feeling assured that he was straight, he described lingering regret that he was so confused at the time. Using the techniques of ERP, Mike eventually learned to manage these thoughts by coming to accept the possibility that he might be gay, while at the same time accepting the possibility that he might be straight. Becoming more comfortable with both possibilities simultaneously was a key skill for Mike. While Mike never saw the obsessive thoughts disappear completely, he learned to manage his response to them such that they were no longer distressing.

### The Impact of OCD on Children and Adolescents in the School Setting and the Role of School Personnel by Gail B. Adams, EdD

Oh, man. There goes the bell for the end of 4th period. I hate this bell. It means I have to go to my locker and unload all my stuff from the first four periods and pick up everything else I need through the end of the day. I only go to my locker once a day and have to cram everything I need in my backpack, because my stupid lock combination has the number "6" in it. Six is a terrible number – it's associated with the dev... well, you know what I mean. And it's right up there with "9" - which is 6, flipped around. I get stuck on the 6 every single time I do my lock combination and have to say a bunch of good numbers, like "2" or "8," to feel better. And all of this takes up a lot of the passing period. On top of this, there's this really weird kid who walks down the hall every day at this time. No way do I want to bump into him, because if I do, I'm afraid I'll get contaminated and become like him. Now THAT just can't happen. So I have to hide out around the corner until he passes by. There goes some more time.

I'm late to 5th period so much that my teacher says she's going to drop me a grade if I'm late one more time. And that would be a disaster. Fifth period is math class, and I spend half the math period mentally saying good numbers because 6's and 9's are everywhere. So I never get my work done. In fact, my grade in math right now is a "D." The teacher thinks I'm lazy or dumb, but I'm not. In fact, a test I took a while back showed I have a really high IQ. Problem is the bad numbers come up a lot in my other classes, too. It feels like the teachers are always yelling at me for not paying attention. I wonder how much work they'd get done if they had all this stuff going on in their heads. Some of them even told my parents they think I have AD/HD. But it's almost impossible to concentrate when there's a war between numbers going on in my head. Sometimes I hate school...

Like the student in this vignette, thousands of children and adolescents with OCD struggle, on a daily basis, in classrooms all over the world. Held hostage by OCD, they cannot perform tasks they have the ability to do. Unable to complete assignments, these students frequently receive poor and even failing grades. Moreover, their social competence is often compromised because of the intrusion of OCD.

### Impact of OCD on Academic Performance

OCD can exact a heavy toll on the academic performance of children and adolescents with OCD – young people who typically have average to above-average intelligence levels. Students experiencing

obsessions and compulsions may appear to be "stuck," or fixated, on certain points and lose the need or ability to go on. OCD may interfere with the student's capacity to listen in class, follow directions, and concentrate on assignments. In addition, students who leave the classroom to carry out rituals (e.g., go to the bathroom to wash hands) frequently miss out on important academic information. The interference created by obsessions and compulsions may delay or halt work completion, lead to a decrease in work production, and have a negative impact on grades. In some cases, deterioration in academic performance may be abrupt and dramatic, sending grades plummeting.

It is important to note that OCD symptoms may be mistaken for inattentiveness and even AD/HD. In reality, the child is paying attention, but not to the task at hand. Indeed, he or she may be unable to disengage attention from obsessions and compulsions. Research has confirmed the presence of attentionrelated difficulties among children and adolescents with OCD: researchers in two independent studies – one conducted in the U.S. and the other in Norway – found that one of the top two school-related problems reported by parents and children alike was concentrating on work.

In some cases, students with OCD appear as if they are noncompliant. During an OCD episode, they may not be able to follow the teacher's directions, but they are complying with OCD's demands – dutifully carrying out rituals, for example, in order to prevent something terrible from happening. Moreover, to the outside observer, these students may appear to be daydreaming, unmotivated, or – worse yet – lazy. When one considers the mental torment many of these students endure, it is evident that such characterizations are inappropriate and unwarranted.

In addition, tardiness and school absenteeism may have a negative impact on the school performance of youth with OCD. Rituals can be tedious, timeconsuming, and interfere with sleep, sometimes resulting in a child's being late to school. Students may become so frustrated by having to complete certain rituals before school, day in and day out, that they (Continued on page 14) The Impact of OCD on Children and Adolescents in the School Setting and the Role of School Personnel (continued from page 13)

opt to skip school entirely. In some cases, children and adolescents are distressed by peer ridicule to the point that they can no longer tolerate school. In other instances, students avoid school because they fear school-based stimuli that trigger their obsessions and compulsions. Tardiness and absenteeism can result in significant gaps in instruction which, in turn, may lead to serious academic problems. A child who misses instruction in important skills is likely to have difficulty learning concepts and new information built upon those skills.

### Impact of OCD on Social Functioning

Social competence, which is closely linked to academic performance, can be severely affected by OCD. Studies have indicated that while the social functioning of some students with OCD is unimpaired, many of these young people are withdrawn and isolated from peers and have few, if any, friendships. Several factors may contribute to social difficulties.

First, OCD symptoms may render interaction with peers extremely difficult. Fears of being contaminated due to touching others, for instance, may preclude involvement in contact sports (e.g., football, ice hockey). Second, some children and adolescents have little time for friends, family, or social activities because ritualizing consumes so much of their time outside of school. In addition to performing rituals they normally complete at home, they may also feel compelled to carry out rituals suppressed at school. Homework may also take up a huge chunk of the child's time due to OCD symptoms. Third, many children are physically and mentally exhausted by their obsessions and compulsions, especially when they suppress them during the school day. The energy students expend concealing OCD at school can be draining, and they are simply too fatigued to participate in sports or other social activities. Fourth, because OCD rituals may involve behavior that appears peculiar to others (e.g., holding one's breath to avoid being contaminated; hoarding scraps of paper, stones, glass, etc., picked up from the playground; walking on the sidewalk in a circuitous fashion to circumvent cracks), some children and adolescents prefer to retreat from peers rather than risk social rejection, humiliation, or bullying. Finally, OCD rituals sometimes disturb or disrupt other

students in the classroom. Students with OCD may become agitated or even panicked when their rituals are interrupted by peers or classroom events, leading to verbal outbursts. Such incidents can have an extremely damaging impact on social acceptance.

Complicating matters even further, the majority of young people with OCD have at least one other coexisting, or comorbid, disorder. Among children and adolescents, some of the most common comorbid disorders are anxiety disorders (e.g., separation anxiety disorder, social phobia); mood disorders (e.g., major depressive disorder, bipolar disorder); attentiondeficit/hyperactivity disorder; disruptive behavior disorders (e.g., oppositional defiant disorder, conduct disorder); and tic disorders, including Tourette's Syndrome. Each of these disorders frequently presents academic and social challenges over and above those associated with OCD.

# The Role of School Personnel in Helping Students with OCD

Research has indicated that for a large proportion of adults with OCD - possibly as high as 80% - the onset of OCD occurs during childhood or adolescence. Because of the serious effect OCD can have on a child's functioning, it is essential that individuals who work closely with young people be aware of OCD and know how to recognize its symptoms. The good news is that school personnel - including general and special education teachers, school psychologists, social workers, school nurses, counselors, administrators, paraprofessionals, inclusion facilitators, educational diagnosticians, and others - can play an integral role in the process of identifying, assessing, referring, and treating children and adolescents with OCD. Indeed, because OCD tends to run a chronic course without appropriate intervention, early intervention during childhood or adolescence can be critical to preventing long-term illness into adulthood.

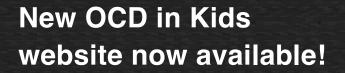
School personnel may represent a first line of defense in the struggle against childhood OCD for several reasons. First, parents may not always be first to recognize that their child has a problem. Although many parents are aware of their child's difficulties, research has indicated that some parents recognize

these problems only after months or years have passed since they began. In some cases in which parents have missed OCD symptoms, children have actually been known to bring their problems to the attention of their parents and ask for help. Second, research clearly indicates that teachers and other school personnel can effectively identify youth at risk. Education professionals have frequently worked with hundreds of students over a period of many years. Thus, they have developed an awareness of and sensitivity to behavior that digresses from the norm. Third, the typical school-aged child spends approximately 1,100 hours per year in the school setting. As a result, school personnel are uniquely positioned to observe and interact with students for extended periods of time on a consistent basis. Therefore, it is essential that educators learn to recognize OCD symptoms in the school setting, assist with assessment and referral, and participate in various facets of treatment.

#### Conclusion

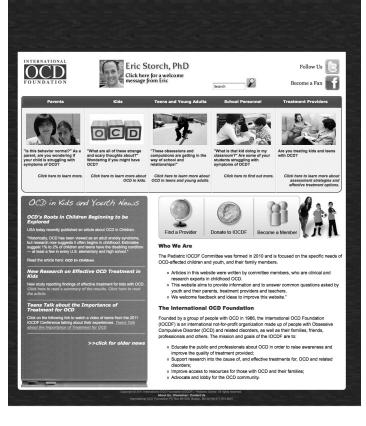
OCD is an illness which, not unlike a thief, may rob children and adolescents of the quality of their youthful lives. If allowed to run its course untreated, it will likely rob them of the quality of their adult lives, as well. School personnel can play a crucial role in the fight against this potentially debilitating disorder and help bright and promising students realize their full potential.

Note: Sections of this article were excerpted from Dr. Adams' new book *Students with OCD: A Handbook for School Personnel,* available at www.ocdhandbook.com



# www.ocdinkids.org

Includes OCD information for kids, teens, parents, teachers, and therapists.



### **Institutional Member Updates**

### Texas

### The Austin Center for the Treatment of Obsessive-Compulsive Disorder

6633 Highway 290 East, Suite 300 Austin, TX 78723 Phone: (512) 327-9494 www.austinocd.com

Bruce Mansbridge, PhD, Director of The Austin Center for the Treatment of OCD, or AustinOCD, is delighted to announce the addition of two highly skilled therapists to our staff. Tamara Bryan, PhD has ten years' experience treating OCD and will be heading up our Adults Services division. She is licensed in New York and New Jersey, and has recently relocated to Austin. Misti Nicholson, PsyD specializes in treating children and will be in charge of our Child and Adolescent Services division. We are excited about the prospect of being able to expand our intensive treatment programs, both for adults and children.

### Wisconsin

Rogers Memorial Hospital 34700 Valley Road Oconomowoc, Wi 53066 www.rogershospital.org

Rogers Memorial Hospital continues to build a new, stand alone building envisioned for the Child & Adolescent Centers. Coming on the heels of opening the new Experiential Therapy Center in September, the expected completion of the CAC is April, 2012. Since opening in 2003, countless children and families have benefited from the world-class treatment at the Child & Adolescent Centers at Rogers Memorial Hospital. We're excited that this new facility will match the life-changing treatment we provide.

### When Automatic Bodily Processes Become Conscious: How to Disengage from "Sensorimotor Obsessions" by David J. Keuler, Ph.D.

Dr. Keuler is a senior clinician at The Behavior Therapy Center of Greater Washington. He is a specialist in the treatment of obsessive-compulsive disorder and related conditions and has been in private practice for well over a decade. Comments regarding this article may be directed to dkeuler@behaviortherapycenter.com

The literature on obsessive-compulsive disorder (OCD) routinely includes detailed accounts of washing, checking, repeating, and undoing behaviors associated with fears of harm to oneself or others. Likewise, descriptions of intrusive sexual or violent imagery; urges to touch, tap, or even-up objects; and concerns about good & bad and right & wrong, populate the pages of scientific and self-help books and articles on OCD. Yet for some individuals suffering from obsessive-compulsive disorder, there is little hope of "finding themselves" in the pages of this popular literature. Their OCD is somehow different: it simply does not conform to these popular descriptions.

One such neglected subgroup of sufferers report distressing preoccupations with bodily processes or bodily sensations. Colloquially termed "obsessive swallowing," "obsessive blinking," or "conscious breathing," these problems fall within a class of complaints that may be aptly described as "sensorimotor obsessions". Sensorimotor obsessions as defined here involve either a focus on automatic bodily processes or discrete physical sensations. Whether technically sensory or sensorimotor in nature, such obsessions share one common precursor: selective attention. Any bodily process or sensation to which one selectively attends can form the foundation of this sensory or sensorimotor obsession. In a typical scenario, individuals begin to selectively attend to their swallowing, for example, and become anxious that they will become unable to stop thinking about their swallowing. Attempts to distract themselves fail, leading to higher levels of anxiety. This anxiety perpetuates the focus on swallowing, leaving them preoccupied and frustrated by their unsuccessful attempts to shift attention elsewhere.

### **Distinguishing Characteristics**

Sensorimotor obsessions as defined here rarely involve elaborated fears of harm to oneself or others. Fears center mainly on the concern that automatic bodily processes or physical sensations will fail to return to their previous unconscious state, thus

### **Examples of Common Sensorimotor Obsessions**

Sensorimotor obsessions often involve one or more of the following:

- breathing [whether breathing is shallow or deep, or the focus is on some other sensation of breathing]
- blinking [how often one blinks or the physical requirement to blink]
- swallowing/salivation [how frequently one swallows, the amount of salivation produced, or the sensation of swallowing itself]
- movement of the mouth and/or tongue during speech
- pulse/heartbeat [awareness of pulse or heartbeat, particularly at night while trying to fall asleep]
- eye contact [unlike social anxiety-based concerns, this form involves awareness of the eye contact itself or which eye one is looking at when staring into the eyes of another person]
- visual distactions [e.g. paying attention to "floaters", the particulate matter that is drifting within the eye that is most visible when staring at a blank wall or awareness of subtle movements of the eyes, such as saccadic eye movements]
- awareness of specific body parts [e.g. perception of the side of one's nose while trying to read or, as in the cases of a young boy and older man, a hyper-awareness of particular body parts such as their feet or fingers respectively]

### How to Disengage from "Sensorimotor Obsessions" (continued from page 17)

forever "driving the sufferer crazy." Such fears are frequently accompanied by the broader concern that the obsession itself will be unending, a concern that Dr. Jonathan Grayson has termed "obsessing about obsessing" (Grayson, 2004). Sensorimotor obsessions are infrequently accompanied by perfectionistic attitudes or beliefs; however, they do occasionally play a role, as in the case of a perfectionistic patient who was constantly preoccupied by smudges on his glasses and by other imperfections in his sensory environment. By definition sufferers report significant levels of distress, particularly as a result of impairments in concentration at work, when socializing, or when attempting to fall asleep. Compulsions in response to sensorimotor obsessions are usually limited to repeated attempts to use distraction to interrupt the fixation on sensory phenomena.

Most people at some point in their lives have experienced transient problems with this sort of sensory hyper-awareness. Stuffy noses, irritated eyes, rashes, coughing and the like represent the normal sensory annoyances that can come to preoccupy individuals for short periods of time. For some less fortunate individuals, their chronic allergies, pain syndromes, and other medical problems cause sustained interruptions to selective attention. However, for a minority of sufferers, their awareness of sensorimotor phenomena elicits anxiety and preoccupation severe enough to warrant a clinical diagnosis of obsessive-compulsive disorder or an obsessive-compulsive spectrum condition.

#### Relationship of Sensorimotor Obsessions to Obsessive-Compulsive Spectrum Conditions

evidence suggests Anecdotal that sufferers diagnosed with this type of sensorimotor OCD are also more likely to have current or past difficulties with other, more common variants of obsessivecompulsive disorder, generalized anxiety disorder, or panic disorder. This reflects the fact that problems with sensory hyper-awareness are not confined to a particular diagnostic entity (such as OCD), but cut across a number of obsessive-compulsive spectrum conditions. For example, individuals with bowel or bladder preoccupations, hypochondriasis (health anxiety), and panic disorder report not only sensory hyper-awareness (such as fullness of the bladder, acute physical symptoms, or rapid heart rate) but also cognitive embellishments that involve specific, catastrophic fears (such as humiliating bowel

accidents, serious illness, or having a heart attack).

Currently, individuals who suffer from the relatively unelaborated sensorimotor preoccupations as described in this article are routinely diagnosed with obsessive-compulsive disorder. Individuals who suffer from elaborated catastrophic fears associated with their sensorimotor preoccupations tend to be diagnosed according to the content of those fears (e.g. a focus on heart rate that leads to fears of a heart attack is diagnosed as panic disorder). Future research will ultimately determine whether sensormotor preoccupations that occur within various clinical diagnostic categories reflect the same or unrelated neurobiological processes.

#### Treatment of Sensorimotor Obsessions

Sensorimotor obsessions can be treated guite successfully by decoupling any sensory awareness with reactive anxiety. In other words, sufferers must ultimately experience their sensory hyperawareness without any resulting anxiety. Anxiety, as is the case in other forms of obsessive-compulsive disorder, serves as the glue that binds particular thoughts to conscious awareness. Once a thought is linked with anxiety, the conscious mind keeps it ever present. This occurs because anxiety is part of the brain's alarm system for danger. The mind clearly does not want us to forget about any danger that may be lurking around. If a particular idea scares us, we tend to think about it over and over. In sensorimotor obsessions, sufferers repeatedly attempt to shift their attention for fear that their sensory focus will become "stuck" and they will not be able to concentrate fully on the task at hand. Here, the thought that "I'm never going to stop thinking about this" leads to immediate fears of impaired functioning. As a result of the pairing between this thought and a feared outcome, the mind holds on tightly to the very awareness that the sufferer is attempting to rid. In many ways this is much like "white bear syndrome," where attempts by individuals to think about anything other than a white bear lead to many more thoughts of white bears (Wegner, 1989).

In order to disengage from sensorimotor obsessions, sufferers must learn "the art of self-awareness." Sufferers must learn how to invite in the sensory awareness with a relaxed and accepting posture, very much like the focus on diaphragmatic breathing during meditation.

### Psychoeducation

The first stage of treatment focuses on teaching patients that selective attention to previously automatic or unconscious bodily processes or sensations is not dangerous in and of itself. Patients are reassured that once their anxiety dissipates, the sensory awareness will shift. This reassurance often sets the stage for "inviting in" the sensations as a means of reducing anxiety.

#### **Exposure and Response Prevention**

In short, sensorimotor obsessions can be outsmarted by voluntarily paying attention to the relevant bodily process or sensation. Patients are instructed to allow the sensation to be present and to invite in any such awareness (exposure) with a casual, dispassionate By purposely focusing on the sensations focus. (exposure), patients stop relying on distraction (response prevention) as the tool for reducing anxiety. Repeated voluntary exposure to the sensations leads to diminished anxiety as patients grow accustomed to embracing any awareness without attempts to avoid or escape it. Imaginal exposure to particular feared outcomes (e.g. "my life will be ruined," "I'll never have peace of mind," "I'll never be able to get rid of this problem," or "this obsession will never go away") may be employed to enhance exposure. Additionally, patients may be asked to invite in the sensations and accompanying fears throughout the day. This is accomplished by having patients place reminders (such as Post-It notes or stickers) at home, in the car, and at work. These reminders help to cue patients to engage in repeated exposures throughout the day, thus increasing the likelihood of successful habituation.

#### **Body Scan and Mindfulness**

Patients are frequently unaware of the changes in perception that occur when selectively attending to their bodies. These changes in awareness can be frightening, as they may represent an uncomfortable and disquieting level of awareness to previously unconscious bodily processes. Patients tend to believe that they must purposely shift attention away from these unusual or previously unnoticed sensations in order to restore them to their unconscious state. Participation in a body scan can help patients fluidly move in and out of their awareness of these sensations without resorting to forced attempts.

A body scan involves shifting attention to various bodily processes or sensations for prescribed periods

of time. Patients are instructed to close their eyes and selectively attend to their feet, for example, until they acquire full sensory awareness. Once this occurs, they can next move to their calves, stomach, upper body, arms, head, or any particular sensorimotor process (such as breathing). Patients learn that they can move gently from one sensation to another without getting "stuck" by focusing and refocusing in the absence of anxiety, apprehension, or active attempts to force a shifting in awareness.

Mindfulness, the art of paying close attention to an experience in the absence of criticism, judgment, or defensiveness, can also play an important role. As stated earlier, eastern meditative practices in mindfulness often involve choosing certain bodily processes to be the focus of meditative practice (e.g. breathing, the rise and fall of the chest or stomach, sensations of air through the nostrils). Patients are instructed to allow their particular sensory preoccupation to become their meditative focus; they are to accept all sensations without criticism or judgment, and observe any sensations with curiosity and interest. Over time patients begin to experience a fading of sensory awareness (or much greater tolerance of it) as their anxiety diminishes and their willingness to invite in the sensations grows.

#### Conclusion

Sensorimotor obsessions likely affect countless thousands of individuals each year. Future research is necessary to determine how prevalent the problem is and how best to treat it. Until such systematic research is conducted, we are left with case studies and anecdotal evidence that suggests that sensorimotor obsessions are best dealt with within a cognitive-behavioral framework. Psychoeducation, cognitive reframing, reassurance, exposure and response prevention, and certain mindfulness and acceptance techniques can all play important roles in diminishing the frustration and distress associated with this maddening and at times incapacitating experience.

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### **Research Participants Sought**

### CONNECTICUT

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### MASSACHUSETTS

Attentional Processes in Scrupulous OCD

(Principal Investigator: Jed Siev, Ph.D.)

Michelle Silverman (617) 724-4354 MCSILVERMAN@PARTNERS.ORG

The purpose of this study is to examine how individuals with Obsessive-Compulsive Disorder (OCD) pay attention to things. OCD is a psychiatric illness characterized by persistent and intrusive obsessions and/or repetitive, time-consuming compulsions. For this study, we are recruiting people whose OCD symptoms are focused on contamination, religious, or moral concerns. Participants will come into the clinic for one visit (approximately 3-4 hours) and complete an interview with a clinician, fill out questionnaires, and complete a series of computerized attention tasks. Participants will receive \$75 compensation for completing the study and reimbursement for parking.

### MASSACHUSETTS

A Cross-Sectional Study of Families with Obsessive-Compulsive Disorder and Body Dysmorphic Disorder

(Principal Investigator: Jeanne Fama, Ph.D.)

Katherine Crowe (617) 643-4387 www.mghocd.org www.mghocd.org/bdd KCROWE2@PARTNERS.ORG

The purpose of this study is to investigate factors associated with symptoms of Obsessive-Compulsive Disorder (OCD) and Body Dysmorphic Disorder (BDD). This study will explore thinking patterns, behaviors, beliefs, and relationships in individuals and families with OCD and/or BDD and those without OCD or BDD. The goal of the study is to improve our understanding of factors that may contribute to the symptoms of OCD and BDD. Such knowledge may ultimately help us to develop prevention/early intervention strategies for these disorders. During participation, comprehensive assessments, including diagnostic interviews, computer tasks, and self-report measures will be administered to children diagnosed with OCD or BDD or no disorder as well as to their first-degree relatives.

#### MASSACHUSETTS

An Open Trial of Cognitive-Behavioral Therapy for Pediatric Body Dysmorphic Disorder

(Principal Investigator: Sabine Wilhelm, Ph.D.)

Lillian Reuman (617) 643-6204 www.mghocd.org/bdd LREUMAN@PARTNERS.ORG

The purpose of this study is to develop and test the effectiveness of Cognitive-Behavioral Therapy (CBT) for children and adolescents suffering from Body Dysmorphic Disorder. CBT is the most effective psychological treatment for adults with BDD. Information we have so far suggests that CBT might prove effective in treating children and adolescents with BDD as well.

### MASSACHUSETTS

Medication Study for Body Dysmorphic Disorder

(Principal Investigator: Sabine Wilhelm, Ph.D.)

Michelle Silverman (617) 724-4354 www.mghocd.org/bdd MCSILVERMAN@PARTNERS.ORG

Some individuals with appearance concerns may suffer from a condition called Body Dysmorphic Disorder, BDD, which is characterized by an excessive concern with a perceived flaw in one's appearance. We are conducting a medication treatment study for adults with BDD that seeks to establish the efficacy of Lexapro, a marketed antidepressant medication, in the treatment of this disorder. Additionally, this study seeks to determine whether individuals who do well on Lexapro will continue to do well after discontinuation of the medication. It is hoped that some of the gains made during medication treatment can be maintained after the treatment has ceased. Lexapro is among the most highly recommended medications for BDD, although there is currently no FDA approved medication for BDD.

### **NEW YORK & PENNSYLVANIA**

#### Maximizing Treatment Outcome in OCD

This study compares the effectiveness of two proven treatment strategies for OCD patients who are currently on a serotonin reuptake inhibitor medication (SRI, i.e., clomipramine, fluoxetine, fluvoxamine, paroxetine, sertraline, citalopram, or escitalopram) but still have residual symptoms. Participants remain on their current medication and receive either cognitivebehavioral therapy (CBT) consisting of exposure and ritual prevention or an additional medication (risperidone).

The goal of the study is to compare risperidone against cognitive-behavioral therapy as add-on treatments, each of which has been found effective in prior studies. All treatment is at no charge. Note: Patients who do not improve after 8.5 weeks of treatment will be offered at no-cost the treatment they did not initially

receive (either the therapy or the add-on medication).

To schedule a confidential screening, contact:

New York Metropolitan area: Dr. James Bender Jr. at (212) 543-5462 or Liane Hunter at (212) 543-5380;

Philadelphia: Center for the Treatment and Study of Anxiety at (215) 746-3327

### **ONLINE STUDY**

Anonymous Online Survey of Obsessive-Compulsive Personality Features

Chance to win \$100 Target gift card

Researchers at Columbia University/NYSPI are seeking adults (18 years old or older) to complete an online survey about obsessive-compulsive personality features. Participation is anonymous and typically takes up to 60 minutes. The information gathered will contribute to a better understanding of the nature of personality-related problems, leading to improved assessment methods and treatment interventions. Participation is limited to once per person. For more information please click on this link:

https://www.surveymonkey.com/s/PhaseIVSurvey

### **ONLINE STUDY**

We at the Bio-Behavioral Institute in Great Neck, NY are investigating the role of certain emotions in individuals with body dysmorphic disorder (BDD), obsessivecompulsive disorder (OCD), or hoarding. If you have been diagnosed with BDD, OCD, and/or hoarding, all we ask is a half hour of your time to fill out some questionnaires. Your participation could potentially be beneficial in reducing emotional distress and provide valuable feedback to you in your treatment. To complete the questionnaires please go to the following link, http://kwiksurveys.com?u=biobehavioral. Or if you wish to receive more information before completing the questionnaires, please e-mail Lauren or Danielle, at biobehavinstitute@gmail.com.

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

### **ONLINE STUDY**

Anonymous Online Survey on Body Movements in Adults with and without OCD

If you are an adult with or without OCD, you are invited to participate in a brief online survey. With the information gathered from this survey, we hope to estimate the prevalence of and begin to understand the function of subtle movements among individuals with OCD. The survey will take approximately 15-20 minutes to complete. While there are no direct benefits for completing the survey, \$1 will be donated to the International OCD Foundation for each participant. All information provided will be kept completely anonymous. If you have any questions, please contact Dr. Marilyn Cugnetto at the NeuroBehavioral Institute at 954-217-1757.

You can access the survey at the following link: https:// www.surveymonkey.com/s/nbi1

### **MULTIPLE SITES**

Potential Adjunctive Treatment for OCD Patients who do not Adequately Respond to Treatment with a Serotonin Reuptake Inhibitor

Need more help for your OCD? Many people with OCD experience only a partial response to currently available medications.

Montefiore Medical Center and multiple sites across the U.S. are seeking volunteers to participate in a clinical trial evaluating the effectiveness of low-dose ondansetron augmentation for the treatment of OCD in patients who have not adequately responded to their current SRI therapy after at least 12 weeks of stable treatment.

Eligible participants will be randomly assigned to receive ondansetron 0.5 mg, ondansetron 0.75 mg, or placebo, twice daily. Participants will continue the current SRI treatment and receive 12 weeks of augmentation. Participants completing the 12-week treatment may have the opportunity to continue treatment for up to one additional year. Treatment is provided at no cost.

Eligibility criteria: Participants must have a DSM-IV-TR diagnosis of OCD as their primary disorder who have been on a stable treatment regimen of clomipramine, fluvoxamine, fluoxetine, paroxetine or sertraline for at least 6 weeks may be eligible for this study. Six additional weeks of stable SRI treatment, without adequate clinical response, will be required prior to randomization, after which the participant will receive SRI plus study drug, for a total of 12 more weeks.

Exclusion Criteria: Exclusion criteria include, but are not restricted to the following:

- Failure to respond to more than 2 SRI treatments
  prior to current SRI
- Hoarding as primary OCD symptom
- Current or past medical history of schizophrenia or other psychotic disorders, schizotypal personality disorder, bipolar disorder, Tourette syndrome, autism or autistic spectrum disorders, eating disorders, PTSD
- Requiring active behavioral therapy
- History of drug addiction or drug, alcohol or other substance abuse within the past 12 months
- Currently taking, or having taken within the previous 8 weeks, any of the following: other SRIs, antipsychotic drugs, lithium, benzodiazepines or other anxiolytics, carbamazepine, oxcarbazepine, phenytoin, or other anti-depressants (including St. John's Wort)
- Likely to use triptans at any time during the study
- · Believed to have suicidal or homicidal risk

Contact: For more information, please contact us at 877-509-6626 or go to www.OCDStudy.info.

Locations: Multiple U.S. sites- Beverly Hills, CA; Imperial, CA; Los Angeles, CA; Orlando, FL; Atlanta, GA; Smyrna, GA; Milwaukee, Wisconsin; Princeton, NJ; Bronx, NY; Great Neck, NY; New York, NY; Raleigh, NC; Avon Lake, OH; Austin, TX; San Antonio, TX

### **MULTIPLE SITES**

Does your child have OCD? Are you currently seeking treatment for your child?

Study Title: D-Cycloserine Augmentation of Cognitive Behavioral Therapy for Pediatric OCD

Researchers at the University of South Florida in Tampa/St. Petersburg, Florida and at Massachusetts General Hospital in Boston, Massachusetts are currently investigating how well a medication called D-Cycloserine (DCS) works to help children with OCD respond better to cognitive behavioral therapy (CBT). CBT is a form of psychotherapy that has already been shown to help kids with OCD.

All children in the study will receive ten sessions of CBT. There is a 50% chance your child will receive the study medication, and a 50% change that your child will receive a placebo pill. The study also involves eight visits to the clinic where you and your child will participate in study assessments. These assessments will involve answering questions about your child's OCD and other psychological symptoms. In addition, we will draw a small amount of your child's blood toward the beginning and end of the study to make sure she or he is healthy.

To be in the study, your child must:

- · Be diagnosed with OCD by the doctors in our clinic
- · Be between the ages of 7 and 17 years
- Not have any health problems that could interfere with study participation

There is no cost to participating in this study. We will not charge you for CBT, the study medication, or any of the evaluations.

For more information, please contact study coordinator Anna Jones at the Rothman Center for Neuropsychiatry at the University of South Florida at (727) 767-8230, or study coordinator Ashley Brown at Massachusetts General Hospital at (617) 503-1436.

Rothman Center for Neuropsychiatry Principal Investigator: Dr. Eric Storch 800 6th Street South, 4th Floor North St. Petersburg, Florida 33701 rothmanctr@health.usf.edu

Massachusetts General Hospital Principal Investigator: Dr. Daniel Geller 185 Cambridge Street Boston MA 02114

### 2012 Research Awards Request for Proposals

### **Submission Period:**

January 2, 2012 - February 29, 2012 at 5pm EST

Promoting research into the causes and treatment of OCD and related disorders is a top priority of the International OCD Foundation. In 1994 the Foundation launched the Research Grant Award Program. Grants range from \$25,000-\$50,000 each and we have been able to fund between three to eight projects each year totaling between \$70,000 to over \$300,000 given out annually. The Foundation has distributed \$2.7 million dollars in research grant funding since the inception of the program.

Funding for these yearly research awards comes from contributions of the Foundation's members and friends with 100% of these contributions going directly toward funding the winning projects. Historically, we have solicited donations for a general research fund. This year we wanted to provide an option for more targeted giving. As a result, in this year's research appeal we are asking donors if they wanted to keep their donation for the general research fund or to earmark it toward a specific area of interest that may affect them directly.

The options for restricting your research donations include:

• OCD spectrum disorders

(Body Dysmorphic Disorder, Trichotillomania, Skin Picking, Tics/Tourette's)

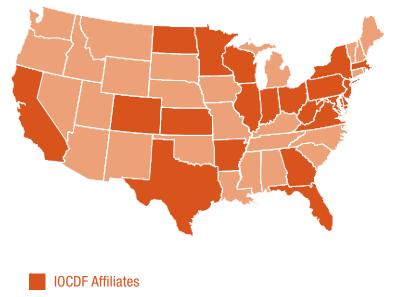
- Hoarding
- Genetics
- Pediatric OCD
- PANDAS/PANS specific research

For information about how to apply please go to: www.ocfoundation.org/Research.aspx

If you have additional questions, please contact Barbara Rosemberg at **ocfresearch@ocfoundation.org** 

### FROM THE AFFILIATES

### Where are our Affiliates located?



### **OCD KANSAS**

OCD Kansas, based in Wichita, is a new affiliate of the IOCDF. OCD Kansas is committed to the mission of the IOCDF and increasing awareness and treatment of all anxiety disorders. OCD Kansas hosts a bi-monthly OCD Support Group. OCD Kansas provides referrals to area psychologists and therapists with experience using evidence-based treatments in the treatment of OCD and other anxiety disorders. OCD Kansas is working to bring experts in the treatment of anxiety to Kansas to train local treatment providers. Additionally, OCD Kansas is coordinating a musical event to fundraise for our efforts and this event is currently planned for April, 2012. OCD Kansas is currently working to develop more connections in the Kansas area that may benefit those we serve.

Current officers of OCD Kansas include: President -Angela Cathey; Vice President- Emanuel VonDran; Treasurer/Fundraising/Grants Officer – Sarah Staats; Community Outreach/Support Group Coordinator – Nakisha Carrisquillo; Secretary – Jay Maneklal.

We would also like to acknowledge the generous support and guidance of Rob Zettle, PhD and Helen Reiner, PhD.

Information regarding OCD Kansas, its activities, and officers can be found at www.facebook/OCDKansas. We can also be reached at OCDKansas@gmail.com or 316-347-7561.

### **OCD NEW JERSEY**

OCDNJ hosted its annual conference/ brunch on October 23rd. IOCDF spokesperson, Jeff Bell, was our main speaker. He was joined by Allen H. Weg, EdD, Vice President on the Board of OCDNJ, who periodically



made clinical observations and comments on the information presented by Jeff.

Jeff's firsthand account telling of his experiences struggling with OCD was sometimes heart-breaking, sometimes heart-warming, sometimes quite funny, but always entertaining. His golden radio voice and engaging manner had the nearly 100 attendees, a mixture of mental health professionals and OCD consumers, wrapped in attention.

His presentation also focused on his own contributions to OCD treatment, illustrating ways to think about choices when faced with the seduction of a compulsive ritual. His talk was entitled, "The Greater Good Perspective Shift- A Field Tested Approach to OCD Treatment Motivation," where he reviewed strategies outlined in his book, "When in Doubt, Make Belief."

For his part, Allen Weg added comments about motivational interviewing, and how Jeff's work fit into the larger ERP framework. He also moderated our "Living with OCD" panel, where persons tell their stories and then take questions from the audience. Panel members included a 14 year old boy and his mother, a young mental health professional who had been on a previous OCDNJ panel as a teenager, and a 9/11 firefighter who not only suffered with PTSD after attending 90 funerals in a year, but developed OCD contamination issues around firefighters everywhere.

A lavish buffet brunch, awards, book sales, and research announcements rounded out a wonderful and satisfying day.