

FROM THE FOUNDATION

New Features, Exciting Sessions Highlight 18th Annual IOCDF Conference in Sunny San Diego



This year marks the 25th Anniversary of the International OCD Foundation and for 18 years, our Annual Conference has been the centerpiece of our efforts. As part of the celebration, we are making this year's conference our biggest yet. Highlights include more than 100 presentations, nearly two dozen support groups, pre-conference sessions for professionals and non-professionals alike, and the most robust child and teen activities in our history. As you will see, no matter your age or relationship to OCD, everyone will find something of interest at this year's conference.

Hotel Information

Every room at this year's conference hotel features a water view and a balcony! All Conference sessions and social functions will be held at the Sheraton San Diego Hotel and Marina (located at 1380 Harbor Island Drive in San Diego, CA). A limited block of rooms has been set aside at a special rate of \$189/night. Reservations can be made directly by going to www.ocfoundation.org/travel.aspx and clicking on "Reserve a Room" or by calling (619) 291-2900 and mentioning the International OCD Foundation Conference. This special room rate will expire on July 6, 2011 but is filling up fast, so please be sure to book your room before then.

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FROM THE FOUNDATION

Letter From The President



Dear Friends,

This year, the International OCD Foundation, formally the Obsessive Compulsive Foundation, celebrates its 25th anniversary. I feel exceedingly lucky to have been involved with such an extraordinary organization for as long as I have, and to have come into contact with so many wonderful people- patients, families, and providers- from whom I have learned so much.

First, I want to pay tribute to the founders of the organization, two of whom we are lucky enough to still have as members of our Board of Directors and one who continues to serve on our Scientific Advisory Board.

Our current board members, Patti Perkins and Fran Sydney, are models of strength and courage. In 1986, when so little was known about OCD, and in the midst of their own struggles with the disorder, they were able to think beyond their own pain, and instead focus on how they could help others find information, support, and treatment. This involved going public with their own stories at a time when even more stigma was attached to mental illness. They will tell you that it was these public appearances on shows like "Oprah", however, that led them to know how great the need was for an educational organization to help the tremendous numbers of people who were suffering from an illness they could not even name. Patti and Fran have paved the way for our modern day spokespeople like Jeff Bell and Elizabeth McIngvale, who continue to understand the power of one's own personal story in helping others to overcome OCD, and how giving back can often be the best medicine.

Dr. Wayne Goodman, also among our founders, has continued to be involved with the IOCDF as a member of our Scientific Advisory Board. He is also one of the originators of the popularly used assessment tool, the

YBOCS, and he is considered by many as a pioneer in research and treatment for OCD. Another one of our Board members, Dr. Michael Jenike, also deserves our thanks for recognizing early on the extreme suffering of OCD patients, and knowing that the psychiatric community needed to understand and treat this disorder more aggressively. For almost 30 years, Michael has been at the forefront of research and treatment of OCD. He has also understood the importance of an organization whose sole mission is to help patients and families access information and education about this illness, but also to fund research so that our understanding of the illness is ever improving. Michael's commitment to the IOCDF has been unwavering, and is a testament to his absolute belief in its mission since his involvement in 1995.

At times, when we still see so many people suffering with OCD, and when we still know how much is left to understand about the illness, it is easy to feel overwhelmed with all that is left to do. However, when we look back and see how far we have come, and how much more is understood now than 25 years ago, we should feel nothing but proud.

Former OCF President Joy Kant recounted to me the other day that when her own son was diagnosed with OCD, she went to her local bookstore to find a book about OCD, and could only find two! We now know there are dozens of books about OCD, and one very good one written by Joy's very same son, Jared. Ironic? I'd rather think of it as paying it forward.

The true vision that the founders of this organization had 25 years ago is that no one needs to continue to suffer in silence with OCD, and this is a goal we are wholeheartedly dedicated to continue working towards for another 25 more years and beyond.

Diane Davey, RN

President, IOCDF Board of Directors

OCD Newsletter

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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.

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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.

FROM THE FOUNDATION

18TH Annual Conference (Continued from front page)

For Those with OCD

2-Day Treatment Group July 27 & 28, 2011

For the second year in a row, individuals with OCD who might otherwise not be able to visit a specialty OCD clinic will get a chance to experience an intensive 2-day treatment program prior to the Conference. From July 27-28, Dr. Reid Wilson, co-author of *Stop Obsessing!* and author of *Don't Panic!*, will be running a 2-day treatment group for people with OCD. Space is limited to eight participants. Four therapist spots will also be available to observe the program. The cost of the program is just \$375 and Dr. Wilson is generously donating 100% of the funds back to the IOCDF. To download a registration and referral form, visit anxieties.com/pdf/registration.pdf. For questions about the program, please contact Dr. Wilson directly at rrw@med.unc.edu or (919) 942-0700.

Thursday, July 28

Learn how to create and manage a support group. For those arriving to the hotel early, IOCDF Spokesperson Elizabeth McIngvale and her family will hold a session called, "Support Groups – From Formation to Implementation" from 7:00-8:30PM on Thursday evening. This event is open to all registered attendees.

Friday, July 29

- Introductory sessions such as "OCD 101" and "Introduction to Hoarding" for those newly diagnosed.
- Several inspirational OCD success stories such as "Coming Out of the OCD Dungeon" and "Working With OCD Following Your Own Battle: Rewards, Challenges, and Directions."
- A collection of animated shorts about OCD in the "OCD Animation Festival."
- Several question and answer sessions with world-renowned therapists including "Medication: What Do I Need to Know?" and "The Scrupulosity Answer Guys"
- Topic-specific evening support groups on compulsive skin picking, hoarding, body dysmorphic disorder, intrusive thoughts, and scrupulosity, as well as format-specific GOAL and Obsessive Compulsive Anonymous groups.
- The now-famous 11th Annual Virtual Camping Trip run by Dr. Jonathan Grayson, his colleagues, and volunteers from OCD Philadelphia. For more information and to see a *Nightline* special on the

program, please visit our conference web site. This program is free to registered attendees.

Saturday, July 30

- Bring your questions! Three different Q & A sessions feature some of the most well-respected names in OCD treatment.
- More success stories in "So Now You Know: My Journey Through Life with OCD" and "How We Beat Our OCD."
- A special session called "Increasing Awareness of OCD in Older Adults" will focus on the special considerations into living with and recovering from OCD in older adults.
- Our always popular "OCD in the Media" session will bring together newscasters, public relations experts, and members of the entertainment industry to discuss how OCD is portrayed in various formats.
- Learn more about the ongoing research on OCD during the Question and Answer portion of our Research Poster session.
- Relax after a long day of programming with some light refreshments, five evening support groups, and a screening of the documentary "OC-87: The Obsessive Compulsive, Major Depression, Bipolar, Asperger's Movie."

Sunday, July 31

- Wrap-up the conference with inspirational recovery stories from the McIngvale family, Jeannie Clerkin, and Roy C.
- Learn more about body dysmorphic disorder, mental rituals, and metacognitive therapy for OCD.
- In "Life After OCD," audience questions about the different aspects of coping with the realistic challenges in recovering from OCD will be answered by several expert therapists.



- CE and CME credits available
- Over 100 presentations with three tracks dedicated to professionals
- Additional pre-conference session for professionals
- Every guest room features a balcony and water view

Sheraton San Diego
Bay Tower

More info at: www.ocfoundation.org/Conference.aspx

FROM THE FOUNDATION

18TH Annual Conference (Continued from page 3)

For Kids and Teens

Thursday, July 28

- For middle school and high school students arriving early, this year we will feature a Thursday evening (6:30-8:00PM) support group run by Jim and Rachael Hatton. This event is open to all registered attendees.

Friday, July 29

- A dedicated track of interactive workshops for to kids and teens with OCD and related disorders begins and runs throughout the conference.
- For those children who are not interested in a particular session, they can take advantage of our Kids and Teens Art Therapy Rooms. These rooms, run by art therapists from Rogers Memorial Hospital, will feature art, leisure, and socialization activities throughout the conference schedule. One room will be dedicated to kids (younger than age 13) and another adjacent room will be dedicated to teens (ages 13-18).
- On Friday evening, support groups for parents, teens, and children of parents with OCD will all run simultaneously, allowing everyone in the family to meet others and share their feelings after an emotional first day.

Saturday, July 30

- After the kids and teens track concludes and everyone has had a chance to grab some food at our Saturday evening social, therapists from the NeuroBehavioral Institute will hold their “3rd Annual IOCDF Fashion Show and Karaoke” – Participants in this interactive workshop will get an ERP-based makeover and compete in the OCD Fashion Show Contest. With the support of fellow attendees and their cheering fans, models on the catwalk and the OCD singers will learn how to fight OCD and think about exposure exercises in a whole new way.
- Another round of support groups for teens with OCD and for their parents will also be held on Saturday evening.

For Parents and Family Members of those with OCD and Related Disorders

Friday, July 29

- Parents of both children and adults with OCD will find help through sessions such as “Untangling Behaviors in Kids” and “Help for Families with Adult Children with OCD.”
- Dr. Alec Pollard will give family members tips about working with their loved one who may not yet want help in “Recovery Avoidance: Why Some People Have it and What Others Can and Cannot Do About It.”
- Evening support groups will be held for parents of those with OCD, families with loved ones with OCD, and families with loved ones with hoarding.

Saturday, July 30

- For parents of children with sudden-onset OCD, some of the leaders in the field of PANDAS research will provide an overview and update on new directions.
- Practical tools for use by family members of those with hoarding will be presented in “Digging Out: Helping Your Loved One Who Hoards.”
- A panel discussion, led by Jim and Rachael Hatton, will feature several couples who have dealt with the impact of OCD on their relationships and in their own lives.
- IOCDF Spokesperson, Jeff Bell, will discuss the benefits of fostering supportive connections between not only individuals with OCD, but also their families, in “Families Helping Families.”
- Two more evening support groups for parents will bring a busy Saturday to a close.

Sunday, July 31

- Parents of children with OCD who are about to enter college will find “OCD and the College Application/Selection Process” to be a very useful session.
- For parents considering residential treatment for their young child or teenager, “Residential Treatment for Kids and Teens with OCD” will help offer some answers.

FROM THE FOUNDATION



For Mental Health Professionals

This year's Conference will feature 34 professional sessions, ranging from introductory to advanced content. Psychiatrists, psychologists, social workers, and mental health counselors can all receive up to 18.5 continuing education credits. Highlights include:

Friday, July 29

- For the fourth year in a row, Dr. Thröstur Björgvinsson will run a three-session introductory series for mental health professionals who are new to treating OCD. Topics covered will include diagnosis and assessment, first line treatment options, and an introduction to working with kids, teens and families.
- For more experienced clinicians, advanced sessions will include "Disgust in Contamination and Intrusive Thoughts" and "When Worlds Collide: Clinical and Theoretical Implications of the OCD/Tourette Interface."
- Friday's research sessions include updates into glutamate as a medicinal intervention for OCD, treatments for youth with OCD, OC related disorders, and African Americans with OCD.

Saturday, July 30

- "Careers in OCD: Which Path Makes Sense for Me?," led by Dr. Charles Mansueto, is a moderated panel of experienced OCD therapists that will assist students, recent graduates, and young therapists by discussing different paths to follow for pursuing a career in OCD.
- For more experienced clinicians, advanced sessions will include "Managing Comorbid Eating Disorders in OCD Treatment" and "Troubleshooting in Cognitive-Behavioral Therapy for OCD: A Clinician's Forum."
- Saturday's research sessions include updates on the research of sudden-onset OCD (PANDAS), hoarding, neurosurgery, and the role that families play in OCD.

Sunday, July 31

- "Teletherapy and Videoconferencing in OCD Treatment: Weighing the Benefits and Risks" will discuss emerging technologies for remote OCD treatment.
- Find out how the word choices in medical slips, medical records, and releases can negatively impact your patients in, "Peril in the Pen: How Those Little Medical Slips Can Cost Your Patients Their Jobs and Their Insurance."

FROM THE FOUNDATION

18TH Annual Conference (Continued from page 5)

Award Presentations

Patti Perkins IOCDF Service Award

Each year the IOCDF's Board of Directors recognizes an individual who stands out as having contributed to the success of the IOCDF's mission and programs. This year, we will honor the contributions of Dr. Fred Penzel with the Patti Perkins IOCDF Service Award. With 30 years treating individuals with OCD, Dr. Penzel is a clinical psychologist and currently the director of Western Suffolk Psychological Services in Huntington, NY and author of books on OCD and Trichotillomania (and theater lighting!).

Dr. Penzel is an inaugural member of the IOCDF's Scientific Advisory Board (since 1987), as well as a member of our Behavior Therapy Training Institute faculty. He is a fixture at the IOCDF Annual Conference having presented at virtually every conference since its inception, and he currently serves on the Conference Planning Committee.

Dr. Penzel is one of our most dedicated OCD Newsletter contributors with over 30 articles including an article in the very first newsletter! He is also a regular contributor to online education including articles on our primary website (www.ocfoundation.org) and the soon to be launched OCDinKids.org website as part of his participation on the Pediatric OCD Committee.

IOCDF Career Achievement Award

New this year, the Career Achievement Award will be given to Edna Foa, PhD. Dr. Foa is a Professor of Clinical Psychology in Psychiatry at the University of Pennsylvania and Director of the Center for the Treatment and Study of Anxiety. She received her PhD in Clinical Psychology and Personality from the University of Missouri, Columbia in 1970. Dr. Foa devoted her academic career to study the psychopathology and treatment of anxiety disorders, primarily obsessive compulsive disorder (OCD), post traumatic stress disorder (PTSD), and social phobia, and is currently one of the world-leading experts in these areas.

Dr. Foa has published several books and over 350 articles and book chapters and has lectured extensively around the world. Her work has been recognized with numerous awards and honors including TIME magazine's 100 most influential people of the world in 2010. Dr. Foa is a pioneer in the treatment and understanding of OCD and we are proud to have her as the first recipient of this award. Although Dr. Foa will be travelling internationally during the conference, her colleague, Dr. Elna Yadin, will be accepting the award in her honor.

Keynote Address

We are thrilled to announce that Chris Trondsen and his mother, Elizabeth Trondsen, will deliver this year's Keynote Address. Chris Trondsen began struggling with OCD as early as age 7. Untreated for 13 years - due to lack of knowledge that the disorder even existed - in October of 2002 he attempted to take his own life to alleviate his suffering. That's when it became clear to his mother and family that there was something wrong. After seeing his doctor, he was diagnosed with OCD at age 20 but told by his primary care physician that his OCD was so severe that he would suffer with it for the rest of his life and could never improve. After research through the IOCDF's website, Chris began treatment at the OCD Center of Los Angeles. With hard work, determination, and the help of the OCD specialists and support of his mom, Chris was able to get his OCD under control. Since completion of treatment, Chris was able to go from being completely home-bound due to 18-hour-a-day crippling obsessions and compulsions (only taking a 6 hour break to sleep) to graduating college, taking martial arts, going to work, and getting his life back. He has since been active in helping others get information and treatment for OCD so they won't have to suffer as long as he did without any knowledge or awareness of what they are suffering from.

FROM THE FRONT LINES

Better Late than Never - Why You Need to Seek Treatment at Any Age for Your OCD by Michael Vinar

The first intrusive thought I had was at a park near my home where I attended day camp. My first thought came out of the blue. It was related to bodily secretions. I had no clue where this thought came from. I actually thought I was possessed. Much later, therapists thought there was a connection between the intrusive thought and my dad because he had atrocious bathroom habits. Dad did what he wanted to do and I feel he was insensitive of how his behavior affected his family.

At age 18, I began to attend a local community college. This is the age where my irrational thoughts began to escalate to a very uncomfortable level. I began to have strange, irrational sexual thoughts that I didn't understand. The thoughts focused mainly on females. I felt helpless! Between classes, I used to sit on the lawn and write down these terrible words, trying to figure them out. It was painful to do because I would never utter these words aloud. They didn't fit my personality. I was so embarrassed and ashamed that I hid my symptoms for years.

In my 30's I began therapy to figure out my irrational sexual thoughts. My thoughts were unwanted and automatic. Each new therapist and I would engage in talk therapy and the same issues would come up each time with no resolution. I used to sit there staring at the ground for about 10 minutes or more because I was so uncomfortable with the subject matter. I didn't want to offend the therapist because women were the focus of my thoughts. The diagnosis of OCD never came up until 2001 when one therapist encouraged me to see a psychiatrist for a medication evaluation. This is when I received the diagnosis of OCD for the first time.

My current symptoms have been going on for 35 years. Over the years I was prescribed a myriad of medications, such as Celexa, Luvox, Anafranil, Prozac, Effexor, Risperdal and Zoloft. Currently, I am taking Paxil and Buspar. Some of the medications had side effects such as hand trembling, short-term memory loss, and a near shutdown of sexual interest. I felt frustrated because I didn't feel any relief from my OCD with just medications and talk therapy.

It got to the point where I felt like I had no other choices and no hope of relief from my OCD. It was then my psychiatrist told me about the International

OCD Foundation website. I checked it out and found therapists who specialize in the treatment of OCD. I finally found something that would help me. I saw a section about intensive treatment programs. I noticed one at UCLA near my home, so I made an appointment for an evaluation and was admitted.

I am now 53 years old and until now I never had the only form of therapy that can successfully treat OCD, which is Cognitive Behavioral Therapy (CBT), specifically Exposure and Response Prevention (ERP). I initially started going to an outpatient therapist but felt that I need something more, so UCLA was the best option for me.

The UCLA OCD Intensive Treatment Program is a 30-day program and meets for 4 hours each day from 9AM to 1PM. I am able to meet with my therapist for an hour each day, and then we have 2 hours of behavioral practice where I face my obsessions through response prevention and habituate to the anxiety. We also have an hour of group therapy where we learn how to cope with our OCD, cognitively restructure our thoughts, prevent relapse, and set weekly behavioral goals.

My experience at the UCLA Intensive Treatment Program has been eye opening. For the first time in 35 years, I am seeing results and learning to manage my sexual thoughts. This can only happen with hard work, determination, and having a razor-sharp focus. My goal is to get to a point where I no longer pay attention to the thoughts- that is, I sit with the discomfort of the thoughts until they naturally subside. I am now able to do this better because of the combination of medications and therapy.

Only a few close friends know my symptoms. I was fearful that if I admitted my strange thoughts, my friends would want nothing to do with me. Fortunately, my friends have been very supportive. They had no idea that I was in such physical and emotional pain.

In closing, I wonder if there are other OCD sufferers who can relate to my OCD symptoms. If you can, please know you are not alone. Get the help you need. If you have not noticed any improvement of your OCD symptoms, please consult the International OCD Foundation website and find a treatment program and get the help you need. I am so glad I did.

ORGANIZED CHAOS

Living, Struggling, and Thriving in the Face of OCD: My Story by Melissa Binstock

After spending much of her childhood and adolescence in doctor's offices and hospitals drowning in symptoms and medications, at the age of 16, Melissa Binstock decided to write a memoir to talk about her experience and give hope to others suffering from OCD and other psychological disorders. 6 years later, *Nourishment: Feeding My Starving Soul When My Mind and Body Betrayed Me* was published. In what follows is an experience Melissa touched on in her book. *Nourishment* is now available at Barnes and Noble and Borders. To find out more about *Nourishment*, please visit www.nourishmentthebook.com.

Books, pencils, pens; books, pencils, pens: This is the mantra I began repeating to myself when I was just 8 years old; this is the mantra that represents the start of my battle with obsessive compulsive disorder.

My OCD began as an innocent attempt to organize my life after I began experiencing symptoms of Tourette's syndrome and dyslexia. The uncontrollable movements my body made and my inability to read left me feeling as though my world had been tossed upside down—I felt as though nothing was in my control. As a result, control became my new obsession. At first, I endeavored to gain control of my environment by controlling my belongings. At school, that began with organizing the books and pencils I kept in my desk. Books had to be arranged in a specific order with the largest on the bottom and smallest on top. Each pencil needed to be perfectly sharpened, aligned, and ordered by length in the plastic pencil holder. After making sure everything was perfectly ordered, I had to perform the ritual of closing my eyes and touching the lead tip of each pencil 5 times before being able to start on my assignments.

If my ritual was interrupted or didn't feel quite right, I would have to start again. My teacher demanded that I "Stop it!" and "Pay attention!" which caused such feelings of complete frustration that those feelings began to overflow like water rushing out of a burst levy. I wanted to cry, stomp my feet, and yell at the top of my lungs, "Just let me be! Just leave me alone!" Couldn't she see I had to perform this ritual? Didn't she understand I didn't have a choice?

I yearned for a safe world, a predictable world. The rituals, I believed, gave me that world. They gave me some sense of stability and coherence. If I couldn't complete the ritual or get it just right, the tension and anxiety over the possibility of losing control would become too overwhelming—my stable world would turn to chaos once more. As time went on, though, controlling my external world was not enough to keep the anxiety at bay.

What I really wanted was control of myself. I believed the most obvious way to do this was first by controlling what I wore and later, what I ate. Each day I had to wear the same faded green and brown-striped T-shirt. Although other kids teased and taunted me for always wearing the same thing, wearing that T-shirt gave me a sense of power and stability. I would be okay as long as I had that T-shirt on. As I grew older, just wearing the same shirt wasn't enough--my desire for control and safety led me to begin to control the foods I ate. I devised a list of rules that had to be followed to the letter; for example, without knowing anything about nutrition, I arbitrarily decided that I could only eat 12 grams of fat per day and 12 grams of sugar per item. For some reason, 12 was a magic number in my compulsive world.

Controlling my clothing and food was tiresome, yet it kept the anxiety at bay. Eventually, my rituals became more elaborate and all-consuming: I could only eat at one restaurant, I could only consume white foods, I could only eat when no one was looking. By the time I got to high school, my OCD had all but taken over

my life. I had to follow a strict routine marked by obsessions and compulsions from the moment I woke up to the moment I went to sleep. Just getting dressed for school became a tedious task of dressing, undressing, and dressing again until I felt like my clothing fit just right. As college approached, I feared what my roommate would think of my idiosyncratic behaviors—my inability to eat in front of people, my strange dressing habits, my odd predilection for white foods. Yet, I also feared the inevitable surge of anxiety I would experience if I relinquished even an ounce of control.

As my freshman year in college began, my simultaneous fears waged a battle against one another, making me feel as though I was at the center of an interminable game of tug-of-war. The safety and solace of my OCD with its meticulous obsessions and carefully crafted rituals was pulling me in one direction, while my desire for normalcy was pulling me in the other. I probably would have sided with my OCD had it not dawned on me that my desire to regain control of my mind and body had actually caused me to lose complete control of absolutely everything.

I began to come to this realization when my restrictive eating habits caused me to pass out one night in my dorm room. I hadn't eaten much of anything during the day, partly because I had been surrounded by people for the majority of the day and couldn't break away to perform my careful and precise eating rituals, which involved eating by myself. The experience left me terrified and helped me realize that my OCD was out of control, and I needed help. And help did come—in the form of a lecture in my psychology class. Although my professor wasn't aware of it, she was simultaneously serving as a professor and a therapist for me during this lecture. This professor taught me about a system of therapy known as cognitive behavior therapy, or CBT.

Learning about CBT was like one of those great ah-ha moments where everything suddenly makes sense. Understanding that my thoughts had a heavy influence on my feelings, and learning that if I could change my thoughts I could also begin to change my feelings, were life-altering concepts. I began to focus on the thoughts that my obsessions and compulsions were based on. One of those thoughts was that the rituals I preformed would help me gain control of my life. Yet, as that night in the dorm room demonstrated, I had entirely and utterly lost control. The reality of the situation made me realize that my obsessions and compulsions were not only illogical, but that they were potentially deadly. And so, I began the difficult challenge of using the tools I acquired from CBT to help me overcome my obsessions and subdue my compulsions. However, I wasn't alone in this process. The professor who first taught me about CBT and who was also a licensed therapist who provided me with support, guidance, and resources along the way.

One of the tools of CBT that was particularly helpful was exposure and response prevention (ERP). During ERP, I forced myself to do an anxiety-provoking activity again and again until it no longer triggered the surge of anxiety I so greatly feared. I would also use the CBT tool of catching, challenging, and changing my destructive thought-processes that fed my anxiety. A particular task I worked on was eating in front of people. Although the anxiety I experienced during this task was painful, I found that the more I engaged in this task and the more I focused on catching, challenging, and changing the harmful thoughts about losing control, the lower my anxiety level became. The process took time, and I cannot sit here and tell you that I am 100 percent anxiety-free today. However, what I can say is that CBT helped me gain control over the obsessions and compulsions that once ruled my life.

ORGANIZED CHAOS

The Girl with OCD by Sharon Corish

I walk into the room. I was so busy rewinding I forgot what I came in here for. I go to open the door again. I touch the knob - no, that thought I had, in the back of my mind, it was wrong. I touch the knob again- another bad thought. I touch the knob again, but 3 is not a good number to stop on...tap, tap, tap, tap...no that thought was bad too. tap, tap, tap, tap...tap, tap - wait how many taps now? I guess I will have to start over again...

“A broken record.” How many times have I read that? In those books people bought for me to help me, to help solve me.

Solve me, because I am that complicated, so complicated there is a name for it- Obsessive Compulsive Disorder. I heard about it when I was 8, mentioned to me from those books.

I did not understand. Why do I worry like this? Why do these worries of mine not make sense to everyone else?

I knew my friends did not worry like me, but still I sat, anxious and jittery, unable to concentrate on anything rational. Always worrying in a world that never really existed, a world my mind created.

Therapy, medication, help. I needed help. Help, because I could not get out of the hole I was digging on my own. Help, because my problems stemmed deeper than I could even imagine. Help, because I was different. “Fitting in” was not an option for me- never. Ever since I was born, I would always be different.

Tap, tap, tap, tap...4, that’s good, right? – no wait, 5 is better, right? Tap...oh wait I had a bad thought...tap, tap, tap, tap...8? No...10 will be a better number... tap, tap, tap, tap...10. Okay, that should do for now.

I don’t make sense. A jumble of worries, compulsions, fears, confusion. Ever changing worries. Fears that adapt to my strength.

Why am I like this? It is a part of life. That’s just how it is. I have accepted it, embraced it. This is who I am, and that is okay.

Tap, tap, tap, tap....

Who is that making the tapping noise? It is her. What is wrong with her?

It is me. I am the one who is tapping.

I am the girl with OCD.



FROM THE FRONT LINES

Living a Nightmare: OCD in Pregnancy and the Postpartum Period by Kristin Burgard

I had always been a “worrier” with some obsessive-compulsive tendencies, but my anxiety ran rampant when I was pregnant with my oldest daughter, Katie. I was terrified about riding in a car, crossing streets, eating un-pasteurized cheese—anything that could possibly harm my unborn baby. And for the first year of her life, I was constantly anxious: I was petrified about her coming in contact with even a speck of lead-based paint, cleaning products, medication, or spoiled food. To calm my anxiety about harm befalling her, I did endless research on the internet and continually asked for reassurance from friends, family members, doctors, and even, much to their annoyance, the poison control center operators. Before a vacation to Arizona, I spent days washing and rewashing “contaminated” clothing. A few days into the trip, my anxiety was so high I drove myself to the emergency room. I had already started therapy to address my OCD, but it was my trip to the ER that made me realize that I also needed medication to get my OCD under control. Once I returned home, I met with a psychiatrist and started taking the medication Celexa. The antidepressant coupled with therapy worked wonders for me, and, a year later, I was back to feeling like myself.

With the OCD under control, I chose to stop taking Celexa before I became pregnant with my second child. I was terrified about taking any medication while pregnant, so stopping the SSRI seemed to be the logical choice. Not surprisingly, during the first two trimesters of my pregnancy, I again obsessed about harm coming to my young daughter or the unborn baby. Although dealing with my irrational thoughts was difficult, it was at least manageable until the third trimester, when my fears turned to the unthinkable—that I might intentionally hurt Katie, then three years old. Was I like Andrea Yates, the mother who killed her five young children in 2001? Was I losing my mind? The thoughts were terrifying. Giving Katie a cup of apple juice was as anxiety-provoking as handing her a loaded gun would have been. As soon as I’d pour the juice into the cup, I’d think, “What did I put in her cup? There is an open bottle of dishwasher detergent. Did I really just pour juice or did I pick up the detergent bottle, too?”. After smelling and visually examining the drink for five minutes, I would often dump the juice into the sink and refill the cup—over and over and over again. The relentless, intrusive thoughts were unbearable. In my opinion, the only reason I didn’t end up hospitalized was because six days per week I was doing intense swimming workouts to take the edge off.

“ Was I losing my mind? The thoughts were terrifying. Giving Katie a cup of apple juice was as anxiety-provoking as handing her a loaded gun would have been. ”

It certainly wasn’t that I wanted my child to die—I loved Katie more than anything (and still do!) and, in fact, I would go to the ends of the earth to protect her from any harm. I repeatedly urged my therapist and psychiatrist to intervene if they thought my child was in any danger. Eventually, my fear of harming Katie was so great that I began to make arrangements for my daughter to live with my sister in another state until I could get the illness under control. I was seeing a therapist and a psychiatrist at the time, and they encouraged me not to do this. They were concerned about the negative impact that a prolonged separation would have on Katie, and they assured me that, if I were truly a danger to my child, they would intervene. In fact, my therapist said she was so confident that I wouldn’t hurt Katie

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that she would have let me babysit her son – not a practical solution, but it conveyed her conviction in my trustworthiness and in my sanity, and was very reassuring to me. As is common for people with intrusive thoughts stemming from OCD, I was afraid of “snapping” or suddenly losing control and acting on my horrible thoughts. My therapist and psychiatrist knew, as Bruce Hyman wrote in his book *The OCD Workbook*, that, as excruciating as my fears were to me, there is absolutely no evidence of this “snapping” actually occurring among OCD patients. Because of their faith in me, Katie remained at home with me.

Once my psychiatrist was aware that my OCD was severely impacting my ability to care for my daughter, she strongly recommended I restart medication in addition to continuing with therapy. Even though OCD had brought me to my knees, I was still terrified about the possible negative impact of medication on the fetus. I cared so much about my unborn child that doing anything that could possibly harm her – no

matter how remote the risk – was still not an option in my mind. So it was completely by chance that, at this critical moment, I received the Winter 2006 issue of the IOCDF Newsletter with the front page article, “But I Love My Kids...: Parents Who Think About Harming Their Children” by Fred Penzel, PhD. In the article, Dr. Penzel mentions that, in his opinion, of all of the issues OCD sufferers obsess about, the thoughts of harming one’s own children are the most punishing. He went on to say that some of the most anxious and depressed people that he has seen in his practice have this condition. Reading the article by Dr. Penzel was a turning point for me; he validated that my situation was pure torture. This, coupled with a comment from my psychiatrist (“You must be feeling better by the time the baby is born. How are you going to prepare a bottle if you are constantly worried about poisoning the infant?”), finally gave me the permission I needed to consider taking medication during my pregnancy. After getting all of the facts about the potential risks of antidepressants on unborn children and learning about the negative affects a mom’s anxiety has on the fetus, I decided to start taking Prozac. It turns out that choosing to take medication to treat my OCD while pregnant was a very positive choice for me, and therefore, also for my children.

Incidentally, Fred Penzel’s article was also the first place I had ever seen the term “postpartum OCD”. However, I didn’t make the connection with my own situation until much later because, in both cases, my symptoms had their onset during pregnancy. Unbeknownst to me, anxiety disorders, including postpartum OCD, can occur during the traditional “postpartum” period but are also common during pregnancy. Fathers can be affected, as well. Also, according to Jonathan Abramowitz in *Beyond the Blues: Postpartum OCD*, most new parents have terrible thoughts from time to time. He states that “...up to 80% of all new mothers (even those without clinical OCD symptoms) report nasty, senseless, unacceptable, unwanted thoughts that are similar to those described by mothers with postpartum OCD.” He goes on to say that at least 66% of healthy new dads have these same unwanted thoughts. The

FROM THE FRONT LINES

Living a Nightmare (Continued from page 11)

difference is that the person with OCD will give great value to the mere existence of these thoughts and become significantly distressed and try to neutralize the anxiety. A person without OCD is generally able to recognize the thoughts as random and bizarre, but totally out of character, and treat them as simply insignificant mental noise.

According to Postpartum Support International (www.postpartum.net), a non-profit organization committed to promoting awareness, prevention, and treatment of mental health issues related to childbearing, approximately 15% of all new mothers (about 600,000 U.S women per year) suffer from postpartum mood disorders. This includes the more-publicized postpartum depression but also includes a number of postpartum anxiety disorders, including OCD, posttraumatic stress disorder (PTSD), and panic disorder. Unfortunately, many women, their partners, and even medical professionals have limited knowledge about these lesser-known, but equally devastating, conditions. To make matters worse, most mothers suffering with OCD are ashamed and afraid to ask for help, and don't recognize the condition as something that is both common and treatable. Part of the problem is that the symptoms of postpartum OCD are particularly confusing and scary to a new mom due to the media hype that surrounds the rare, but critically dangerous, disorder known as postpartum psychosis. It is true that both OCD and postpartum psychosis bring on bizarre thoughts; however, the similarities between the two illnesses stop there. With postpartum psychosis, the strange thoughts are the woman's reality. With postpartum OCD, a woman is severely distressed and recognizes her distressing thoughts as irrational, so there is little to no actual risk to the baby. However, the negative impact on the mother is incredible: OCD often severely limits her ability to care for herself, her baby, and her family. At the very least, OCD robs a mother of the pleasures of parenthood, which was definitely true for me.

After a few months of medication, swimming, and Cognitive-Behavioral Therapy (CBT), a form of

psychotherapy that focuses on how your thoughts and behavior affect your mood, I was able to function again, and a year later I was truly feeling like myself. My experience is a testament to the fact that, with proper treatment, a mom can successfully overcome her OCD and regain control of her life. My girls, now 5 and 8 years old, are healthy and happy. Because of the expert care I received, support from family and friends, access to organizations like the IOCDF, and my own hard work and determination, OCD no longer rules my life. And, in the process, I have reclaimed the best gift of all – enjoyment in my life and in my role as a mom.

Visit the Postpartum Support International website (<http://www.postpartum.net>) for more information on postpartum mental health conditions.



THERAPY COMMUNITY

Clinician's Corner

by Bruce Mansbridge, PhD

Director, The Austin Center for the Treatment of OCD

This column presents motivational strategies for doing Exposure and Ritual Prevention (ERP; aka Exposure and Response Prevention). Note that these strategies are independent of the specific type of ERP that you might be doing or the particular type of OCD concerns that you might be wrestling with.

The Emotional Gamma Knife

In my last column I presented the concept of “the roommate,” in which I suggested that you think of the bully living in your brain as a roommate that you can’t stand and want to leave. The idea is that it’s much easier to tolerate the discomfort and anxiety of doing your ERP if you conceptualize the situation as one in which the evil roommate (OCD) is the one who is upset (“having the hissy fit”). You basically assign all of your distress to that small part of your brain that is upset by the ERP. You can see “yourself” as calm and even proud, while the OCD roommate is the one that is bothered, hopefully to the point of moving out.

In the real form of surgery known as the Gamma Knife, weak beams of radiation are beamed from many different sources into the body or brain. The radiation is so weak that it passes harmlessly through most tissue and bone. But at the one small spot where all the beams converge, the radiation is concentrated, and is thus strong enough to destroy that small area. The huge advantage to this kind of surgery is that a small area deep inside the body can be essentially removed without making a single cut with a scalpel.

Now we get to mix our metaphors a little. Imagine the little roommate in your brain being bombarded with your ERP anxiety the way the Gamma Knife bombards a small area with radiation. One of my OCD patients relabeled this anxiety as “therapeutic energy.” The greater the anxiety – I mean, therapeutic energy – the stronger the deadly force on the evil OCD roommate. The anxiety from the ERP may still not be exactly pleasant, but you may be able to tolerate a surprisingly high amount of it if you know it’s destroying the OCD.

Hiking In the Himalayas

In April 2006 my partner Elaine and I went on a trekking vacation to Bhutan, a beautiful little kingdom in the Himalayas. (Read the Wikipedia entry on Bhutan and enlarge the picture of the Tiger’s Nest Monastery, which we visited on a day hike.) It was the best trip of my life (so far!).

Elaine is an experienced hiker, and I’m, well, not so athletic. In order to get in shape for the trip, we both hiked for months. Two or three times a week I used to take a 3-mile walk near our house in Austin that included walking up a very steep hill. One day, slogging up that miserable hill, I was asking myself, “Are we having fun yet?” when I had the following idea.

I thought of this fellow named Bruce who had walked this hill for the first time 6 weeks ago. He had a much tougher time than I was having that day. In fact, he had to stop two or three times on the way up to catch his breath. And today I could walk the whole thing without stopping. So I thanked him for that gift, acknowledging that he had worked harder that day than I was working today.

And I also thought of this other fellow, oddly enough also named Bruce, who would be hiking in the Himalayas 6 weeks from now. And he would be enjoying himself, in good shape, and not holding the others up. I wanted him to be able to enjoy the trip of a lifetime. That was going to be my present to him.

And those two thoughts cheered me up. I felt very different about all of the energy I was expending. Not so much the sarcastic, “Are we having fun yet?” but looking forward to the trip with genuine pleasure and excitement.

In the same way, you can look at your previous efforts at ERP, appreciate the beneficial effects those efforts have yielded, and think about the glorious future when you’re not bothered so much by OCD. Interestingly, the more OCD is interfering with your life right now, the more true and more powerful is the statement, “Man, I’ll be glad when OCD is not a big part of my life anymore.” You can be both the donor and recipient of one of the best gifts of your life.

THERAPY COMMUNITY

Storytelling in the Treatment of OCD

by Allen Weg, EdD

Dr. Weg is a licensed psychologist and founder and director of Stress and Anxiety Services of New Jersey in East Brunswick, NJ. He is co-founder and vice president of OCD New Jersey, an IOCDF affiliate. His most recent book, "OCD Treatment Through Storytelling: A strategy for successful therapy," has just been published by Oxford University Press. He can be reached through his web site at www.StressAndAnxiety.com

I have rarely read a book on OCD where the author did not rely on some sort of storytelling or use of metaphor to help illustrate or explain some aspect of OCD symptoms or treatment. The same could be said for any clinical presentation on OCD that I have ever been to. No matter what specific aspect of OCD is being discussed, there always seems to be an anecdote or illustration of some kind that is shared with the audience in order to clarify some concept. The most common of these, and the ones which you are probably most familiar with, include the idea of OCD being like a "bully," or of obsessions being like "hiccups of the mind." But these metaphors are only the very tip of the iceberg.

I have a theory as to why storytelling is so popular amongst OCD professionals. In general, when a person is trying to share something that is difficult to explain, especially when it is unusual or complicated in some way, she or he will look for some kind of "common ground," something familiar to the listener, to help clarify a point. OCD, for instance, is relatively easy to describe in clinical terms, but it is something again to fully understand it. Teaching about it calls for something more than mere instruction.

I remember the first time I learned about the cyclical relationship between obsessions and compulsions in OCD. The instructor explained that obsessions were like a hungry lion that comes at you threateningly. You may throw it some meat and it will then leave you alone for a while, just as compulsions will often quiet anxiety-producing obsessions, at least temporarily. But the lion then goes for a nap, and the meat it has eaten is broken down by digestion, resulting in the release of body-building proteins. Sooner or later, the lion, now bigger and stronger because of what you previously fed to him, returns to you, as hungry as before, only this time more threatening and requiring more meat to satisfy it.

That was over 25 years ago, and still I remember the story. That visual of the lion and the meat- of not only the anxiety that I would feel in such a situation,

but that sense of being "trapped" by my predicament, knowing that if I used the one strategy that was at my disposal, I would buy some time but ultimately worsen my situation- captured the experience of OCD in a way that mere instruction never could have. The instructor could have simply said, "those with OCD react with anxiety to their obsessions and engage in compulsive behaviors in order to assuage that anxiety, only to have the obsessions return, sometimes immediately and sometimes after a while, but often stronger, and with greater capacity to debilitate." I would have probably understood the concept if it were taught to me in that way, but I would not have "gotten it" the way I did with the story.

The story made me *feel*, it made me imagine. A story does not only communicate an idea, but it presents the very foundation of that idea. A person providing instruction shares information, but a person telling a story shares an *experience*. This is important, I believe, especially in therapy, because if you have OCD and you are going to go on a journey towards OCD recovery (or at least better symptom management), and you will be utilizing the always uncomfortable, sometimes terrifying intervention of ERP to get you there, you want to know that your therapist, who will be guiding you through this process, really understands what your experience is, and is not judging you crazy.

Many of the stories I use, and ones I have heard others use in writing or teaching about OCD, are autobiographical in nature. These stories help clients to feel less isolated and misunderstood, while also "reassuring" them (without breaking any ERP rules) that I understand their experience, not only professionally and intellectually, but personally. Many clients, for example, fear that they are particularly disturbed because they find themselves on the one hand terrified of engaging in a specific behavior, while at the very same time recognizing that the behavior is completely benign, that there is no danger, and they report feeling that they are being silly or stupid for being so scared. Yet they find that they can't talk themselves out of the fear. They often report to me that they worry they are - to misuse a diagnostic label, "schizophrenic"- because they feel like they are split into two parts.

After I explain that Schizophrenia and Differential Identity Disorder (what used to be called Multiple Personalities) are distinct and unrelated disorders, I proceed by sharing my own experience with this very dynamic. "My son is an ice hockey player," I begin.

THERAPY COMMUNITY

And after I share some relatively irrelevant details regarding my son's fanatical interest in the sport, and how this leads to a family vacation in Toronto where one can find the Hockey Hall of Fame, I build up to a scene where I find myself in the observation deck of Toronto's CN Tower; 181 stories in all, the tallest man made structure in all the Americas.

"As you walk around the indoor observation deck," I go on to tell my story, "there is a section of the floor, shaped in a square and covering an area of approximately 16 feet x 16 feet, which is made entirely of see-through glass. While you can walk around it, the challenge to visitors is clear- 'Dare you walk across this glass, where you can clearly see over 100 stories below you?'"

The story continues, "I was intrigued by this challenge and so I walked up to the edge of where the glass began. The glass floor section itself was made up of several glass panels, each about four feet wide and four feet long, separated by steel beams a couple of inches in width. I looked down and could see the cars hundreds of feet below, looking smaller than toys, and I found myself experiencing a curious reaction. My heart was pounding wildly, and I could clearly hear the sound of blood rushing in my ears. My muscles were extremely tight, I felt just a touch light-headed, and my stomach felt as if it was turning on itself. It was a little hard to breathe. I was experiencing what essentially was a mild panic attack, yet at the same time realized that I did not believe in the slightest that I was actually in any real danger." After continuing to expand on this incongruent experience, I explain how I slowly and methodically began to walk across the glass, carefully shifting my weight, starting by walking on the beams first and then moving towards the center of the glass panels. This story therefore also serves to model facing one's fears and developing a hierarchical exposure program.

But by sharing my experience of terror yet simultaneous recognition that there was no real danger, I believe I captured my clients' experience in a very special and powerful way. It helps me to earn their trust, because they see that I really know what their experience is all about. And this trust leads the way to a greater willingness to be open to ERP treatment.

Storytelling is not a method for treating OCD, it is merely an effective delivery system for teaching the empirically validated methods that most of us already use, with ERP as its main ingredient. Storytelling has always been a powerful way of communicating and educating people. Philosophers and religious leaders have used storytelling as a form of instruction since

the beginning of civilization. The stories in the Hebrew bible are understood by some not as a historical review of events which actually took place, but rather a presentation of moral, ethical, and religious instruction through the use of storytelling. The New Testament likewise is full of parables which require interpretation to best understand the message being delivered.

In the arts, whether we are referring to dance, music, painting, writing, poetry, theatre, or film making, there are countless examples of an emotion, a struggle, or an experience of some kind, which is communicated indirectly and expressed through the artistic medium. This artistic representation, when done effectively, allows the audience to better understand what is being communicated than if the idea being presented was done so by mere instruction.

Finally, well-told stories, whether they are about one's personal family history, one's people, culture, religion, or country, or stories about humankind in general, demand to be repeated. "Daddy, tell us again about how you and Mommy met!" is the kind of refrain heard in many a household. Most parents are surprised at how their children never seem to tire of hearing the same bedtime stories over and over again, night after night. And how many of us revisit a movie to recapture some part of the experience, even though once we've seen it, we already know how it ends?

For those of you who are mental health professionals, I encourage you to create your own stories. As you move through the therapeutic process of teaching and employing ERP with your clients, you can share personal or well-known experiences that are relevant, and that serve to convey to your client meaning that goes beyond mere description. Retell them, again and again, or use different versions of the same story as you guide your client through the therapeutic process.

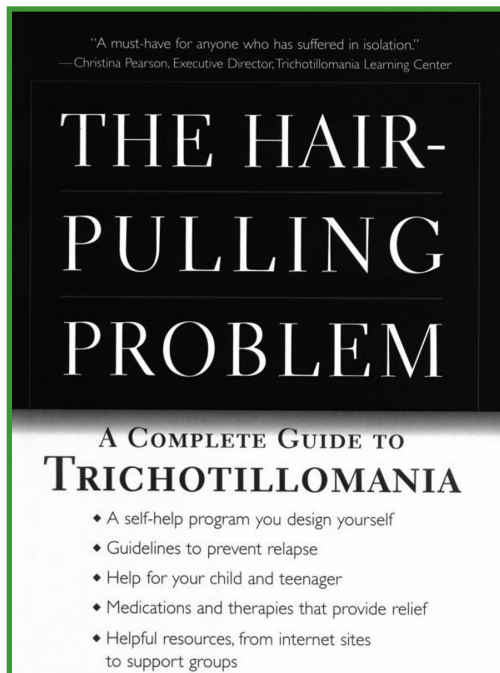
A final note to those of you who experience OCD firsthand: I find that this line of work forces me to be more honest with myself about generally facing my own fears (which is why I had to take on that challenge of walking across the glass in the CN Tower). I would hope and expect that the same dynamic would operate for you. By sharing your stories with others, by helping them to face their fears, you may ultimately feel compelled to fully challenge yourself, and fly into the darkness at every opportunity.

THERAPY COMMUNITY

Book Review: *The Hair-Pulling Problem: A Complete Guide to Trichotillomania*

by Fred Penzel, PhD

Reviewed by: Nancy J. Keuthen, PhD and Kathleen Trainor, PsyD



There are books that everyone should own when they, or a loved one, suffer from a specific disorder. This is one of those books. So if you, or someone you love, have trichotillomania, do yourself a favor and go get a copy of *The Hair-Pulling Problem: A Complete Guide to Trichotillomania* by Fred Penzel, PhD.

Dr. Penzel wrote this book primarily as a primer for those who struggle with hair pulling and for the parents of youth with this disorder. One could also argue that it is equally invaluable to those professionals who provide clinical care for hair pullers. Not only is this book informative and comprehensive, it is extremely readable. The author presents theoretical models of the disorder and different treatment strategies in a format that is digestible and instructional for both patients and treatment providers alike. As such, it goes a long way towards bringing trichotillomania out of the dark ages and further securing its status as a disorder worthy of empirical study and clinical focus.

In my opinion, the strengths of this book lie in its emphasis on psychoeducation, coupled with its cogent chapters addressing some of the more thorny issues involved in treatment. Among the latter are how to address the burden of shame often associated with this disorder, how to maintain recovery, the role of parents, and whether to disclose the problem to others. The compassionate tone with which Dr. Penzel addresses his audience shines

throughout the text. It makes me feel like I would want him to be my therapist if I suffered from this disorder.

Trichotillomania can be an overwhelming disorder when it touches your life or that of family or friends. Dr. Penzel breaks this disorder down into its component parts, thus making it feel more easily addressed. By simultaneously recognizing the challenges inherent in recovering from trichotillomania, and clarifying that recovery is not simply a matter of willpower, he makes it easier for sufferers to step up to the plate and embark on the road to getting better. The roadmap he provides for the sufferer makes the journey less confusing. His practical, easily implemented strategies empower one to take charge and limit hair pulling severity as well as the distress and functional impairments often associated with it.

Similar to his earlier guide on OCD, one of Dr. Penzel's trademarks is the wealth of information and resources he compiles for the reader. His compendium of techniques, including stimulation substitutes, habit blockers, helpful changes in routines and environments, cueing strategies and motivational suggestions, is so comprehensive that every reader is sure to discover new tools. His clinical vignettes interspersed throughout the book go far to exemplify the specific concepts and coping strategies presented. Without a doubt, his shared insights will make you feel understood if this disorder has somehow touched your life.

There's little not to like in this book. The majority of chapters are timeless in their discussion of pertinent issues, including how acceptance is a prerequisite to starting treatment, and additionally, essential steps to achieving and maintaining recovery. Dr. Penzel also describes trichotillomania as a condition that is not a symptom of an underlying psychiatric disorder or bad parenting, which is reassuring for parents and sufferers alike. The tone of this book serves to reduce the shame felt by individuals with trichotillomania and their family members, making them more open to treatment.

In the few years since this book was published, the field of trichotillomania has (thankfully!) had a few advances in assessment and treatment approaches. Currently, however, there is no alternative resource that provides everything this book does, plus recent updates. Maybe, just maybe, if we are really lucky, Dr. Penzel will provide us with a revised version of this text in the not-too-distant future.

THERAPY COMMUNITY

Institutional Member Updates

Connecticut

The Institute of Living
Anxiety Disorders Center
200 Retreat Avenue
Hartford, CT 06106
(860) 545-7685

The Anxiety Disorders Center at the Institute of Living is offering a group intensive program for adolescents with OCD. This program will run for one week this August (9AM to 3PM daily). Treatment will focus on psycho-education regarding OCD, exposure and ritual prevention, and relapse prevention. A portion of the program will include parental involvement. Please see our website (www.instituteofliving.org/adc) for more information or to complete our online referral form. The Anxiety Disorders Center can also be reached by calling **(860) 545-7685** or by emailing ADC@harthosp.org.

Wisconsin

Rogers Memorial Hospital
34700 Valley Road
Oconomowoc, WI 53066
1-800-767-4411

Rogers Memorial Hospital has recently increased its capacity to treat individuals as young as 12 in its program for co-occurring eating disorders and OCD or other anxiety disorders. The program now accounts for 10 beds in the Eating Disorder Center, offering intensive evidence-based cognitive behavioral therapy interventions combined with nutritional recovery. The average length of stay is 60-90 days.

In addition, the Obsessive-Compulsive Disorder Center Day Treatment Program has expanded from 8 to 12 patients per day. Rogers Memorial Hospital has established contracts with most major insurance companies, reducing the out-of-pocket expenses for patients and their families.

The International OCD Foundation is pleased to announce this year's Advanced Behavior Therapy Training Institute (ABTTI) topic:

Cruel Reflections:

What you need to know about treating
Body Dysmorphic Disorder



Sabine Wilhelm, PhD
Associate Professor, Harvard Medical School
Director, OCD & Related
Disorders Program
Massachusetts General Hospital
Boston, MA

Thursday, July 28, 2011
1:00-6:00 PM
Sheraton San Diego
Hotel & Marina
San Diego, CA

Held on the afternoon before our Annual Conference, the Advanced Behavior Therapy Training Institute (ABTTI) is a five-hour training session exclusively for mental health professionals.

4.5 contact hours. Additional \$100 registration fee. Space is limited.

Visit www.ocffoundation.org/conference.aspx for more information or to complete your registration today.

RESEARCH NEWS

International OCD Foundation Genetics Collaborative at a Turning Point by S. Evelyn Stewart MD

The IOCDF Genetics Collaborative hosted their most recent meeting in Whistler, Canada from April 15-17, 2011. This group of international experts on the genetics of OCD was initially brought together by Dr. David Pauls with the support of the International OCD Foundation. Given the potential of this group to further the scientific understanding of genetic impacts on OCD, it also won funding from the National Institutes of Health (NIH) to continue its regular meetings. While it is clear that environmental, non-genetic influences are important for understanding the development of OCD, there is no doubt that inherited genetic factors also play a significant role in this illness. By advancing OCD genetics research, this may result in the discovery of new treatment directions, leading the field closer to a cure.

This year represented a turning point for the IOCDF Genetics Collaborative, as it has achieved its initial goal and begins to look forward to future opportunities. The original goal of the IOCDF Genetics Collaborative was to encourage genetic researchers from different countries and universities to combine their efforts. It was believed that this cooperation would allow faster scientific progress and also the completion of very large studies that no single site could achieve on its own. Since the original establishment of

this collaborative, several clusters of researchers within this group have completed research studies together for the first time. In addition, a highlight of this year's meeting was the presentation of findings from their first large combined project, a genome-wide association study (GWAS). Thus, the founding hopes and beliefs of this group have now been realized.

The GWAS project combined participants from 21 different sites across North and South America, the Middle East, Africa and Europe. It included over 5,000 OCD-affected individuals, their family members, and healthy controls to compare differences in their DNA. With the help of evolving genetic technology, the support of a private donor, as well as the NIH, the GWAS gathered and analyzed information from over half a million locations on the DNA of each participant. In doing this, the DNA of separate individuals was examined more closely than it has ever been studied to date in the research of OCD.

Results of the GWAS indicate that there are likely to be a multitude of genes (rather than only one), which combine to increase the risk for OCD. As such, it is a more challenging and "complex" illness to study when compared to other 'Mendelian' genetic disorders, such as cystic fibrosis or Huntington's disease. This means that larger sample sizes are needed to confirm findings and to apply these to improving treatment. For example, when looking at another "complex" genetic illness such as type 2 diabetes, it was only by completing follow up GWAS studies and combining their results that risk genes were clearly identified to guide development of new treatments. Similarly, further OCD GWAS studies are likely to prove helpful in confirming initial findings. Although the OCD Collaborative Genetics Association Study (OC GAS) research group will be conducting a GWAS in the coming year, similar to the case for diabetes, further studies will likely be necessary before results



RESEARCH NEWS

can be applied to “real life” patients. This was one aspect of discussion as the IOCDF Genetics Collaborative group began to consider its future goals, recognizing that over one thousand unstudied OCD DNA samples are now available across its sites.

Members of the IOCDF Genetics Collaborative are keenly aware that the ultimate value of their work lies in attempting to ‘translate’ and apply their research findings to improve the lives of families affected by OCD. This will involve a dedicated approach to understanding genetic and other influences over OCD onset, long-term course, and response to treatment. It will also undoubtedly guide the future direction, mission, and outcomes of the group.

Inspired by the keynote talks of Dr. Nancy Cox and Dr. Jim Knowles on future approaches in genetic analyses and technology, several questions and ideas emerged throughout the Genetics Collaborative meeting. These included the following: 1) Should the collaborative stay focused on genetics only or should it expand to include imaging and neurosurgery researchers? 2) How do we best and most meaningfully apply results from the past 10+ years of genetics research? 3) Given that the NIMH is projected to cut meeting grants, how will this group continue to meet? and 4) Although the group has a sufficient GWAS replication sample, how will it raise funds to conduct this study given the current international ‘funding draught’ for health research?

As the 2011 IOCDF Genetics Collaborative meeting came to a close at the site of the last Olympic Winter Games, many of the above questions were left to be answered in the coming months. However, what remained were characteristics embodying the Olympic spirit: teamwork, determination, and a focus on the goal despite the challenges that may lie ahead.



Dr. David Pauls, Chair of the Genetics Collaborative, addresses the membership

RESEARCH NEWS

Research Participants Sought

CALIFORNIA

Treatment of Late Life Compulsive Hoarding

This study will examine a new behavioral treatment for older adults with compulsive hoarding.

What is involved?

Participants will be randomized to a new behavioral treatment for compulsive hoarding or case management. There are no fees or costs associated with participation. This is a non-medication study.

Who is eligible?

To participate, you must be over the age of 60 and live in San Diego, California.

Who do I contact?

Please call Catherine Ayers, PhD., ABPP at **858-552-8585 ext 2976** for more information.

VA Career Development Award: Treatment of Late Life Compulsive Hoarding (Ayers PI; CSRD-068-10S)

CALIFORNIA

Group Therapy for Adults with OCD

Have you been diagnosed with or suspect you are suffering from OCD? We are investigating a group treatment that utilizes principles of Acceptance and Commitment Therapy (ACT). ACT has been shown through research to reduce suffering in OCD when used in an individual format.

Study participants will receive group therapy at no cost.

Inclusion criteria:

- Age 18 or older
- Meet diagnosis for OCD (we can screen if you are not sure)
- Able to come to 8 group therapy sessions in Berkeley, CA
- Willing to participate in at home practice and fill out research questionnaires

Exclusion criteria:

- Already currently in another treatment for OCD
- Recent medication changes (within 1 month)

For more information and to see if you are eligible contact:

Megan Foret, MA at mforet@wi.edu or **(510) 863- 4OCD**

CALIFORNIA

Does your child have Obsessive Compulsive Disorder (OCD)?

Does he/she:

Have recurring thoughts that make no sense, but makes him/her feel bad?

Wash excessively or have fear of touching "contaminated" things?

Check and double-check more than necessary?

Have to do things over and over again?

Or does your child have tics?

Does he/she:

Have motor movement and sounds they can't control like:

Eye blinking, shoulder shrugging, nose wrinkling, coughing, sniffing, and throat clearing?

UCLA Research Study for kids and teens 8-17 with OCD or tics is studying non-medication Attention Training Treatment for child OCD and tic disorders. Eligible participants will receive 5 weeks of a novel computer-based treatment for attention along with free diagnostic and cognitive assessment and electroencephalogram (EEG) recordings.

(310) 825-0122 for more information

UCLA Department of Child and Adolescent Psychiatry
Susanna Chang, PhD, John Piacentini, PhD, & James McCracken, MD

RESEARCH NEWS

INDIANA

Paliperidone Study for Adults with OCD

Have you been diagnosed with a problem called Obsessive-Compulsive Disorder (OCD) and not responded to past medication or counseling treatment? If so, you may be eligible for a study examining if adding a medication called Paliperidone helps reduce your OCD symptoms. The Department of Psychiatry at IU School of Medicine is conducting this study.

To be eligible, you must be at least 18 years old and have problematic OCD symptoms despite having tried at least two OCD medications. If you participate in this study, you will be randomly assigned, that is by chance as in the "flip of a coin," to receive either the study medication (Paliperidone) or a sugar pill in addition to the medication you are currently taking. There will also be seven psychiatric evaluations that take place. Study medication and the evaluations will be provided at no charge. Financial compensation is available for qualified participants. Risks associated with the study will be disclosed prior to study participation. For more information call **(317) 948-0038**.

PENNSYLVANIA

Child and Adolescent OCD, Tic, Trich and Anxiety Group (COTTAGE)

Do You Or Your Child Have Obsessive-Compulsive Disorder?

If so... your family may be eligible to participate in a research study examining possible genetic links among individuals with OCD.

Dr. Martin Franklin at the University of Pennsylvania's Child and Adolescent OCD, Tics, Trichotillomania and Anxiety Group (COTTAGE) is conducting a research study in conjunction with Johns Hopkins University (JHU) to explore the possible genetic links among families with children or adults with OCD. Participants with a diagnosis of OCD and their two biological parents will be asked to come in to the COTTAGE for one visit that will involve a blood draw from all three family members. This study is funded by the National Institute of Mental Health. Participants who continue on to complete the other phase of the study with JHU will be compensated by JHU.

For more information call **215-746-3327**

Visit our website at www.med.upenn.edu/cottage

MULTIPLE SITES

Obsessive-Compulsive Disorder Genetics Research Study

Six academic institutions across the U.S. have joined together to examine the relationship between genetics and OCD. Recent advances in molecular biology and statistical genetics make it possible to identify and describe specific genes involved in complex illnesses such as OCD.

If you have been diagnosed with OCD, and have two living parents who may be available to participate in this study, you may be eligible. Participation includes a confidential interview for you, and a blood sample from you and your parents. The interview and blood draw will be scheduled at a time and location convenient for you. Compensation is available.

YOUR HELP COUNTS!

Contact information for all sites is provided below; if you are unsure of the closest participating site, please contact Johns Hopkins University.

Johns Hopkins University (Baltimore, MD): Krista Vermillion, at **(410) 923-2918**, or kvermil1@jhmi.edu

Brown Medical School (Providence, RI): Nicole C. McLaughlin, PhD, at **(401) 455-6608**, or nmclaughlin@butler.org

Columbia University (New York, NY): Katie Bucholz, at **(212) 543-5364**, or cuocgas@gmail.com

UCLA (Los Angeles, CA): Don Nathanson, at **(310) 206-1350** or DONathanson@mednet.ucla.edu

Massachusetts General Hospital (Boston, MA): Casey Walsh, MSW, at **(617) 724-9505**, or cwalsh@pngu.mgh.harvard.edu

RESEARCH NEWS

Research Grant Funding Update

The primary mission of the IOCDF is to help alleviate suffering for individuals with OCD. The IOCDF has always prioritized supporting research to help improve our understanding of OCD and related disorders as a critical part of this mission. In fact, since 1994 the IOCDF has raised and awarded over a million dollars in research grant funding.

This year we have raised \$150,000 for research grants. This is a significant amount of funding towards research that can change lives, and we appreciate your support. OCD research remains dramatically underfunded from most sources, and additional research funding is needed. We currently stand on the threshold of many new and exciting discoveries regarding the causes of OCD and new treatment options.

We also continue to look for ways to increase funding for research. We believe one way to do this is to target donors' interests more effectively. As a result, in this year's research appeal in the Fall, donors will have the opportunity to earmark their donation toward a specific area of interest or to give to our general OCD research fund. Targeted funding categories include:

1. Spectrum Disorders
 - Tics/Tourettes
 - Body Dysmorphic Disorder
 - Trichotillomania/Skin Picking
2. Hoarding
3. Genetics
4. OCD in kids and teens
5. PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) and related disorders

Our Grant Review committee – headed by Sabine Wilhelm, PhD – will continue to review proposals as they come in so that we are funding only the top projects. For many of you, the opportunity to continue to contribute to the general OCD research fund will be primary. We also wanted to recognize those of you for whom donations for a specific area of interest is paramount. Maybe you or a family member are directly affected by hoarding or Body Dysmorphic Disorder, and consequently would like to ensure that your support goes to these areas of research.

There are a finite number of talented researchers working on neuropsychiatric disorders such as OCD and OC related disorders. Providing funding allows them to continue this crucial research. The only thing holding us back from progress in understanding more about these devastating disorders is additional research funding, but you can help by donating to the IOCDF's research fund.

We need your generosity to assist us in finding the causes of OCD and related disorders and for helping to develop new and more effective treatments. 100% of every dollar you contribute goes to research funding. And those dollars help relieve suffering in those afflicted with OCD. Please help!

Sincerely,

Michael A. Jenike, MD

Chair, International OCD Foundation Scientific Advisory Board
Professor of Psychiatry, Harvard Medical School

FROM THE AFFILIATES

OCD Texas

<http://public.ocdtexas.org>



We will be having our next quarterly OCD Texas meeting on June 11th in Houston. Our keynote speaker is singer-songwriter Kevin Putnam, known for his song “Breakin’ the Symmetry” (www.youtube.com/watch?v=7YZ7X3NPcHw). Kevin also coordinated a ping pong tournament (www.pingpong4ocd.com) on Saturday, April 16 in order to raise funds and awareness about OCD. Kevin has been a part of the mentorship group at the Houston OCD Program and is working toward forming a support group in his area. Thröstur Björgvinsson, PhD will be the opening presenter at the conference, discussing “The Basics to Understanding and Treating OCD.” Please go to our website at <http://public.ocdtexas.org> to find out more information about OCD Texas and our next quarterly meeting.

OCD New Jersey

www.ocdnj.org



Jeff Bell
IOCDF National Spokesperson

Our next quarterly meeting will be on Monday, June 13, at Robert Wood Johnson Hospital in New Brunswick, NJ. Dr. Allen Weg will present, “Use of Storytelling in the Treatment of OCD- revisited”. Dr. Weg is co-founder and board Vice President of OCDNJ, and a Scientific Advisory Board Member of the International OCD Foundation. This is a follow up to a presentation Dr. Weg made on the topic at an OCDNJ quarterly meeting several years ago.

On Sunday, October 23, 2011 we will hold our annual brunch conference at the Doubletree Hotel in Somerset, New Jersey. Our keynote speaker will be Jeff Bell, nationally-known author, news anchor, and motivational speaker, and national spokesperson and board member for the IOCDF. He is co-anchor at KCBS Radio, the CBS Network’s San Francisco flagship, and has written several books that document his struggle with OCD. The annual brunch/conference will also feature a “Living with OCD” panel, where those with OCD and their family members will share their stories and take questions from the audience.

OCD New York

www.ocdny.org



OCDNY held an educational parent workshop in March titled “Knowing Your Child’s Educational Rights.” Presenters Scott Sokolow and Natascha Santos reviewed the services, modifications, and accommodations available from school districts to help children with anxiety succeed academically. OCDNY is currently working on plans for a walkathon to be held this summer, as well as its second annual conference which will be co-sponsored by Hofstra University PhD Program in Clinical Psychology during OCD Awareness week this October. To find out more information about OCDNY, please go to our website: www.ocdny.org.

FROM THE AFFILIATES

OCD Midwest

OCD-Midwest is looking forward to getting up and running. It has been quite a process with paperwork and lawyers (Many thanks to Ropes & Gray for all of your assistance!) and coordinating a regional affiliate, but the time has come.

Please visit us on our new OCD-Midwest Facebook page. We will soon have an OCD-Midwest website, so keep an eye on the IOCDF website for more information about this in the coming months.

We look forward to bringing an official affiliate of the IOCDF to the Midwest. Some have asked why such a big undertaking, and sometimes we have wondered that ourselves! But it really is a great way to get several things going at once:

- Develop relationships between the providers in the Midwest;
- Serve as a regional source for information about OCD;
- Develop a regional conference on a yearly basis to support OCD research and individuals with OCD;
- Fundraise together to have a larger pool of funds so that we can put on big programs throughout the region without having to recreate the same program across multiple affiliates.

If you are interested in helping OCD-Midwest get off the ground, we would love to hear from you. Any assistance is appreciated, and we will utilize your talents to best assist this growing affiliate.

Currently, our officers are:

Patrick B. McGrath, PhD
President (representing Illinois)

Brad Riemann, PhD
Vice President (representing Wisconsin)

Charles Brady, PhD
Secretary (representing Ohio)

