

Exciting New Workshops & Events Featured at the 19th Annual Conference in downtown Chicago this July!



Join us in Chicago for this year's conference!

Everyone at the International OCD Foundation is very excited to call Chicago the home of our 19th Annual Conference being held this year at the Chicago Marriott Downtown Magnificent Mile. Pre-conference activities begin on Wednesday July 25 with the conference program running between July 27-29. Not only is this the perfect space for the Conference, but we will be in the heart of downtown Chicago, where there are many fun things to do and explore. We will also be in close proximity to all modes of transportation, making it easy for folks coming from all locations of the United States and from around the world.

This year's Conference will feature over 100 workshops, twodozen support groups, new and exciting events every night during the Conference weekend, as well as expansions of our more popular programs from recent years. All members of the OCD community - whether you have OCD yourself, you are a family member or friend of someone with OCD, you are a kid or teen, or you are a professional, student, or researcher – will find countless opportunities to learn, connect, and find support. The next few pages give you some highlights of the exciting programs and events that we have in store!

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Letter From The President - Denise Egan Stack

It is an exciting time at the International OCD Foundation, and I am privileged to be a part of it as the newly elected President of the Board of Directors. Throughout my fifteen year involvement, I have witnessed the IOCDF accomplish many amazing things, and this year will be no different. The organization is embarking on its next multi-year Strategic Plan and is poised for growth. Over the next three years, the IOCDF intends to expand membership, programming, affiliates and strategic partnerships nationally and internationally; increase research grant awards; expand education and training opportunities for consumers and professionals; and increase awareness about OCD and related disorders. These are substantial goals and the IOCDF is ready to meet the challenge.

Because you are reading this newsletter, you value these efforts and personally understand how necessary it is for the IOCDF to broaden its reach. You have chosen to be a part of this community because it has successfully reached you in a meaningful way and you want to stay connected. As I reflect on the ways the OCD community has affected me in my own life, one important person stands out.

Lisa Jo Pate, PhD, and I worked at the McLean Hospital OCD Institute for several years when the program first opened. Being a behavior therapist for people with OCD was her dream job and Lisa's enthusiasm for her work was palpable. She became a champion for people with OCD; she embraced complex cases and never gave up hope that her patients would get better. Lisa's work ethic, respect for those suffering and her positive attitude served as a model for everyone working at the OCD Institute and have remained a source of inspiration for me today.

Lisa was also dedicated to helping the IOCDF pursue its mission. She joined the Scientific Advisory Board, wrote articles for the newsletter and presented at many conferences. Lisa was involved in forming the OCD Mid-Atlantic affiliate and joined the task force that helped plan the 2010 Annual Conference in Washington, DC. Lisa worked on behalf of OCD sufferers until she developed terminal cancer and her illness prevented her from continuing.

This month the IOCDF is launching a Memorial Day Appeal, which is an excellent opportunity to remember a loved one. A gift given in memoriam to a cause near and dear to your heart can help bring consolation at a time of grief or serve to memorialize and celebrate a loved one's life. Your gift will help their memory live on by funding the vital work we do at the IOCDF. I will be donating in honor of my friend and colleague, Lisa Jo Pate, who passed away on January 24, 2012.

Who is your Lisa Jo Pate? Will you consider donating to the IOCDF in their memory? The IOCDF will use your support to broaden its efforts to serve those affected by OCD. And we will do it on behalf of those we loved.

Danior Egan Stock

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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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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Thursday, July 26 - Pre-Conference Workshops and Events (continued from front page)

Pre and Post Conference 2-Day OCD Treatment Group & Professional Training

Group #1 Wednesday, July 25 - Thursday, July 26, 2012

Group #2 Sunday, July 29 - Monday, July 30, 2012

For the third year in a row, individuals with OCD who might otherwise not be able to work with an OCD specialist will get a chance to experience an intensive 2-day treatment program prior to the Conference. Because last year's treatment group was so popular, Dr. Reid Wilson, co-author of Stop Obsessing! and author of Don't Panic!, will be running two 2-day treatment groups for people with OCD. Space is limited to eight participants. 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 www.anxieties.com/pdf/registration. pdf. For questions about the program, please contact Dr. Wilson directly at rrw@med.unc.edu or (919) 942- 0700.

Advanced Behavior Therapy Training Institute (ABTTI):

Promoting Treatment Engagement & Managing Non-Adherence in OCD

Dean McKay, PhD, ABPP

Thursday, July 26, 2012 1:00-6:00 pm

Held on the afternoon before our Annual Conference, the 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.ocfoundation.org/conference for more information or to complete your registration today.

Pre-Conference Support Groups

Thursday, July 26

7:00-8:00рм

Ice Breaker Support Group for Kids

7:00-8:00рм

Parents Support Group for parents and family members of those with OCD

8:30-9:30рм

OCD and Homebound support group

8:30-9:30рм

Young Adult OCD Group

Improv for Anxiety with The Second City



The world famous Second City Comedy Theater and Training Center will be presenting a 3-hour "Introduction to Improv" workshop for patients, professionals and family members on Thursday, July 26 from 6:30-9:00pm, the opening evening of the Conference.

Following the workshop, Kerry Sheehan, President of Training for The Second City, and Mark Pfeffer M.S., Director of the Panic Anxiety Recovery Center, will discuss a collaborative, demonstration project using improv as a recovery tool for people with anxiety disorders. The project is currently underway at Second City in Chicago, IL. Registration for this program has not yet opened. Please check back with us around late May and keep an eye on the conference website for more information on this program and how to register. Auto-renewal for IOCDF memberships is now available online- ask us more about this today

FROM THE FOUNDATION

Overall Program Highlights - July 27-29 (continued from page 3)

For Those with OCD

There are many exciting workshops taking place for individuals with OCD during the Conference weekend. On Friday, July 27, come hear a personal story of triumph over OCD from both the patient's and therapist's perspective in "One Man's Journey From Morbid Thoughts: - Live From Both Sides of the Desk" with Dr. Fred Penzel and Edward Clementi. Hear Dr. Michael Jenike talk about the latest medications for the treatment of OCD, and find out more about the latest research into computer-based OCD treatment at "Computer-Assisted Care for OCD: BT Steps" with Revere Greist and Dr. John Greist.

On Saturday, July 28, participate in the interactive workshop "Handling Hoarding: An Experiential Workshop" presented by Drs. Christiana Bratiotis and Jordana Muroff and learn all about OCD and the dating world from Drs. Jonathan Hoffman, Steven Poskar, and Rebecca Sachs in the workshop "OCD and Dating". On Sunday, July 29, sit in on a discussion on OCD treatment between therapists and patients in "Through the Looking Glass: Understanding OCD Treatment from the Other Side of the Couch" with Nathaniel Van Kirk, MS, Elizabeth McIngvale, LMSW, and Drs. Richard Baither and Thröstur Björgvinsson.

Spanish Mini Track

For the first time, we will be offering a Spanish mini-track on Saturday, July 28 during the conference program. Two sessions on the diagnosis and treatment of OCD and related anxiety disorders will be offered entirely in Spanish from 2:00-5:30pm. This will be followed by a support group for Spanish-speaking individuals from 7:30-9:00pm. For more information about this program and how to register, please call us here at the IOCDF office at (617) 973-5801.

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

On Friday, July 27, learn about what you can do if your child has sudden onset OCD in the workshop "Can My Child Wake Up with Severe OCD? PANDAS-Sudden Onset or Explosive OCD" with Dr. Elizabeth Latimer and Vicki Blavat, and receive some support and gain insight at the parent/child panel "What Do I Do if My Loved One Refuses or is Struggling With OCD Treatment?". On Saturday, July 28, gain some practical skills and helpful hints in the 2-part workshop

For Kids and Teens

On Friday, July 27, learn how to stay organized and how to deal with OCD at school in "Study and Organizational Skills for Students with OCD" with Mary Kathleen Norris, LPC, and hear from other teens and how they conquered their OCD during the alwayspopular Teen Success Panel. On Saturday, July 28, join other kids and teens in the morning for an exciting ERP adventure in the big city of Chicago with Rogers Memorial Hospital counselors Greg Palibicki and Jesse Leonhardt in the workshop "Exploring Chicago: A Magnificent Mile of Exposures". In the afternoon, join in on a Harry Potter scavenger hunt around the Conference Hotel with Jennifer Wells, LICSW-S and Dr. Charles Brady. Then on Sunday, July 29, learn how to stand up against bullies in the workshop "Dealing with Teasing and Bullying: How to Shrink 'Em to Size" with Mary Kathleen Norris, LPC and Lexie Norris.

Art Therapy Rooms



When not in a workshop you 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).

"Families Unite: Successful Tools for Managing OCD" with Drs. Barbara Van Noppen, Michele Pato, Felicity Sapp, and Perrie Merlin, LCSW, and learn about what it's like for the siblings of a child with OCD at "My Sibling Has OCD – What It's Like For Me" with Dr. Michelle Witkin, Dr. Jenny Yip, Mattew Witkin, and Sally Straus.

On Sunday, July 29, learn how to work with your child's school system in "School and the Child with OCD: What Families Need to Know to Successfully Navigate the School System" with Dr. David Jacobi, Dr. Stephanie Eken, Melvina Johnson-Young, and Wendy Halloran.

For Mental Health Professionals

This year's Conference will feature 44 different sessions that professionals can count toward their CEU/CME's, ranging from introductory to advanced content. Psychiatrists, psychologists, social workers, and mental health counselors can all receive up to 18.5 continuing education credits.

For those professionals new to the treatment of OCD and related disorders, you can attend the 3-part workshop "Introduction to OCD Treatment" run by Dr. Throstur Bjorgvinsson and other experts on Friday, July 27. Also learn about the latest in OCD research in the symposium "Research Updates from IOCDF Grant Recipients", and the ins-and-outs of treating hoarding at "Features, Conceptualization, and Treatment of Hoarding Disorder" with Drs. Gail Steketee and Randy Frost.

On Saturday, July 28, learn about how to treat OCD and other co-morbid conditions in the workshops "PTSD and OCD" with Drs. Edna Foa and Elna Yadin and "Eating Disorders and OCD: Treating the Dually-Diangosed Patient" with Dr. Stephen Tsao. On Sunday, July 29, hear from Drs. James Knowles, Carol Matthews, and S. Evelyn Stewart on genetics and OCD during "Genetics of OCD: The Beginning of an Understanding of the Molecular Basis of the Disease?", and learn about the basics of ACT and how it can be used for OCD in the workshop "How Does ACT Really Fit Into the Treatment of OCD?" with Dr. Michael Twohig, Nate Gruner, LCSW, Dr. Jen Cullen, and Dr. Jesse Crosby.

Special Programs- Friday, July 27 & Saturday, July 28

Friday, July 28

On Friday evening, we will hold 9 support groups, including:

BDD

- GOAL Group
- Teens & young adults with OCD
- Scrupulosity
- Obsessive Compulsive Anonymous
- OCD in older adults
- PANDAS Q&A
- Parents of children
 5
 with OCD
 - 5 Mile evening run with Paul Barr

12th Annual Virtual Camping Trip with Dr. Jonathan Grayson

During one of our most popular events, participants in the Virtual Camping trip will go on a field trip throughout Chicago with Dr. Grayson, his colleagues, and volunteers from OCD Philadelphia during which they will experience the exhilaration of conquering OCD fears in a group. Visit the IOCDF conference website for more information about this program.

Ping Pong 4 OCD

Join Kevin Putman of RUN OCD and OCD Midwest for a fun-filled night playing ping pong! Held on Friday evening, this event will be a great way to meet others attending the Conference and start the weekend off with a bang. Refreshments will be provided. Visit the IOCDF conference website for more information about this program.

Saturday, July 29

Research Poster Q&A Session and the Saturday Evening Social

From 5:30-6:30pm, following the last workshops of the day, students and researchers at the Research Poster Q&A session will present their research projects and attendees will be able to learn about the latest advances being made in the research of OCD and related disorders. The Saturday Evening Social will follow from 6:30-9:00pm, allowing an opportunity for the entire Conference community to relax and socialize after a full and busy day. Refreshments and light hors d'oeuvres will be available.

4th Annual Karaoke & Fashion Show

After the kids and teens track has ended and everyone has had a chance to grab food at the Saturday Evening Social, therapists from the NeuroBehavioral Institute will hold their Karaoke & Fashion Show. Participants in this interactive workshop will get an ERP-based makeover and participate in the OCD Fashion Show Contest and sing some karaoke.

4 more free support groups from 7:00-8:30pm, including:

- Compulsive hoarding
- Intrusive thoughts
- Family members of those with compulsive hoarding
- Spanish-Language Support Group

Keynote Address and Conference Awards

Keynote Address: *From Private Anguish to Public Advocacy* Liz Woolcock



Liz Woolcock, this year's Keynote Speaker

We are pleased to announce our speaker for this year's Keynote Address: Liz Woolcock. Hailing from Brisbane, Australia, Liz is our first international Keynote speaker, which we are all very excited about. Liz first struggled with OCD at age 12 in her first year of high school, when she was bullied by her peers. As the bullying continued through high school, and her four older siblings gradually left home, her grades plummeted and she became a full-time employee of OCD. She had no idea that OCD existed and the depth of her self-stigma and shame stopped her from seeking help so she suffered in silence. Eventually everything fell apart and she became bed-ridden and needed 24 hour support. Already feeling her own suggestions were discredited and demeaned by socalled expert 'help', she was finally told her only option for treatment was institutional care. This prospect became the catalyst Liz needed to commence her personal journey of recovery, with the unfailing support of her devoted parents.

Liz vowed that when she recovered, she would devote the rest of her life to educating kids and adults about mental health and that is exactly what she has done. She has subsequently become a grade and middle school teacher, educating school communities about mental health promotion, prevention and early intervention and is an adult mental health educator, delivering training on mental illness and suicide intervention. Liz has also devoted much time and effort as a volunteer at the IOCDF national office.

IOCDF Patricia Perkins Service Award

Each year, the International OCD Foundation (IOCDF) Board of Directors presents the Patricia Perkins Service Award to a distinguished member of the organization. The award is intended to honor anyone who has stood out as a long-time, active contributor to the organization in multiple ways and in the intrepid spirit of IOCDF cofounder, Patricia Perkins. This year, the award will be given to Joy Kant.

Joy and Doug Kant joined the IOCDF in 2001 after their son, Jared, was diagnosed with severe OCD. The IOCDF provided the Kant family with guidance, community and, most importantly, a sense of hope. Joy's gratitude for this quickly translated into passion for helping the IOCDF realize its mission. Almost immediately, she became involved in significant ways.

Joy played a prominent role on the IOCDF Board of Directors for eleven years. During her tenure, she served on 13 different committees and task forces, some as Chair or Co-Chair, and held several officer positions. Joy was also an active fundraiser for the organization. She hosted the first "house party" fundraiser, launched the Behavior Therapy Training Institute Fund and personally wrote hundreds of thank you notes to donors.

Most notable, Joy was President of the Board during the organization's transition from Connecticut to Boston in 2008. Joy's tireless effort and leadership during this tumultuous period helped to successfully establish the organization in Boston, laying the foundation for the robust organization that it is today.

The strength of the IOCDF lies in its constituency, and Joy Kant exemplifies this. Please join us in congratulating Joy Kant this summer at the 19th Annual Conference in Chicago where she will be presented with the Patricia Perkins Service Award for her invaluable service to the IOCDF.



This year's recipient, Joy Kant

Conference Hotel & Other Information

All Conference sessions and social functions will be held at the Chicago Marriott Downtown Magnificent Mile (located at 540 North Michigan Avenue in Chicago, IL). 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 1-877-303-0104 and mentioning the International OCD Foundation Conference. This special room rate will expire on July 6, 2012, but the hotel is filling up fast, so please be sure to book your room as soon as possible to guarantee yourself a spot. We have also secured discounts on airfare through American Airlines, rental cars through Avis, airport shuttles through GO Airport Express, and admission to local attractions in Chicago. For more information about these opportunities, visit the conference page on our website.



To view the entire Conference program, learn more about the city of Chicago, or to register online, visit: **www.ocfoundation.org/Conference**

An Update on PANDAS and PANS -History in the Making

The initial description of PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep) was published in 1998. However, in 2010, a conference sponsored by the National Institutes of Mental Health (NIMH), Yale and the International OCD Foundation (IOCDF) convened researchers and clinicians around the country to discuss the possibility that infections resulting in sudden-onset pediatric OCD may not be limited to strep. Dr. Susan Swedo and her colleagues recently published a paper in the journal Pediatric Therapeutics detailing this new understanding. PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome) is a new research definition that expands the idea of PANDAS, underscoring that other infections can trigger these symptoms. PANDAS will continue to refer to acute onset OCD and/or Tics triggered by Strep, however.

A copy of Dr. Swedo's article along with other new information and resources about PANDAS and PANS – including two new Public Service Announcements – can be found on our website: **www.ocfoundation.org/ PANDAS**. Parents are encouraged to forward the doctor PSA to their local pediatricians or caregivers.

Parents and advocacy groups across the country have tirelessly advocated in recent years to change the face of this devastating illness. Their efforts, combined with the research from Dr. Swedo and her colleagues, inspired Dr. Thomas Insel to write an impactful blog about PANDAS and PANS on the NIMH website. The NIMH also updated their website to include information and recommendations about these disorders that will help physicians better treat the children. These now correspond with recommendations made by the Scientific Advisory Board of the IOCDF. The discoveries resulting from PANDAS research may have far reaching implications for much of mental health. You can read more at the NIMH website on PANDAS/PANS and Dr. Insel's blog: http://intramural. nimh.nih.gov/pdn/web.htm and www.nimh.nih.gov/ about/director/2012/from-paresis-to-pandas-pans. shtml.

The IOCDF would like to give special thanks to all of these parents, advocacy groups, researchers and doctors, whose tireless work has inspired these critically important changes. Learn about volunteer and advocacy opportunities on our website: www.ocfoundation.org/ volunteer.aspx.

P.S. Join us at our national conference in Chicago to hear the latest PANDAS & PANS research, resources and stories of hope: www.ocfoundation.org/conference.

IOCDF International Outreach Initiatives

In the past few months three new international outreach initiatives were launched. First, we have been working with other OCD Foundations around the world to develop "Global Partnerships". A list of our current partners can be found on our website here: www.ocfoundation.org/global_partners. In addition, we have been working with groups interested in forming OCD Foundations in other countries. Recently the IOCDF office was visited by Drs. Masaru Horikoshi and Masaya Ito from the National Center for Cognitive Behavior Therapy and Research in Tokyo, Japan. During this visit we talked about how they might try to launch a Japanese OCD Foundation in the upcoming year. We will be working with Drs. Horikoshi and Ito along with our other Global Partners to ensure that OCD Awareness Week, the week of October 8-14, is really an international event.

Second, this past March we held our first international Behavior Therapy Training Institute (BTTI) in Vancouver, Canada. This BTTI was hosted by Dr. Evelyn Stewart, a member of our Scientific Advisory Board (SAB), who is currently at the University of British Columbia. This BTTI was a huge success and joins four other BTTI's we are running nationally in 2012: one in conjunction with the University of Southern California in Pasadena, CA this past January; a second one in New York at Mt. Sinai Hospital in May; our third at Rogers Memorial Hospital in Oconomowoc, WI in September; and finally back in Boston, MA at Massachusetts General Hospital in November.

Third, the IOCDF's executive director Dr. Jeff Szymanski was invited by Lijun "June" Ding to Xiamen, China this past January where he and IOCDF SAB member Dr. Throstur Bjorgvinsson and Dr. Szu-Hui Lee trained 80 Chinese mental health therapists in the use of Cognitive Behavior Therapy for Anxiety Disorders including OCD. This training was sponsored and funded (no IOCDF funds were used) by Xiamen Mental Health Center at Xiamen's Xian Yue Hospital. For more about the state of mental health care in China, please see the next article for IOCDF's executive director Jeff Szymanski's interview with Drs. Xu Yong and Jianping Wang.

We hope to continue to reach out to all individuals suffering from OCD and will continue to update you on our progress nationally and internationally as we go forward.

Mental Health Care in China: An Interview by Dr. Jeff Szymanski Executive Director, International OCD Foundation

In May 2011 I had an opportunity to co-lead a training on Anxiety Disorders in Shanghai, China. While there I took the opportunity to interview two of the leading mental health specialists in China: Dr. Xu Yong, the Director of Education and Training at the Shanghai Mental Health Center and at the Medical School of Jiaotong University; and Dr. Jianping Wang, a Professor at the school of psychology at Beijing Normal University, and the Vice Director of the Department of Clinical Psychology at Capital Medical University in China.

Jeff: I recently co-led an intensive workshop training at Shanghai Mental Health Center. The focus of the training was how to use Cognitive Behavior Therapy for Anxiety Disorders. Dr. Yong, you organized this training. How do you see Cognitive Behavior Therapy (CBT) fitting into mental health care in China?

Dr. Yong: For a long time, treatment approaches for people with mental illness in China have predominantly used a hospital-based service model, and institutionalization and psychiatric and pharmacological treatment were mainly provided. The services delivered by clinical psychologists, social workers and occupational therapists were mostly unavailable. The over-reliance on the organic-medical approach to mental health care has yielded a narrow emphasis on symptom relief rather than recovery and improvement of life quality and social function. There is a huge gap between the supply and the demand of psychological intervention for mental disorders. I believe CBT, an evidence-based psychological intervention, can help us to bridge the gap.

Jeff: Dr. Wang, you completed a three-year training in the United States learning Cognitive Behavior Therapy. What is your view of the role of Cognitive Behavior Therapy in mental health care in China? What are the differences you see in how Cognitive Behavior Therapy is practiced in the United States versus China?

Dr. Wang: Over the past 20 years, some people in China claimed to have been using CBT; however, their homegrown practices are a far cry from what CBT really is. In a sense, CBT only began in China in the past 3 years (the first CBT conference in China was held in 2008). Since then, clinicians and students in universities started to become more interested in taking training courses and participating in workshops to learn real CBT.

The differences between practicing CBT in the US and China are big in many ways. Generally speaking, CBT in the United States has gone through three

stages or waves since the late 1950s, from classical Cognitive Therapy (CT) for depression by Aaron Beck, to a combined approach (Cognitive Therapy + Behavior Therapy) for anxiety disorders by D. Clark and D. Barlow, and now a more integrated approach incorporating eastern philosophy for personality disorders, like DBT by Marsha Linehan.

There has also been a lot of research done to test the outcome of treatment in the United States. In mainland China, we are just starting to learn the basics as the United States did in the 1960s through 1970s.

Jeff: How would each of you describe mental health care in general in China?

Dr. Yong: Mental health has been recognized as a significant social and public health problem in China. A recent epidemiological survey in four provinces in China showed that the prevalence of at least one current mental disorder in adults was greater than 17% in 2001-2005, and mood disorders and anxiety disorders are the most prevalent types. The World Health Organization (WHO) has warned that the financial burden from mental disorders in China will constitute 1/4 of the total burden from various diseases in 2020.

The remarkable social and economic changes in China during the last three decades have made the Chinese people realize the importance of mental health. Chinese people experienced many fast and significant societal changes, such as the termination of social security, internal migration, the one child policy, young adults caught between conformity and autonomy, the breakup of traditional family structure, and the individual search for happiness, and therefore experience much more psychological pressure than before. The demand for mental health service is on the rise, as is shown by the increased utilization of both outpatient psychiatric and mental health counseling services and the tremendous popularity of hotlines and radio call-in programs. By 2009, the Shanghai Mental Health Center was providing psychological counseling to an average of 400 patients each day, a 300% increase from two decades before (data from Shanghai Mental Health Center). The most common reasons for seeking help were school-related problems, family/relationship difficulties, mental disorders, and insomnia. Financial worries and anxiety about adapting to the changing demands of the marketplace have also been identified as key concerns for many Chinese people.

Dr. Wang: In the past decade, there have been tremendous changes in many areas in mainland China. Mental health care is one of them. It is much better than before. Mental health is getting more attention by the public and government alike, especially in the aftermath

of SARS in 2003 and the Wenchuan earthquake in 2008. There is also less stigma associated with seeking help for one's mental health as compared to 20 years ago. Almost every university has a psychological counseling center to provide services free of charge, and almost every general hospital has a psychological counseling clinic. Some of them have inpatient units, although not all of them are up to appropriate standards. There is an enormous need for qualified therapists, as more and more clinicians in mental health centers learn psychotherapy and combine therapy with medication in their clinical work; and clinical psychologists are trying their best to develop clinical psychology training programs and register systems based on available resources to provide psychological help services. But there is still much room for improvement.

Jeff: What do you see as the main needs for mental health care in China?

Dr. Yong: The main need for mental health care in China is to provide mental health services to the rural population.

Dr. Wang: The main needs in my view are: (1) quality training programs for clinical psychology in professional institutions, (e.g., psychologydepartments in universities); (2) additional work by professional organizations, like CPA (China Psychological Association) to pool resources to provide and monitor quality training programs for students and young therapists; and (3) registration and licensure requirements for clinicians.

Jeff: What are the differences in mental health care between urban centers such as Shanghai and Beijing compared to more rural areas of China?

Dr. Yong: Cities like Shanghai and Beijing have established infrastructures and greater material and human resources in contrast to rural areas. People in rural areas are still poor and many psychiatric patients are not able to afford the mental health care they need. There is also a shortage of basic inpatient and outpatient mental health services. The lack of follow-up and maintenance services contributes to the severity of illness.

Dr. Wang: When comparing farmers and urban residents in mainland China, there are enormous differences in many aspects of life. Health insurance, or lack of it, is one of them. For farmers, they simply lack health insurance coverage (in recent years however, a few rural areas have started to develop health insurance systems run by local governments). It is very hard for farmers to get proper or timely medical help, and mental health help is even harder to get. People in rural areas often have no sense of what psychological help is. In the past decade, psychological help needs increased at a very rapid pace (continued on page 10)

Mental Health Care in China (continued from page 9)

in cities, especially in the larger urban centers. In fact, most professional providers of mental health services are in the larger cities, like Beijing and Shanghai.

Jeff: What is the attitude of the average Chinese person toward mental illness and mental health care in China?

Dr. Yong: In Chinese society mental illness is still strongly associated with shame and stigma. And although people's attitudes toward some mental disorders, such as depression or anxiety disorders, have changed a lot because of the increased awareness and knowledge about these disorders, the stigma of schizophrenia is still very severe.

Dr. Wang: In China, people find it easier to accept "psychological problems" than "mental illnesses". People with mental illnesses would seek help by going to psychological help centers instead of going to mental health centers or hospitals. Unfortunately, many psychological help providers have no knowledge of psychopathology and have little or substandard training in clinical assessment and diagnosis. In general, the attitude of the average Chinese person toward mental illness is still negative. They are in denial or fear or shun individuals with mental illness. Additionally, the social status of a psychiatrist continues to be lower than other medical specialties. On the positive side, it has been getting better in the past 10 years and more and more students are choosing to become psychiatrists after graduation from medical school.

Jeff: What would you like to see different in mental health care in China?

Dr. Yong: The Chinese government has already acknowledged the growing mental health problems and has been paying more attention to this field than it did before. Because of the lack of mental health professionals and the awareness of the significance of mental health and high demand of mental health service, more people were attracted to this field, and different



Attendees of the Xiamen, China Anxiety Disorders Training

kinds of counseling and psychotherapy training programs were provided. However, because counseling and psychotherapy in China are new, and in the past, there were no counseling or clinical psychology courses taught in the universities, the question of "how to train qualified counselors or clinical psychologists" has become a very critical issue. As China is still a developing country, it is unrealistic to expect to meet the mental health needs of a massive population with limited resources within a short time. Therefore, specific strategies will need to be developed with the Chinese mental health service.

Dr. Wang: In addition to some of the issues I have already addressed, I believe we also have to improve education for the general public to make people aware of their mental or psychological problems, to reduce the stigma they are subject to, and to get treatment in a timely manner.

Jeff: What do you see as the biggest challenges for mental health care in China?

Dr. Yong: The biggest challenge for mental health care in China is the shortage of trained mental health professionals. There are only about 16,000 psychiatrists among a population of 1.3 billion, and there are few qualified clinical psychologists and social workers in the mental health field.

Dr. Wang: The biggest challenge for mental health care in mainland China is a lack of systemic and high-quality training programs. Chinese people do not get quality treatment because there are not enough qualified professionals to provide services, especially in rural areas.

Jeff: How do you see mental health treatment changing in the future for China?

Dr. Yong: In the last two decades, many psychotherapy approaches were introduced in China. In Shanghai Mental Health Center, we organized psychoanalytic psychotherapy, CBT, group psychotherapy, and family psychotherapy. In the future, patients will have more choices to meet their needs.

Dr. Wang: I am an optimistic person. I would say mental health treatment in China is progressing very fast and becoming more and more professional. In the future, people will gradually have increased awareness and become more tolerant toward mental illness; the government will place more importance on people's mental health and set aside more funds to this field, and service providers will be better trained. But there is still a long way to go.

This interview was originally posted on www.jeffszymanski.com

Spring 2012

FROM THE FOUNDATION

In Memoriam

Fran Sydney 1944 - 2012

Fran Sydney, a founding member of the International OCD Foundation, then known as the Obsessive Compulsive Foundation (OCF), died on February 26, 2012, after a long and courageous battle with cancer. Throughout the years, Fran contributed to the development and management of the foundation in many significant ways.

Most notably, Fran served on the Foundation's board of directors from its inception in 1986 until she passed away. Even when she was too sick to travel, Fran participated in every board meeting via conference call. She was also the first Treasurer of the board, helping to put in place the policies and procedures that enabled the IOCDF to become the premier national group for people affected by OCD that it is today.

Until the Foundation had its first permanent office and meeting place in November of 1988, Fran regularly opened her house to the Foundation's directors and members to work on building the organization. In March of 1988, 20/20 ran a feature on OCD, the first of its kind. Fran manned the Foundation phone at her house, which was set up to respond to calls about the show. She stayed in her nightgown for two straight days after the segment aired in order to answer the deluge of calls from people with OCD and their family members. In addition to sharing information about the disorder and its treatment, Fran gave the callers hope by telling them about her own personal struggle with OCD.

In the early years, Fran promoted the Foundation's mission by giving TV, radio and print interviews about OCD and its treatment. She also traveled to professional OCD conferences, where she manned

the Foundation's booth and shared information on OCD and its treatment.

Fran was also instrumental in establishing and promoting the Foundation's research program. Every year, along with soliciting funds to underwrite the Foundation's research program, she participated in selecting the researchers to whom the grants were to be given. Today, the research program awards about \$200,000 in grant money each year and is considered to be an important resource for researchers in the field.

For 26 years, Fran devoted herself to helping people with OCD. The most recent board of directors' meeting was held on March 3, 2012. It was the first time in years that Fran didn't take part in the meeting. She was greatly missed.

In honor of Fran, the IOCDF Board of Directors voted to launch the Frances Sydney Conference Scholarship Fund. If you would like to donate to this fund please contact the main office at (617) 973-5801 or go online to donate at **www.ocfoundation.org/ donate** and be sure to make sure you mention the Frances Sydney Memorial Scholarship Fund in the notes of your donation.

Scholarship Funds will be used to reduce conference registration fees for those who would otherwise not be able to attend.

For more information about this, feel free to send an email to the conference planners at **conferences@ocfoundation.org.**

FROM THE FRONTLINES

Life Experience is the Greatest Teacher by Kathleen

At this year's Annual Conference in Chicago, Kathleen will be running the Parents Support Group for parents of children with OCD and related disorders on Thursday evening, July 26, from 7:00-8:00 pm. This support group is free for all Conference attendees. For more information about this support group and others at this year's Conference, call the IOCDF office at (617) 973-5801.

The support group I started for parents of children and teens with OCD and related disorders was born from my own pain and suffering, and my effort to more skillfully be with that suffering. I'd like to share with you where I've been and where I am now.

There are lots of versions of OCD, and plenty of versions that would be uncomfortable to share with your family or friends, like forbidden obsessive sexual thoughts or images, or a fear of acting on an impulse to harm someone. But in our case, our daughter had a debilitating fear of throwing up. The way it manifested itself was in constantly seeking reassurance with questions such as "Am I all right?", "Am I ok?", "I don't know if I'm ok.", "How do I know I'm ok?", or "What if I get sick?". They call OCD the doubting disorder for a reason! All of a sudden, our child who used to delight in so many things started to disappear. She was imprisoned by constant worries about throwing up; in a way, we were all imprisoned. I couldn't see the joy in her eyes anymore because day after day, week after week, and month after month, she was obsessed with whether or not she was going to throw up. Our child had been kidnapped by OCD and I didn't know when she was coming back. There are no words in the English language that can describe the grief I felt during that time.

We received the help we needed through cognitive behavior therapy, simulated exposure therapy, and medication. She became well again, but I lost a part of myself during that time. There is the saying that "you're only as happy as your unhappiest child", and while it sounds rather co-dependent, there is a lot of truth to it. I shared our struggles with family and friends, but most of my time was spent educating them, which left little room to feel supported.

Often the help parents receive is focused on the child, which was the case for us. While that is all well and good, my mental health was and is just as important

as my child's! So I realized that I have to show up for myself, because no one else is going to do it for me. I became convinced that parents of children with OCD and related disorders need each other's support. It was too isolating and lonely for me to continue this journey by myself. I needed a tribe; a tribe of parents with lots of experience that cared deeply about being well themselves. A place where you can share your struggles, longings, and darkness until you find your way back into the light. A place where you learn how to have compassion for yourself, where whatever you share stays within the group and you can be heard and honored without judgment.

So I decided to start a support group, which has been an absolute gift to me. I know that I'm not alone and I was never alone, I just had to find the other members of the tribe. It has been said that compassion is born from the ashes of isolation and when we feel disconnected and afraid, we long for peace and comfort that can come from belonging to something larger than ourselves. I needed to have a voice and share it.

Suffering is an experience that awakens compassion. I've learned that kindness and acceptance will take me much further in this life than resistance and resentment. And trust me, I had a lot of resistance to work through, which was that part of me that didn't want to deal with OCD- I just wanted it to go away. When we transform suffering into compassion, we begin to see past appearances and recognize that we are all interconnected, and that we are not alone. It's through our vulnerability that we're connected. It takes courage to be vulnerable and it takes courage and awareness to learn not to take pain personally. My pain became much less personal when I knew that I wasn't alone. It went from being "it's my story" to "it's not my story- it's our story, all of us". The experience of being truly seen and honored by other parents who have experienced different versions of the same disorder has been invaluable to me. I can skip all the preambles, because I know they get it.

Though there's not a lot to be thankful for when it comes to OCD, when I think about where I was when I started this journey, and where I am today, there are a lot of things I'm thankful for. I'm thankful for the lessons that I've learned from having a child with OCD, like knowing that there are things that I can change and things that I

FROM THE FRONTLINES

can't, and the things that I can change usually have to do with whether I'm reacting or responding to the situation. I'm thankful that I don't take ordinary things for granted, like watching my child eat and knowing she's not afraid to eat. I'm thankful that just by virtue of becoming a parent, I'm more than I used to be, and by parenting a child with OCD, I've become more than I thought I could ever be. I'm thankful that my heart has been expanded and that every time it's been broken, it got a little bigger. I'm thankful for the professionals that helped us along the way because we couldn't do it by ourselves. And I'm thankful to our daughter for being one of my greatest teachers and the most courageous person I have ever known.

The journey continues. I accept that OCD is a part of our lives. I have witnessed it morph into other versions, and try to take her away again, but with the tools that we have, the noise that it likes to make has weakened and I've gotten a lot better at just being right here, right now, because this moment is all that we really ever have. The conditions and circumstances within our lives are always changing and the reality that life is filled with uncertainty will forever be our teacher.

Additional Resources for Families:

- www.ocfoundation.org/family.aspx
- A new video from Chris and Liz Trondsen about the effect of OCD and BDD on the family on the page listed above
- www.ocdinkids.org
- Visit our online and in person support group database at www.ocfoundation. org/findhelp.aspx
- Visit our list of books for families at www.ocfoundation.org/books.aspx
- Attend our annual conference. See page 4 of this newsletter for highlights.



In an attempt to raise awareness of OCD and effective treatment, the IOCDF will hold its national event in Boston, MA this year at the Sheraton Boston Hotel. Building on last year's creative expression event, this year we will again be inviting members of the OCD community to submit their films, stories, music, and poetry to be voted on by our website visitors. The winning entries will be featured as part of the internet broadcast. We will begin accepting entries in May.

Categories will be:



Make a difference in the lives of those with OCD: www.ocfoundation.org/donate

FROM THE FOUNDATION

Leave a Lasting Impact – Legacy Giving at the IOCDF "From a tiny acorn grows the mighty oak."

Like the acorn in this old maxim, regardless of the size of a bequest, it can grow into a lasting legacy.

There are many reasons people donate to the International OCD Foundation. For many, it was a personal and positive experience with the foundation; perhaps they called the office and found help through a provider listed in our treatment provider database. Or, they attended the annual conference and discovered they were part of a larger community. Others make a gift to remember a friend or relative, a need to help others less fortunate, or because of a desire to give back to the community (and the extra-added bonus of a tax benefit!).

Whatever the reason, a gift to the IOCDF helps the foundation continue to be the primary resource for people living with OCD, their families, treatment providers and others seeking to learn more about the disorder or get help.

Donors have a wide range of gift opportunities to make a difference in the lives of others through planned giving. For some, that means an outright gift of cash or appreciated property; for others, it is a deferred gift arrangement such as a charitable bequest or as a beneficiary of a life insurance policy. Sometimes it is a combination of gifts carefully planned to help support a program that is meaningful to them. Our Behavior Therapy Training Institute is a popular example of this.

One of the easiest ways to leave a legacy and support the IOCDF in a truly significant way is to include us in your will. There is no immediate cost to you. You can change it at any time, and you will be making a critical impact on the IOCDF's ability to serve the OCD community well into the future.

The IOCDF is pleased to announce the launch of The Legacy Society. The Society honors individuals who have made a provision for a future gift to the IOCDF through a bequest in their will or other arrangement such as a retirement plan or life insurance beneficiary designation. The Legacy Society affords the foundation the opportunity to extend our warm appreciation to those who notify us of their thoughtful gift intentions. There are no dues or other obligations, but Society members will receive a certificate of membership and a small memento, as well as recognition in our annual donor listing, thus inspiring others to join the Society.

If you have included the IOCDF in your estate plan, please let us know! If you join the Society before the end of this year, you will be listed at a Charter Member, unless you wish for your participation to remain anonymous.

I hope you will consider becoming a member of The Legacy Society. Taking this small step now will have an impact on future generations for years to come. Please contact Jeff Smith, Director of Development if you would like to notify the IOCDF of your intent to include us in your estate plan, or if you would like further information about planned giving opportunities.

Jeffrey Smith, Director of Development



DONOR PROFILE: DENIS ASSELIN

Dare to Believe YOU can Make a Difference

Nathaniel Asselin

Donors to the International OCD Foundation are a wonderfully diverse group of moms and dads, siblings, friends, grandparents and people living with OCD and related disorders.

They come from all walks of life. Their gifts of support are often accompanied by a personal story, and most often include a desire to help others through their struggle with OCD and related disorders.

In this issue, we would like to share a moving story of a young man and his family. Of the pain and loss of losing a child and the courage and strength that is manifest, as a brave family comes to terms with their loss...yet is filled with a passion and desire to help others, and transform their pain into hope.

When a spiritual seeker once asked the Buddhist teacher, Thich Nhat Hanh, how to recover from the loss of her son, he pondered and then firmly answered, "Walk!"

Last May, after the death of their son and brother, Nathaniel, the Asselin family, Denis, Judy and daughter Carrie, took this advice to heart. They flew to Spain to walk the Camino de Santiago, the ancient pilgrimage route, to reflect on Nathaniel's life and walk in his memory. Upon returning from their trip, Denis, Nathaniel's dad, caught "Camino Fever" as he puts it, and developed the irresistible urge to walk.

It was during one of his many long walks that the "**Walking with Nathaniel 2012 Project**" was born. On April 24, 2012, Denis will begin his walk from Cheyney, PA to Boston, MA, site of the International OCD Foundation office. On the 487 mile route, Denis will stop at various hospitals, clinics, doctors' offices, and treatment facilities—the places that his son Nathaniel frequented during his 13 year affliction with OCD and Body Dysmorphic Disorder (BDD). Denis will also include places of joy that held significance in Nathaniel's life, such as the Bryn Mawr Birth Center, Goshen Friends School, Westtown School, The Shipley School, and the West Goshen EMS

Ambulance unit where he often volunteered. Denis's journey will take him several weeks, when he hopes to arrive in Boston - his final destination - in early June. At times throughout his journey family members and friends will join Denis. Please join the IOCDF staff and Board of Directors at an OCD/BDD Awareness Rally in downtown Boston from 11:30am-1:30pm on Thursday, June 7 to welcome Denis at the end of this 487 mile journey. More information will be posted on our website: **www.ocfoundation.org** as well as our Facebook page regarding the details of the rally.

Denis says, "My primary goal is to pay it forward—to raise much needed money to support research and education into this crippling brain disease. With the help of the IOCDF, I will meet with medical professionals to learn more about how treatment for patients with this brain disorder has evolved since Nathaniel's death." Denis hopes that through his very personal, and yet public, pilgrimage that he will put Nathaniel's face and story on OCD and through doing this, he will help others along the way. As Denis says, "I am not the same person that I was before Nathaniel's death...but I don't yet know what that means." Denis hopes that this journey will help him discover the person he has become.

If you would like to make a contribution in support of Denis on his journey, you may do so by going to www.ocfoundation.org and clicking on "Donate", or by filling out and sending back the donation envelope that is included on this page. You may also follow Denis on a website that he will launch later this spring. There you can see where Denis is and hear about his journey. You will also be able to learn more about Nathaniel, his illness and view photographs of him and the important people in his life.

When a spiritual seeker once asked the Buddhist teacher, Thich Nhat Hanh, how to recover from the loss of her son, he pondered and then firmly answered, "Walk!" "

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FROM THE FRONT LINES

OCD, Aging and Time by Joan Chabrowe

At this year's Annual Conference in Chicago, Joan will be cofacilitating the Older Adults Support Group on Friday evening, July 27, from 7:00-8:30pm. This support group is free for all Conference attendees. For more information about this support group and others at this year's Conference, call the IOCDF office at (617) 973-5801.

It is difficult to have OCD at any age. Yet there is a coveted advantage, when younger, of thinking we at least have some extra time on our side. When the hourglass is fuller rather than emptier, when more of life lies ahead rather than in back of us, it allows us to think we have the extra time we're always wishing for – time for our OCD to play itself out, followed by time in which to recover from a mistake, try a new challenge, enter a new relationship, discover a new way of being. Time also gives us hope, born of anticipating a better future, which in turn helps motivate us to change.

As human beings, we function in the continuum of time. We start off young and hopefully end up old. In the journey between the two, we try to achieve some of our goals and dreams and make a life for ourselves. When we're young and subject to the fears and avoidance of OCD, we can at least fantasize about a future free of OCD in which we're able to pursue a life unimpeded by obsessions and compulsions. When we are young, time gives us a chance to breathe and to hope. The occasional grace periods from the guilt we feel about lost opportunities, which time affords us in our youth, are permissible because we can anticipate a future. We think, my OCD is preventing this now, but in the future, I'll be able to catch up or finally do something I missed or avoided in the past because of crippling anxiety.

For some of us, that better time never comes, and the illusion of extra time disappears as the years pass, and new experiences are forfeited to anxiety. We get used to unfinished projects, piles of unsorted paperwork, and still-unpacked boxes sitting in the corner of a room like furniture. We await the day when we can finally finish, catch up and move on. At the same time, we begin to lose hope of being able to make the necessary decisions and take the needed actions, all so painful for us that years pass by as things remain unfinished, procrastination gains momentum, plans fade, and anxiety prevails.

Aging – adapting to a much-truncated sense of time, learning to live with a disquieting awareness of mortality, and making peace with losses of every kind -- is difficult enough without OCD. For someone with OCD, aging often becomes more challenging. Time no longer stretches out with reassuring abundance. And hope of regaining the valuable time we know we are losing to fear and anxiety starts to die in some of us who, like me, become weary and resigned. We may not be able to control our fears, but we are deeply aware of our loss of precious time. This loss only becomes harder to bear, the more finite time becomes.

I have lived with OCD since I was a teen. My most lifediminishing symptom is perfectionism, a misnomer for a characteristic that has nothing perfect nor life-enhancing about it. No matter what I achieve, I immediately, reflexively, set the bar higher for myself. I rarely reach the impossibly high standards I impose, and hardly ever enjoy the feeling of being good enough. I've suffered for years by limiting what I do for fear of not being competent enough, or of making the wrong decisions - things such as completing my Ph.D., entertaining, cooking, writing, having a will drawn up, and updating my insurance - in others words, I avoid, avoid, avoid. I've also spent countless hours, over decades, cleaning compulsively and making sure that everything is in the right place. And, like many fellow OCD sufferers, I have beaten myself up for years.

Now as an older adult, I find that aging with OCD often feels like navigating in mine-filled waters. We have to decide if, when and where to retire, which new doctors to see, which procedures to have done or not, as we deal with disease and chronic pain. We must learn how to make new friends, accept the death of old, dear friends and family, get used to unfamiliar surroundings, deal with physical and mental decline, and make peace with our apprehension about both change and the uncertainty that often accompanies decision-making.

I know now how little time I have left for the kind of change I truly want. I have become more afraid of remaining frightened for the rest of my life than I am at the prospect of changing. And so I recently began cognitive-behavioral therapy with a new therapist, an

FROM THE FRONT LINES

OCD specialist, someone with experience and the right chemistry to inspire my trust and willingness to take on new challenges and to feel hope again.

One of the sorriest features of getting older is the resignation that sometimes sets in when people feel it is too late to seek treatment. However, I am learning that it is never too late to change, and I am not an optimist by nature. We can learn how to utilize time in action rather than try to hold back time's passage, protecting a toxic status quo where nothing ever changes and our avoidance hangs heavily over each passing year. Also, we can attempt to attract more attention from therapists and researchers, and more outreach for this aging community of OCD sufferers, many of whom live in isolation.

Even if OCD has kept us in a stranglehold for most of our lives, that is not reason enough to give up now. To think otherwise would be too painful, a complete capitulation to fear. We need to believe in change, make the best of available support, and seek treatment using such pro-active modalities as cognitive-behavioral therapy, medication, support groups, and meditation, rather than succumb to passive avoidance. Because seniors sometimes lack the resources and mobility to seek one-on-one treatment, it would make sense to have an online support group, and in-person support groups where feasible, geared to the concerns of middle-aged and senior adults.

It's interesting to note that for those in my generation and for many baby boomers trailing us, who did not have the advantage of widely-diffused knowledge and treatment of OCD until our middle years, the developments in OCD treatment and support networks during the past quarter-century have been amazing. We grew up without hearing about, reading about, or seeing TV programs about OCD. Then came an explosion of research grants and knowledge. Information about OCD reached the general public in the final decades of the last century.

While much of this research has focused on the young and middle-aged, for good reasons, those of us who are older also have age-specific issues worthy of research. As older adults, we accommodate to an aging body, loss of energy, loss of memory, loss of

hearing and, sometimes, the fading of our vibrancy and skills. And, of course, our greatest loss – of time, of possibility, of anticipation and of hope – makes our struggle with OCD that much more intense. It's enough to have lost much of the past to anxiety and avoidance. We don't wish to lose what little time is left. It's a now-or-never moment, for sure, which is why research and treatment geared to older adults would make sense, and sooner rather than later. The number of seniors who need help with their OCD will only increase as longevity becomes commonplace rather than exceptional.

If we start to talk across the generations, maybe we'll come up with a useful dialogue that will help all generations involved. We can help those younger than ourselves by providing ample proof that there is no escaping the need to maximize time, not diminish it by putting off treatment. Those that are younger can help us by validating our insights and experience. Maybe we could attempt a cross-generational panel to address relevant issues at one of our IOCDF annual conferences, with each age group speaking from its unique perspective. Perhaps helping other generations to better comprehend what each of us faces will help us all gain greater clarity and vision. Whatever other rewards we reap by helping others and making vital human connections, we also discover more about ourselves in trying to understand the world of others.



How To Defeat OCD By Surrendering by Fred Penzel, Ph.D.

Fred Penzel, Ph.D., is a licensed psychologist who has specialized in the treatment of OCD and related disorders since 1982. He is the executive director of Western Suffolk Psychological Services in Huntington, Long Island, New York, a private treatment group specializing in OCD and related disorders. He has written numerous articles that have been featured on the IOCDF website and in many issues of the OCD Newsletter.

Over the years, I have watched my OCD patients putting great amounts of emotional, mental, and physical energy into the struggle against their symptoms. OCD, as we know, is especially characterized by doubt, and they seemed to believe that there just had to be a way to overcome their crushing doubts and the severe resulting anxiety. They usually did this by trying to achieve perfect certainty in one way or another. They had to get their compulsions 'just right' to make sure that something bad had not already happened, wasn't happening now, or wouldn't happen in the future. Unfortunately, they had all overlooked the major flaw underlying these attempts, which was that there is no such thing in life as perfect certainty. It is quite understandable why someone with OCD would do this. You might say it is instinctive to try to be perfectly certain in an uncertain and potentially threatening situation.

Given the fact that we do not live in a perfect world, that human beings are all basically flawed and imperfect, that we cannot predict the future, and that we cannot control very much outside ourselves, it is easy to see why the quest for certainty will always be doomed and hopeless. Clearly, anyone starting out with a doomed project is going to waste a lot of time and effort, and that only anger, anxiety, and depression can result. This is one future happening we really can predict.

So, with this in mind, what's an OCD sufferer to do, if relief from anxiety and doubt is their goal? We already know what doesn't work, so that eliminates a lot of possibilities, including compulsive checking, counting, avoiding, repeating, reassurance seeking, washing, questioning, analyzing, undoing, saving, performing magical rituals, etc.. I like to remind my patients that these tactics never worked in the past, aren't working in the present, and are unlikely to ever work in the future. We can file them all under 'Hopeless.' Granted, it isn't always easy to convince sufferers that their tactics really are hopeless. Some folks have to sink to the bottom and suffer major losses in their lives before they are finally willing to admit that their compulsive attempts to relieve their anxiety really are hopeless.

Logic would seem to indicate that when you are clearly fighting for a lost cause, have been defeated at every turn, and have no chance of ever retreating, regrouping, and turning things around, your only other option is to 'give up.' Basically, this involves symbolically raising your hands, raising the white flag, and saying, "I surrender." Understand, too, that this surrender must be unconditional and total. You cannot surrender some of your symptoms and still keep others.

So is that it? The answer is, "Not exactly."

In the world of OCD, one of the big truths you come to discover is that it is a realm of opposites. OCD turns out to be something known as a paradox. One definition of a paradox is - "A statement contradictory to received opinion." In this case, it would be the statement that, "All the things you thought were going to make you better, will only make you worse." That is, the compulsions you thought were going to make the thoughts and the anxiety go away only ended up taking over your life by making you addicted to them, and ultimately, paralyzing you. Put another way, your attempts to use compulsions (no matter what kind) start out as solutions to the problem of obsessions, but they gradually become the problem itself. In this world of opposites, however, it also turns out that, "The things you thought were going to make you worse, happen to be the very things that make you better." How does this get turned into something that you can use to help yourself?

In line with this being paradoxical, it means that you need to stop escaping and avoiding, and face the very thing you fear. Obsessive thoughts are internal mental events that run on their own biology, independent of your other thought processes, and therefore can't simply be shut off. They are not something in your external environment that can be run away from. The truth is, there is no escape from what you fear, and therefore the only real option you have is to face it. If you look carefully at any good treatment for fears, phobias, and anxieties, they are all ultimately based on facing what you fear. Facing what you fear is a way of getting closer to the truth. You are no longer speculating about what might happen - you are finding out what really happens. Everyone with OCD has a theory about what will happen if they do or don't do their chosen compulsions. I like to tell my patients that facing your fear is like being a scientist testing your theories to arrive at the truth. In the case of OCD, the truth people discover is that their theory is disproved, and the dreaded consequence never happens. Just telling them this, however, is not enough. People have to experience this for themselves for it to have a real impact.

In practical terms, what this means is learning to gradually surrender your compulsions and it means learning to agree with all your intrusive unpleasant doubts. I make it a point of informing patients that the anxiety isn't the real problem. The compulsions are the problem, and are what tie their lives up in knots. Many of you will remark at this point, "Easy for you to say. The thoughts seem so real that I can't refuse to act on them. How can I stop doing compulsions? If could do that, I wouldn't have OCD." The thought of opposing your thoughts isn't always easy to grasp. This is because we humans tend to walk around with the idea that because we think something, it must mean something, must be important because we thought it, and must be acted on. In the case of OCD, however, this doesn't turn out to be true. An engineer and former patient of mine found it helpful to label his frightening obsessions as synthetic thoughts. I think this is a good way to characterize them. Even if you can't label them in a helpful way, you can at least try to take it on faith that what the thoughts are telling you may not be accurate.

In addition to the thoughts seeming so real, many sufferers seem to have the idea that, "OCD makes me do these things." My answer to this is to say - No, OCD can only whisper in your ear and tell you dislikable things. It cannot make you do anything. While it is true that obsessions are biologically generated intrusive thoughts, compulsions are simply very bad solutions you, yourself, have invented as a way of dealing with the anxiety resulting from your obsessive thoughts. You make yourself do compulsions. You have created them, and all the rules governing them. You rehearse them and turn them into habits. The bulk of the problems occurring within your OCD come from you. The main reason that compulsions seem so hard to stop is because you have rehearsed them so often that they have become very automatic habits that are easy to do without thinking. You get good at things you rehearse a lot.

This is where we get to the good news. I say this, because if you are creating, carrying out, and practicing these things, then you should also be able to stop them. You made the all rules, it is your game, and you can therefore change the rules. Is this easy to do? The obvious answer is, "No." Tackling them is hard work. No question about it. I would never say that overcoming OCD is easy, and I never use that word when it comes to OCD. Most of the important things in life never are.

So how do you go about getting yourself out of this paradoxical OCD fix? In order to do this, you need to first accept several things:

- 1. There really is no escape from what you fear
- 2. The compulsions don't work, will never get you to a place where you can live life as you really desire, and must be surrendered
- 3. The responsibility for your compulsions is yours, and yours alone, and that you are making yourself do them not OCD
- 4. You are really the only one who can eliminate your compulsions (although you may need guidance in doing this)
- 5. Your compulsions must be faced one way or another if you are to recover, and that it will not be easy to do
- 6. You will have to eliminate all of your compulsions if you are to stay recovered

Once you have accomplished the above, the next step is to get yourself into treatment, whether it is of the selfhelp variety, or done with the help of an expert therapist. This treatment should take the form of what is known as Exposure and Response Prevention (ERP). In a nutshell, it involves gradually exposing yourself to, and agreeing with, increasingly fearful and challenging obsessive thoughts and situations that will cause the thoughts, while at the same time resisting the urge to do the compulsions you have used to relieve your anxiety. Going back to our title, you have to gradually surrender to having to face your fear, and surrender your compulsions. In doing this, you will gradually build a tolerance to the things you fear, and also weaken the connections you have created between having your doubtful, fearful thoughts, and performing compulsions. You will find that your anxiety decreases as your tolerance increases, and that the thoughts have less and less impact. Eventually you can accept that you can have an obsessive thought and not have to act on it in any way. A good therapist can set up and help you with a treatment plan designed to accomplish all this. Medication, too, can help this process by lessening the intensity and frequency of the thoughts.

How long will this take? That depends upon how many thoughts and compulsions you have to work on, whether you get help from medication, and how willing you are to take on your symptoms. Don't wait around. If you procrastinate about it, it certainly won't happen any sooner. Start working on your surrender.

Communities Respond to Hoarding Disorder through Multidisciplinary Task Forces by Christiana Bratiotis, PhD, LICSW

Christiana Bratiotis, PhD, LCSW is an Assistant Professor at the University of Nebraska, Omaha. Dr. Bratiotis' primary area of research is multi-disciplinary community hoarding task forces, written about in her first-authored book *The Hoarding Handbook: A Guide for Human Service Professionals.*

Bernard is a 47 year old man who is unmarried and lives alone in a multi-family home in a northeastern suburb. Bernard recently lost his job and because of his job loss is having difficulty paying his rent. He is now 3 months behind on rent and his landlord is demanding payment. When the landlord recently stopped by to inquire about the late rent, Bernard was home but did not answer the door.

Bernard struggled with gathering free things and saving too many objects for most of his life. His home contains tens of thousands of miscellaneous objects, especially newspapers, periodicals and parts for electronic equipment. Bernard has every issue of his city's newspaper dating back to the late 1960's when he moved to town. These papers are stacked in narrow rows approximately 10 feet high. He's especially proud of this collection and is certain that it's both monetarily valuable and of interest to many in his community. He is therefore unwilling to part with it.



Bernard's hoarding behaviors have led to a life of social isolation; he never has friends to his home because he's embarrassed by how it looks and worries about what other people will think. He finds himself constantly hiding this part of his life and feels shame when he tells others that he'd rather meet at a restaurant or the library and not at his home.

Bernard is sure that he will be evicted if the landlord learns of his hoarding problem and the ways in which the amassed clutter has taken a toll on the house. Bernard's stove hasn't worked in many years and the floorboards seem to be giving way beneath the stacks of newspapers. The kitchen sink backs up and because of the many pots and pans in it, the water often spills to the floor where there is now black mold in the cracked floor. The guest bathroom is filled with objects and papers. Bernard worries about the smell that comes from behind the closed bathroom door.

Bernard recently learned that his city has a hoarding task force. He is nervous about calling the number that was on the flyer he saw but wonders if they could help him talk to his landlord about the condition of his home. Bernard doesn't want to get himself or anyone else in trouble but is worried that without help things will only continue to get worse.

Hoarding is a serious mental health disorder which may result in situations that endanger a person's physical health and housing stability—like in Bernard's case. In addition, hoarding may create circumstances that put family, friends, animals and the surrounding community at risk of neglect, fire or infestation. In Bernard's case, being one of three residents in a multi-family home means that there is risk for Bernard and his immediate neighbors.

In over 85 communities throughout North America -- large and small, urban and rural, human service professionals are forming and becoming part of networks and collaborations aimed at coordinating intervention services and providing support for people who hoard, like Bernard (see **www.ocfoundation. org/hoarding/task_forces.aspx** for a list of task force locations). Human service professionals such as protective service workers, mental health clinicians, first responders, public health officials, housing

personnel, animal control officers and professional organizers along with members of the legal and medical community are joining together to provide a community level hoarding response. People who hoard and their family members sometimes participate as well.

Most hoarding task forces meet on a regular basis. During these meetings, cases of hoarding that require intervention by public and private agencies are often discussed. The range of personal and public health and safety problems that are sometimes associated with hoarding often require diverse disciplinary expertise. In cases like Bernard's, hoarding can threaten housing stability. In other cases, hoarding can lead to the need for protective service involvement for children, elders or animals. Sometimes hoarding situations create environments where medical conditions can't be attended to properly.

Task force members strive to thoughtfully plan and implement ethical, compassionate interventions that use evidence-based strategies. In some communities the hoarding task force offers a place for professionals to consult with others about cases of hoarding while in other communities the task force members actually join together to collaboratively intervene with people who hoard.

While attending a task force meeting on the west coast, I observed first-hand this unique crossdisciplinary collaboration. As the official meeting was winding down, I noticed that a visiting nurse and an environmental health officer were gathering their things to leave together. Through the task force, they realized that they were both working with the same person with a hoarding problem in a nearby town. They decided that if they went together to the client's home, they could more easily communicate both what needed to be done so the client could come into agreement with housing regulations and what supports could be offered to the person in order to help them achieve those goals. When I asked the environmental health officer about this decision, she responded -- "Well, we know that we need both the stick and the carrot. I'm the stick and I can't do my job effectively without a carrot. I know because for

20 years I tried just an enforcement approach and got nowhere with people who hoard. I need to do something differently and this seems to work."

Human service workers who participate on hoarding task forces are devoted to finding compassionate, effective and timely solutions. They work with people who hoard to keep them at the center of all decisions and interventions. Many task forces focus on educating their members and the community about topics such as: strategies for talking with someone who has a hoarding problem, available treatments, increasing motivation to address the hoarding problem and using harm reduction strategies. Task forces sometimes sponsor educational programs such as annual conferences, symposiums, movie nights and lectures. In addition to educational opportunities, some task forces offer psycho-education and support groups for people who hoard and their family members.

Inspired by the commitment of the human service professionals that volunteer time to lead and participate on community hoarding task forces, *The Hoarding Handbook* was conceptualized and written to help diverse disciplines in understanding their role and the role of others in hoarding intervention. Through the book's case studies and practical tips and strategies, my co-authors and I sincerely hope that we are promoting collective community hoarding solutions where clients like Bernard are helped and supported in addressing their hoarding.

In over 85 communities throughout North America -- large and small, urban and rural, human service professionals are forming and becoming part of networks and collaborations aimed at coordinating intervention services and providing support for people who hoard.

(see www.ocfoundation.org/hoarding/task_forces.aspx for a list of task force locations)

Institutional Member Updates

OCD Institute – McLean Hospital

115 Mill Street Belmont, MA 02478 Phone: (617) 855-3279

Website: www.mclean.harvard.edu/patient/adult/ocd.php

The OCD Institute will be expanding its capacity in the residential program by 3 beds this summer. This will allow us to continue to maximize the number of patients we can treat in order to meet the ongoing demand for our services.

We are also thrilled to welcome Jesse Crosby, PhD, who has accepted a two-year research postdoctoral fellowship at the OCD Institute. Dr. Crosby is interested in behavioral addictions and the underlying process of change in therapy. He is a graduate of Utah State University and completed a predoctoral internship at McLean Hospital. He will work closely with Dr. Jason Elias, Director of Psychological Services and Clinical Research, and the entire OCDI staff to examine treatment outcome effectiveness in a naturalistic setting with the goal of improving the effectiveness of ERP, especially for patients who have not responded to traditional interventions.

Rogers Memorial Hospital



Rogers new Child & Adolescent Center

OCD Center and CBT Services 34700 Valley Road Oconomowoc, WI 53066 Phone: (800) 767-4411 ext. 1347 Website: rogershospital.org/residential-center/childadolescent-centers

Update from Rogers: The construction for the new Child and Adolescent Centers is coming along wonderfully. The space is designed for patient-centered care for kids with family-friendly comfort and privacy, and is expected to be completed by August. The designated area for cognitive behavioral therapy and exposure and response prevention is absolutely outstanding and demonstrates our commitment to our patients and families. Our clinical and medical directors understand the incredible process families go through before seeking our help and then their expectations of us, gave great input on the Centers' design

The Houston OCD Program



The Houston OCD Program located at 1401 Castle Court, Houston, TX 77006

1401 Castle Court Houston, TX 77006 Phone: (713) 526-5055 Website: www.HoustonOCDProgram.org

We are excited to announce the expansion of our services with the addition of The Outpatient Clinic at the Houston OCD Program. We now serve the Houston area from two locations; our residential and intensive programs are located at 1401 Castle Court and our Outpatient clinic is located at 1401 Richmond. Our trained behavior therapists Susan Heffelfinger, PhD, Ginny Fullerton, PhD, and Emily Anderson, PhD, have been joined by Naomi Zwecker, PhD, Post-Doctoral Fellow, Wesley Clayton, LMSW, Christen Sistrunk, LPC-Intern and several practicum students offering various fee structures. The Outpatient Clinic provides a wide range of evidence-based treatments, particularly cognitive behavioral therapy services for anxiety, phobias and depression. Our expert therapists are specialized in the treatment of children, adolescents, adults, older adults, families and couples.

If you are interested in finding out more about our services or in scheduling an appointment with one of our expert therapists, or a practicum student, please contact our Program Manager Saharah Shrout, MA at (713) 526-5055 or **info@houstonocdprogram.org**. You can also visit our website at **www.houstonocdprogram.org**.

African Americans with OCD: A Hidden Population and New Research by Monnica Williams, Ph.D. and Ashleigh Steever

Ethnic Minority Involvement in OCD Research

Great progress has been made in the understanding and treatment of obsessive-compulsive disorder (OCD), but not all parts of our society have benefited from these improvements. OCD in ethnic minority groups has been, and continues to be, a neglected area of research.

In 1993, the National Institutes of Health (NIH) stated that funded research must include a certain amount of participation by racial and ethnic minority groups, and researchers were required to include in their research project proposals strategies they would use to achieve diversity in their samples. Our own comprehensive review of the literature found that the absence of minority groups from research studies was widespread and had continued to occur in recent years (Williams, Powers, Yun, & Foa, 2010; Wetterneck, et al., 2012). Among nearly all major studies done in North America, ethnic minorities were either underrepresented or minority participation was not reported at all. For example, less than 2% of all participants in OCD studies were African Americans. Researchers have not followed NIH guidelines regarding the involvement of special populations, and greater involvement of ethnic minorities is clearly needed to fully understand issues related to OCD in non-White populations.

African Americans and OCD

Earlier work done with non-clinical samples of African Americans found differences in reports of contamination anxiety and worries about animals. This research was interesting, but it was not clear if these findings would reach African Americans with OCD. Very few studies in the existing literature included African Americans diagnosed with OCD, drawing tentative conclusions from non-clinical student or community samples. Other than a few encouraging case studies (studies of one specific patient) (Hatch et al., 1996; Williams et al., 1998) and one naturalistic study (a study where a researcher observes patients during their day-to-day lives) (Friedman et al., 2003), there were no published studies focused on the appearance of symptoms, assessment, or treatment of African Americans with an OCD diagnosis.

Many wondered if it was even possible to identify and recruit African Americans with OCD. There were some concerns that low research participation in this group was because African Americans were not interested in treatment, that OCD symptoms were perhaps less harmful, or that the rate at which African Americans can have OCD was lower. It seemed there must be a reasonable explanation, but studies to date had yet to discover any useful information regarding OCD in African Americans.

Using data from the National Survey of American Life (NSAL) study, Himle et al. (2008) showed that African Americans were suffering with OCD in the exact same numbers as the larger US population, but were less likely to receive treatment (Kessler et al., 2005; Himle et al., 2008). Among those with severe OCD, 93% of Americans receive some type of treatment (NCS-R; Ruscio et al., 2008), but this was true for only 60% for African Americans (NSAL; Himle et al., 2008). Even among those who were able to access clinical care, few received specialized treatment and only 20% were using an SRI, which is a medicine for OCD (Himle et al., 2008).

These findings were compelling, but left us with even more questions. If the rate at which African Americans can have OCD was the same the larger US population, what was keeping African Americans from finding help? Did African Americans have different types of symptoms, which could potentially lead to an incorrect or missed diagnosis? Were there aspects of African American culture that did not encourage people to seek treatment? Were there obstacles in the mental health care system that made it difficult to find help?

These questions could only be answered through an in-depth study of African Americans with OCD. Philadelphia, with a population that is 50% African American, was the right place to do this important work, and the International OCD Foundation made it possible with a generous research award.

Recruitment of African Americans

Careful data collection was important for the recruitment of a population that was basically invisible. We set aside a large portion of the budget to outreach and advertising so we would be sure to find our target population, and

African Americans with OCD (continued from page 19)

we carefully kept track of what worked. We reached out to community organizations, discussed the study on local radio stations, ran ads on buses and the Internet, and placed ads in community newspapers. Print ads featured images of African Americans and wording that directly addressed our audience.

Many African Americans are uncomfortable participating in research due to experiences of discrimination and other difficulties. There is a cultural memory of abuses such as the US Public Health Service Syphilis Study at Tuskegee, which continues to affect medical decisionmaking (Gamble, 1997), and more recent research abuses, such as the Baltimore Lead Paint Study which also negatively affected minorities (Spriggs, 2004). To reduce possible fears associated with medical research, our study minimized use of terms like "research" and instead used "project" or "study".

Completion of this work allowed us to describe effective recruitment methods for African Americans with OCD. Our project's first paper, published in Contemporary Clinical Trials, provided a road map to help improve minority participation in future studies (Williams et al., 2012). No longer will those conducting OCD research need to wonder if they can find African Americans. Now every study can expand their sample, building on our work funded by the IOCDF.

Barriers to Treatment

Recruitment into research is only a part of the problem, as one of our overarching goals is to allow everyone with OCD to obtain treatment. Our study found that there are many barriers to treatment among African Americans with OCD, including the cost of treatment, stigma/shame, fears of therapy, believing that the clinician will be unable to help, feeling no need for treatment, and treatment logistics (Williams, Domanico, Marques, Leblanc, & Turkheimer, 2012).

Among our lower income participants, problems with the community mental health system were an obstacle, including a low priority for the diagnosis of anxiety disorders in these clinics, and a true lack of community mental health providers suitably trained to provide OCD treatment. There were also issues with the recognition and then reporting of OCD symptoms, and symptoms not being reported to health care providers. There were some cultural issues noted among our

sample, including not wanting to take part in mental health care and a tendency for viewing anxiety as a spiritual problem to be resolved through religious outlets. However, the most common issue volunteered by our participants was that the person did not realize s/he had a disorder or that there was a treatment for it.

One participant noted, "I was just embarrassed. Getting this type of help has, and continues to be, like a sore thumb in the African American community. Unfortunately, I don't have insurance, so my fear was that if I sought help, it would not be good because I couldn't afford it." For many, simply the process of being evaluated and discussing treatment with a clinician brought about a change of thinking. Another said, "I was unaware, deluded, or in denial about the level of impact my condition had on life. Too much tolerance for deficiencies."

We compared concerns expressed by our sample to a sample from a previous study of barriers to treatment (Marques et al., 2010). While there were no group differences in worries about cost of treatment, shame, and stigma, African Americans were significantly less likely to know where to go for help, and almost 1 in 4 expressed fears about discrimination. These issues are uniquely important to long-term goals concerning outreach and treatment among African Americans.

Although ours was not a clinical treatment study, treatment was discussed with all participants. The vast majority expressed an interest in being treated, and a notable number tried to find or even started treatment during the follow-up period. Unfortunately, many who expressed interest were unable to get it, thus an important avenue of future work will be removing these barriers.

Symptom Dimensions

It is important to accurately understand symptom differences in African Americans because patients who do not meet the most common kinds (i.e., excessive washing and obvious repetitive checking) may not be quickly identified by medical professionals. African Americans are consistently over diagnosed with psychotic disorders and more likely to be hospitalized, (Snowden, Hastings, & Alvidrez, 2009). Given the bias toward a psychotic diagnosis for this group, it is possible that African Americans with the most severe

OCD, especially those with unusual obsessions or compulsions, may be misdiagnosed as psychotic (Hollander & Cohen, 1994; Ninan & Shelton, 1993). Effective treatments for OCD are typically very different than those for psychotic disorders. Thus, it is critical that clinicians have a good understanding of OCD symptoms when assessing and treating African Americans.

To this end, we examined the specific OCD symptoms reported by participants, and compared these to symptoms reported by African Americans in the NSAL study (Heeringa et al., 2004). Although the NSAL data set provides fewer specific details about OCD symptoms, we were able to make some broad comparisons to aid us in understanding this disorder in African Americans nationally.

We found six symptom dimensions, which were similar to those of previous studies in primarily white samples. These dimensions included contamination/ washing, hoarding, sexual obsessions/reassurance, aggression/mental compulsions, symmetry/ perfectionism, and doubt/checking. African Americans with OCD reported more contamination symptoms and were twice as likely to report excessive concerns with animals as European Americans with OCD, which is consistent with studies conducted with non-clinical samples.

Future Directions

The data collected from this study has many implications that could be important to future research. We will continue to analyze and publish the data we have to understand more about African Americans and OCD. Work in progress includes studying the relationship between hoarding, OCD, and other co-existing conditions, and studying how well popular measures of OCD work in African American populations.

Another important step is to use the things we have learned from this study to ensure minority representation in future studies and research. It is a priority to raise awareness within the African American community about OCD, improve knowledge of effective treatments, and educate more providers so that treatments are available and accessible in underserved communities.

References

Friedman, S., Smith, L.C., Halpern, B., Levine, C., Paradis, C., Viswanathan, R., & Ackerman, R. (2003). Obsessive-compulsive disorder in a multi-ethnic urban outpatient clinic: Initial presentation and treatment outcome with exposure and ritual prevention. Behavior Theraoy, 34(3), 397-310.

Hatch, M. L., Friedman, S., & Paradis, C. M. (1996). Behavioral treatment of obsessive-compulsive disorder in African Americans. Cognitive and Behavioral Practice, 3(2), 303-315.

Himle, J. A., Muroff, J. R., Taylor, R. J., Baser, R. E., Abelson, J. M., Hanna, G. L., ...Jackson, J.S. (2008). Obsessive-compulsive disorder among African Americans and blacks of Caribbean descent: Results from the national survey of American life. Depression and Anxiety, 25, 993–1005.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. Archives of General Psychiatry, 62(6), 593–602.

Ruscio, A. M., Brown, T. A., Chiu, W. T., Sareen, J. J., Stein, M.B., & Kessler, R. C. (2008). Social fears and social phobia in the USA: Results from the national comorbidity survey replication. Psychological Medicine: A Journal Of Research In Psychiatry And the Allied Sciences, 38(1), 15-28.

Snowden, L. R., Hastings, J. F., & Alvidrez, J. (2009). Overrepresentation of Black Americans in psychiatric inpatient care. Psychiatric Services, 60(6), 779-785.

Wetterneck, C., Little, T., Rinehart, K., Cervantes, M. E., Hyde, E., Williams, M. T. (2012). Latinos with Obsessive-Compulsive Disorder: Mental Healthcare Utilization and Inclusion in Clinical Trials, Journal of Obsessive-Compulsive & Related Disorders, 1(2), 85-97.

Williams, M., Powers, M., Yun, Y. G., Foa, E. B. (2010). Minority Representation in Clinical Trials for Obsessive-Compulsive Disorder, Journal of Anxiety Disorders, 24, 171-177.

*Williams, M. T., Domanico, J., Marques, L., Leblanc, N., Turkheimer, E. (2012). Barriers to Treatment Among African Americans with OCD, Journal of Anxiety Disorders - Special Issue, 26(1), 555.doi: 10.1016/j.janxdis.2012.02.009

*Williams, M.T., Elstein, J., Buckner, E., Abelson, J., Himle, J. (to appear). Symptom Dimensions in Two Samples of African Americans with Obsessive-Compulsive Disorder.Journal of Obsessive-Compulsive & Related Disorders.

*Williams, M. T., Proetto, D., Casiano, D., Franklin, M. E. (2012). Recruitment of a Hidden Population: African Americans with Obsessive-Compulsive Disorder.Contemporary Clinical Trials, 33(1), 67-75.

* Indicates publications from this study to date

Find more research studies on our website at www.ocfoundation.org/Participants.aspx

RESEARCH NEWS

Research Participants Sought

CALIFORNIA

UCLA RESEARCH STUDY

Cognitive-Behavioral Therapy for Obsessive-Compulsive Disorder (OCD)

This study is investigating what, if any, changes in brain chemistry take place in adults with OCD as a result of cognitive behavioral therapy (CBT). We will measure amounts and distribution of glutamate in the brain using MRSI (Magnetic Resonance Spectroscopic Imaging) scans before and after 4 weeks of CBT.

The study offers:

- · Diagnostic evaluation
- 4 weeks of FREE intensive CBT (exposure and response prevention): 90 minutes/day, 5 days per week
- MRI/MRSI brain scans
- Neurocognitive testing

General inclusion/exclusion criteria for our study:

- Have no history of bipolar disorder, a psychotic disorder, or substance dependence
- · Are in good physical health
- Have not already had more than 30 hrs of CBT for OCD
- Are right-handed
- Between the ages of 18 and 65
- Either not taking psychiatric medications or on a stable dose of a serotonin reuptake inhibitor (only) for at least 12 weeks

Study conducted by Jamie Feusner, M.D. and Joseph O'Neill, Ph.D.

For more information about the MRI/CBT study call (310) 206-0468

MASSACHUSETTS

Duloxetine for the Treatment of OCD

(PI: Darin Dougherty, MD)

Tina Chou

(617) 643-4742

www.mghocd.org

TCHOU@PARTNERS.ORG

This study is for people with OCD who are not currently taking any other psychiatric medications (other meds, including birth control, are fine). The study runs for 17 weeks, and involves 6 visits to our clinic in Charlestown. During the first visit subjects are interviewed about their past psychiatric history, and complete a variety of questionnaires. The first study visit is the longest (1-2 hours), but visits after that take 20-30 minutes each. At these visits, subjects fill out some short symptom assessments, and discuss how treatment is going for them. At the final visit we will assess the patients' progress and discuss future treatment options. There is no compensation for the study, but the medication is provided free of charge. Patients who wish to enroll must not be on any psychiatric medications, nor can they be undergoing current behavior therapy. Patients with comorbid bipolar disorder or psychosis are excluded, as are patients who have had a depressive episode in the last 12 months.

MASSACHUSETTS

Attentional Bias in Body Dysmorphic Disorder

(PI: Jennifer Greenberg, PsyD)

Lillian Reuman

(617) 643-6204

www.mghocd.org/bdd

LREUMAN@PARTNERS.ORG

We are seeking adults who are very worried about how they look to participate in a research study involving a clinical interview, questionnaires, and computerized tasks. Participation includes two visits to MGH, and up to \$100 compensation.

NEW YORK

Treatment of Obsessive Compulsive Disorder (OCD) with Transcranial Magnetic Stimulation (TMS)

Please refer to this study by identifier #5926R

Principal Investigator

Dr. Antonio Mantovani

Overview

This study is a research clinical trial of a non-invasive investigational treatment, called Transcranial Magnetic Stimulation (TMS), for people with obsessivecompulsive disorder (OCD) that do not respond to medications or cannot tolerate medications side effects.

TMS applies a magnetic field to the brain by placing a magnetic coil on the scalp. Each TMS session is 30 minute-long and is delivered every weekday for a series of weeks.

TMS has been approved by FDA for the treatment of depression. In this NIH sponsored clinical trial we are testing whether TMS can treat OCD as well.

Participants will be randomly assigned to receive either active TMS or sham (placebo) TMS for 4 weeks. If patients do not improve after 4 weeks, they have the option of receiving active TMS for 4 more weeks. All evaluations and treatment are provided at no cost to the research participant.

ClinicalTrials.gov number: NCT00106249

Key Eligibility Criteria

18-70 years; both genders

Key Inclusion Criteria

- OCD is the primary problem
- Key Exclusion Criteria
- Metal in the head
- History of seizure or stroke
- Pregnancy/breastfeeding

Location

Columbia University Department of Psychiatry, New York State Psychiatric Institute, New York

For more information, please contact:

Anouk Allart (study coordinator)

Tel: 212-543-5615

E-mail: aa2274@columbia.edu

Dr. Antonio Mantovani (principal investigator)

Tel: 212-543-6081

E-mail: am2518@columbia.edu

MULTIPLE SITES

Call for submissions

Submissions of short stories, short creative non-fiction, and art pieces are requested for possible appearance in an academic/scholarly book tentatively entitled "A Lesson in Doubt: the social and linguistic construction of OCD." Pieces of up to five double-spaced pages will be considered. They can be written/created on any aspect of OCD, from a number of perspectives

including but not limited to first person accounts/takes from sufferers, family members, doctors or community members, etc. Submissions will be accepted until April 15th, 2011. They will be assessed on their literary/ artistic merit and appropriateness given the aims of the book. Please paste your written submission to the body of an email message and send it to patricia. friedrich@asu.edu. For art, please contact me first. If your piece is selected, you will have the option of publishing it under your name, a pseudonym, or anonymously. You must be at least 18 years old to send your work. By submitting your text/art, you are acknowledging that it is your original work and that you grant permission for publication/reproduction in the book. Should your work be accepted for publication elsewhere during the process of review, you agree to withdraw your submission.

ONLINE STUDY

Take Part In A Psychology Research Study

-Do you dislike the way any part(s) of your body look?

-Do you try to hide, change, or check your appearance?

-Do you feel the need to do certain things "just right?" Does this interfere with work, school, family, or friends?

If you answered yes to any of these questions, you might have Body Dysmorphic Disorder (BDD) or Obsessive Compulsive Disorder (OCD).

This study might be a good opportunity for you to learn more about your symptoms.

If you answered no to all these questions, you can still help us learn more about these disorders

Visit www.bddocdstudy.com for more information and how to participate.

Participants will be entered in a raffle to win a \$50 Amazon.com gift certificate.

FROM THE AFFILIATES



OCD Texas

www.ocdtexas.org

Online registration is now open for the next OCD Texas Quarterly Meeting! The meeting will be held in Houston, TX on Saturday, May

19, 2012 from 9:00am-5:00pm. Donations are appreciated, but the Conference is free of charge. To find out more about this Quarterly Meeting or to register online, go to: www.ocdtexas. org/houston-may-2012. If you would like to volunteer, sponsor, donate, or help in any other way, please contact the meeting coordinators, Christen Sistrunk & Wes Clayton, at **meeting-Houston@ocdtexas.org**.

OCD Kansas

OCD Kansas, based in Wichita, is a newer affiliate of the International OCD Foundation. OCD Kansas is committed to the mission of the IOCDF and increasing awareness and treatment of all anxiety disorders. We host a biweekly OCD Support Group and an online 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- this event is currently planned for April, 2013. We are also 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. We would also like to acknowledge the generous support and guidance of Rob Zettle, PhD, Lisa Hale, 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

www.ocdnj.org

On Monday, June 11, 2012, we will have our quarterly meeting at Robert Wood Johnson Hospital in New Brunswick, where Dr. Robert Zambrano, a psychologist at Stress & Anxiety Services of New Jersey, and who also heads one of the committees at OCDNJ, will speak about OCD and Tourette Syndrome. Previously, Dr. Zambrano worked for the Tourette Syndrome Program at Rutgers University. Presently, he gives presentations to educators and families across the state on behalf of the Tourette Syndrome Association of New Jersey. As always, this quarterly meeting will be free and open to the public.



OCD Massachusetts www.ocfboston.org

Les Groderberg Memorial Lecture Series McLean Hospital, De Marnef

McLean Hospital, De Marneffe Cafeteria Building Belmont, MA 02478

OCD Massachusetts, in conjunction with McLean Hospital, presents a series of preeminent speakers in the field of OCD and related disorders. Each presentation takes place from 7:00-8:00pm.

May 1, 2012

Meta Cognitive Therapy for OCD Jim Claiborn, PhD South Portland, ME

June 5, 2012

Medication Q & A Michael Jenike, MD Massachusetts General Hospital OCD Clinic

Hyannis Support Group for People with OCD and their Friends and Family

3rd Wednesday of the month - 6:30-8pm Hyannis Youth and Community Center, Board Room

New Lecture Series and Support Group starting in Worcester

2nd Thursday of each month, 6pm Contact Carla Kenney at (781) 775-1127 for more information.

OCF of Western Pennsylvania

www.ocfwpa.org

Registration is now open for "Understanding and Treating Hoarding Disorder" featuring Randy O. Frost, PhD on Friday, May 18 in Monroeville. This year we have scheduled a continuing education session from 10am - 4pm and an added a session from 4 - 6:30pm for questions from the general public. Patients and their family and friends are invited to attend the continuing education session but should be aware that the material presented will be technical in nature. The open question and answer session is available to them at a much reduced tuition if they are more comfortable in this more relaxed environment. We also invite treatment providers to stay for the open question and answer session on a spaceavailable basis.

We are excited for this program and hope that you can help us pass the word. Registration is available online at **www. ocfwpa.org/ocf_conf_registration-hoarders.html**, as well as on the day of the event.