

## Message from the President



Earlier this year, I was elected by the OCF Board of Directors to serve as its President for a two-year term (as Co-President with Joy Kant until September, 2008.) I'm delighted to serve the Foundation in this leadership position and to work with the Board, staff, members, supporters and volunteers as we continue to advance our shared cause to raise awareness, provide information, and strengthen research to find more effective treatments for people with OCD.

As part of our effort to raise awareness and understanding of the disorder and those who suffer from it, I'm pleased to report that OCF is creating a Speakers Bureau that will include people with OCD, treatment providers and researchers. Jeff Bell, who many of you know is a passionate advocate on behalf of people with OCD, will join our Board in August, and has already agreed

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## Intensive Treatment at the Austin Center for the Treatment of Obsessive-Compulsive Disorder: *An Interview with the Director, Bruce Mansbridge, Ph.D.*

*Could you describe your intensive treatment program?*

Sure. First of all, we're an outpatient facility, so we don't have a place for people to eat or sleep. We provide intensive outpatient treatment. The insurance companies sometimes refer to this as an intensive outpatient program (IOP).

The program is quite different for adults than it is for children. Adults usually come for between one and three weeks. Children come for four days, usually over a weekend. People stay in one of several nearby extended-stay hotels, where they have a suite, kitchenette, high-speed internet, etc. We generally recommend that adults and older adolescents come with at least one family member. For younger children, we encourage both parents or all significantly involved family members to attend, since the goal in those cases is not so much to treat the child's OCD directly but rather to train the family members, so that they can return home confident that they know how to work effectively toward treating their child's OCD. With older adolescents, we can put together a kind of hybrid program that would best meet their needs. We're a small enough operation that we can tailor-make a program for each individual.

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## Dissociative Disorder: Experiential Similarity to Philosophical Obsessions and Rumination on Distress

*By Fugen Neziroglu, Ph.D., ABBP;*

*Katharine Donnelly, MA; Bio-Behavioral Institute; Great Neck, New York*

Jamie is a 22 year old who has experienced feelings of unreality for a year now. In her first semester in college after smoking marijuana she had a panic attack and then shortly after that began to feel detached from her environment and herself. During her first session she described her experience as if "I am living in a dream world except that I never wake up". She said the dream or rather the "nightmare" went on for days. Finally that foggy feeling cleared up and she felt relieved only for the feeling to return years later. Her current state of unreality is unbearable and never seems to go away. She wakes up feeling detached from everything and everyone around her. Although, she knows very well what she is supposed to experience she feels nothing but extreme distress over her overwhelming experience.

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## BULLETIN BOARD

**MRI Study of Repetitive Behaviors**

At The Pediatric Brain Imaging Lab at the New York State Psychiatric Institute

Has your child been diagnosed with Obsessive Compulsive Disorder? If so, and your child is between the ages of 4 and 13, you and your child may be eligible to participate in a 5-year research study that uses MRI to learn more about repetitive behaviors in childhood. Participation in our study will include annual visits over a 5-year period. Each study visit will require 6-7 hours of your time and include interviews, games and puzzles, and an MRI to take pictures of your child's brain.

This is not a treatment study. Children will receive compensation for their time. For more information please call 212-543-6072 or email MRISTUDY@childpsych.columbia.edu. All calls will be kept confidential.

**Monitoring Daily Experiences: Participant Recruitment**

- Do you have Obsessive-Compulsive Disorder (OCD)?
- Are some days better than others?
- Do you want to help increase knowledge of factors that make symptoms worse and better?
- Do you want to contribute to science without leaving your own home?

If you answered YES to these questions, you may be eligible for a research study conducted by researchers at Binghamton University (State University of NY at Binghamton) in Binghamton, NY. The purpose of the study is to examine the daily occurrence of OCD symptoms and life events. Participants must be at least 18 years of age and fluent in spoken and written English.

Participation entails completion of self-report questionnaires for about 15 minutes on two occasions and a 1.5-2 hour telephone interview about anxiety, mood, and other psychological experiences. Eligible participants will be asked to complete a checklist of the life events they experience and answer a few questions about their OCD symptoms and their mood, twice a day for 4 weeks. These activities should take no more than 10 minutes a day. Participants will be paid \$40 and will be entered in a drawing to win one of three gift certificates worth \$250, \$100, and \$50.

If you are interested in helping us better understand experiences that lead to increases or decreases in OCD symptoms, or would like more information, please call Ashley Pietrefesa, M.A., at 607-777-5006.

**Obsessive Compulsive Disorder Genetics Study**

The Butler Hospital OCD Research Program (Alpert Medical School of Brown University, Providence, RI) has joined with five other academic institutions across the U.S. in examining the relationship between genetics and OCD. Recent advances in molecular biology and statistical genetics make it possible to identify and describe specific genes involved in complex illnesses such as OCD.

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

**YOUR HELP COUNTS!!**

For more information, contact Nicole C. McLaughlin, Ph.D. at (401) 455-6608 or nmclaughlin@butler.org.

**OCD Study: Compulsivity vs. Impulsivity**

Do you suffer from Obsessive Compulsive Disorder (OCD) or another anxiety disorder?

Do you live in the N.Y. area?

Researchers at Fordham University are conducting a study of OCD involving the underlying neurobiology of compulsivity and impulsivity. In order to participate:

- you must have an anxiety disorder
- you must be between 18 and 70 years of age

By increasing our knowledge of neuropsychological functioning and decision making processes in OCD, researchers may be able to improve future treatment of the disorder. By participating, you can make a difference. The study takes approximately two hours. Participants take part in an interview, fill out several brief self-report questionnaires, and complete several simple tasks.

Participants receive two free movie tickets as a thank you; and are entitled to a free feedback session.

For your convenience, sessions will take place at two New York locations. You can choose either:

Western Suffolk Psychological Services, 775 New York Ave. Suite 200, Huntington, NY 11743  
or  
Institute for Cognitive Behavior Therapy & Research, 333 Westchester Avenue, White Plains, NY 10605

If you have questions or would like to participate, please contact Patricia Gruner, M.A. at 631-745-7972 or write to pgruner2@aol.com.

**Imaging the Serotonin System in OCD  
IRB#5494R**

P.I. Dr. H. Blair Simpson

To schedule a confidential screening, contact:

Jose Hernandez #212-543-5367 or Dr. Michael Maher #212-543-5370

**Overview of Study:**

The study examines whether the brain serotonin system is different in patients with obsessive-compulsive disorder (OCD) than in those without OCD. One of the brain serotonin receptors will be measured using a standard imaging procedure called positron emission tomography (PET). An anatomical picture of the brain using magnetic resonance imaging (MRI) is also done. Subjects are compensated \$500 for their participation and offered three months of OCD treatment at no cost to them.

**Eligibility:**

18-55 years, both genders

**Key Inclusion Criteria:**

- OCD is the primary problem.
- Not currently on psychiatric medications.

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**OCD NEWSLETTER**

The OCD Newsletter is published  
by the  
Obsessive Compulsive Foundation, Inc.

Phone: (617) 973-5801

Fax: (617) 973-5803

Email: info@ocfoundation.org

Website: www.ocfoundation.org

Diane Davey and Joy Kant,

Co-Presidents,

Board of Directors

Michael Brogioli, Interim Executive Director

Patricia B. Perkins, J.D.,

Editorial Consultant

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The Obsessive Compulsive Foundation (OCF) is a not-for-profit organization. Its mission is to increase research into, treatment for and understanding of Obsessive Compulsive Disorder (OCD). In addition to its newsletter, the OCF's resources and activities include: an annual membership conference, website, training programs for mental health professionals, annual research awards, affiliates, and support groups throughout the United States and Canada. The OCF also sends out Info Packets and Referral Lists to people with OCD.

**DISCLAIMER:** OCF 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.

## The Effects of Hormones on OCD

*By Eda Gorbis, Ph.D., Assistant Clinical Professor, UCLA School of Medicine; Founder and Director of the Westwood Institute for Anxiety Disorders; with J. O'Dea M.D.*

The relationship of hormones and mental illness has been a fruitful area of research. The questions of whether or not the hormones-particularly sex hormones-might have significant effect on OCD in terms of its initial onset, its prevalence and its severity has come to mind on numerous occasions during my years of practice. An assessment of three patients demonstrated a possible connection between hormones and OCD.

The relationship of OCD symptoms to hormonal abnormalities is most likely very complex and no doubt important. I asked myself about the possible link between hormones and OCD. Most OCD outbreaks first occur in pubescent boys newly rich in testosterone, around the age of 10 to 12. In girls, most OCD outbreaks first appear in time of adrenal maturation, which is when the masculine hormone DHEA starts production without ovarian hormones to balance it out. The idea of a relationship between hormones and OCD was reinforced in my mind by the report of post-partum OCD occurring in women after childbirth, as their estrogens and progesterone levels fall dramatically, increasing the impact of their masculine hormones.

Over the past few months we have had three patients for whom this connection seemed to be relevant and I would like to report the outcome of their cases as they related to hormones. It is noteworthy to mention that all three cases involved women, because women go through hormonal changes more often and with higher intensity than men.

The first was a young woman of 25 who had been previously diagnosed with Polycystic Ovary Syndrome (PCOS). She suffered from severe adult acne, which worsened in synch with her OCD symptoms, in a cyclic menstrually-related fashion.

The second was a woman, age 32, with an eating disorder as well as severe OCD and severe migraine headaches. Both her OCD and her migraines were closely and repeatedly related to her menstruation cycles.

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## OCD Genetics Collaborative Update *by David Pauls, Ph.D.*

The sixth annual meeting of the Obsessive Compulsive Foundation Genetics Collaborative (OCFGC) was held April 4-6, on Lake Como north of Milan, Italy. Fifty-nine individuals representing 38 different institutions attended the meeting. The first plenary lecture was presented by Dr. Guoping Feng, Assistant Professor of Neurobiology, Duke University School of Medicine. His lecture was entitled "Synaptic and Circuitry Mechanisms of Obsessive Compulsive-like Behaviors in Mice" in which he reported the findings of his recent work of a potential animal model of OCD. Knockout mice that do not have the SAPAP3 gene showed excessive grooming behavior. Following Dr. Feng's presentation, three separate groups presented their findings of association studies of the SAPAP3 genes and its human homologue, DLGAP3, in patients with OCD. First, Joseph Bienvenu MD, PhD, representing the Obsessive Compulsive Genetics Collaborative Study comprised of investigators from the Medical Schools from Johns Hopkins University, Brown University, Columbia University, Harvard University, UCLA, USC and a laboratory at the NIMH, presented results of studies using an OCD affected sib-pair sample that also had information regarding trichotillomania (TTM) and other grooming behaviors. While there were some moderately positive results, none withstood correction for multiple testing. The most interesting association was with TTM. The next presentation was by Stephan Züchner MD representing investigators from the University of Miami Miller School of Medicine and Duke University Medical School who presented data that support a limited role for multiple rare non-synonymous mutations in DLGAP3 in OCD and TTM. Finally, Paul Arnold MD, PhD, FRCPC representing a collaborative group comprised of investigators from the Medical Schools of the University of Toronto, UCSF, University of Michigan, University of Sao Paulo and Harvard University, presented findings from a family based association study of OCD with DLGAP3. Again, there were some moderately positive findings, but none held up to corrections for multiple testing. Unfortunately, this group did not have information regarding TTM and other grooming behaviors so no direct comparisons could be made with the other two samples. Nevertheless, the fact that three separate groups formed separate smaller collaborative efforts to pursue a very exciting lead toward finding a susceptibility gene for OCD in humans is indicative of the success of these meetings. They have brought together investigators who otherwise would not have been able to collaborate.

Following this initial plenary session, the attendees took part in one of five working groups. The working groups focused on the following topics: Group A: Secondary Analyses of GWAS data; Group B: Statistical Methods for the analysis of GWAS data; Group C: Animal Models and OCD; Group D: Endophenotypes/ Intermediate Phenotypes; and Group E: Pharmacogenetics of OCD. As noted in last year's Progress Report, the OCFGC has undertaken a Genome Wide Association Analysis of OCD with samples collected from 19 different sites which are part of the OCFGC. Altogether, more than 3,600 DNA samples have

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## A Special Bracelet to Benefit OCF

*By Jane McNulty*

My son Rick has suffered from OCD for many years, and while I have always wanted to contribute to the OCF, I haven't been able to because of the amount of time this illness has taken away from me and my family. My friend Ruth Adomunes inspired me when she began making and selling bracelets for special causes. She has recently designed a specific bracelet to benefit OCF with my son in mind. Since our home was on Martha's Vineyard for the past twelve years, she chose colors that correspond to the Island (pale green and purple—the colors of a vineyard.) Along with many other close friends, I am glad to join Ruth in her effort to promote special causes by helping her to sell this jewelry.

The bracelets will be on sale for \$25.00 at the OCF Annual Conference bookstore during the three days of the conference. Ruth is also going to sell other styles of bracelets at the bookstore. All net proceeds of bracelet sales will benefit OCF.



## My Personal Story

Phil Weiner, May 11, 2008

*Imagine a life where people around you perceive you as calm, thoughtful, reliable, and a good listener, but on the inside you are continually experiencing the most disturbing thoughts imaginable with absolutely no insight or understanding of their origin or how to deal with them. What if the kitchen knife I'm using to make a salad suddenly became a murder weapon for stabbing someone in my family? What if a sound I heard while backing up the car was me running over a child who wandered into the driveway? Did I bump into someone on a subway platform and they were crushed under a train? How can I know for sure that these things might not actually have happened? These are just a few examples of my everyday thoughts.*

The bolt of anxiety that comes next triggers a belief that the thought could be reality and then come the seemingly endless rituals, both active and mental, to "prove" that the thoughts were just thoughts and not reality. The compulsive aspect of this cycle could persist for hours, days or even occasionally for weeks. Sometimes the thought would go wherever these thoughts go and then suddenly reappear again in the future. It's like having an infinite line of credit. As soon as one evaporates, there's a brand new one to take its place. All the time this is happening, I'm working overtime to hide these thoughts and behavior from everyone around me, even my family, friends and coworkers. The only thing that keeps me going is the belief that if I can just get through this most recent horrible thought and resolve it, then I'll be okay and entitled to live a normal life. Yet that ultimate relief never comes.

I was born in 1947 and grew up at a time where I'm not sure obsessive compulsive disease was even a diagnosis. It's difficult to look back that far and try to remember how OCD did or didn't impact my life growing up. Some of the behaviors I recall are having to eat exactly the same thing every day (vegetable soup for breakfast), avoiding stepping on cracks on the sidewalk, songs in my head that would play over and over, and needing to count the syllables of every word in a sentence on my fingers to see which finger the final syllable landed on. These minor inconveniences were a precursor of things to come as an adult.

The full-blown version of my OCD arrived about 25 years ago in response to a major life change involving my wife and me moving to a new city for career changes. Every day became a series of alarms going off about some imagined harm I had done to others, both in the past and future. Driving was a series of pedestrian kills that sometimes required hours of driving back over my route to convince myself I hadn't run over someone. Looking back at this period, which went on for years, two things continue to amaze me. The first is that I never discussed this with anyone, including my wife, and went to elaborate lengths to hide my behaviors and attribute my endless hours of mentally obsessing to being "distracted" or "concerned about a work issue". I was very careful not to display OCD behaviors around anyone I knew.

After a year of the full-blown OCD, I did seek professional help but would not even confide to a therapist what was really going on. I later learned that it's not particularly unusual to conceal OCD even from a therapist. I framed everything in terms of adjustment to a major life change, the recent death of a parent, relationship concerns, etc.

The truth is that I thought these issues were the source of my bizarre feelings and behaviors and that coming to grips with these issues would eventually cause the feelings to disappear. I don't recall if I even knew what OCD was, or if I did, I probably thought it was specific to people who

are germ phobic and spend a lot of time washing their hands.

After a year or two of struggling with life's "issues" with a therapist, I convinced myself that I was actually feeling better and could manage without professional help. However, nothing was really improving and the truth is that the only time I wasn't experiencing the OCD is when I was asleep. I returned to my therapist and somehow finally found the courage to describe some of the OCD-related thoughts and behavior which resulted in referral to an OCD specialist for help. It is impossible to describe the sense of relief that I felt at finally having a plausible explanation for the nightmare and connecting with someone who could help. What ensued over the next couple of years was a combination of cognitive behavioral therapy coupled with an SSRI medication that gradually allowed me to understand the many manifestations of my OCD.

Although the OCD can not be "cured", I have learned to live with it and have significantly cut down on the amount of time I devote to OCD-type thinking and behaviors. My one major setback was believing that I could manage without taking medication. I realize that many people do cope with OCD without ongoing medication, but I'm definitely not one of them. After a year of being off medication, the acute OCD slowly but surely returned and I finally conceded to being back on medication. There's a small part of me that still (incorrectly) believes that I should be able to deal

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# Obsessive-Compulsive Disorder in Children and Adolescents

*By S. Evelyn Stewart, M.D., Child Psychiatrist, MGH OCD Clinics, Assistant Professor, Harvard Medical School*

OCD is one of the most common psychiatric illnesses affecting children and adolescents. Previously thought to be rare, OCD is reported to occur in 1-3% of people. It is the fourth most common mental illness after phobias, substance abuse, and major depression. OCD has peaks of onset at two different life phases: pre-adolescence and early adulthood. Around the ages of 10 to 12 years, the first peak of OCD cases occur. This time frequently coincides with increasing school and performance pressures, in addition to biologic changes of brain and body that accompany puberty. The second peak occurs in early adulthood, also during a time of developmental transition, when educational and occupational stresses tend to be high. It has been argued that childhood-onset OCD may represent a unique subtype of the disorder with distinct characteristics. This article focuses on OCD as it occurs in children and adolescents, compared with OCD in adults.

Numerous OCD-affected adults had childhood-onset of their illness. Sadly, many of these individuals went through childhood before recognizing that they had OCD. Without an alternate explanation, they may have come to believe that they were 'crazy' or that they must keep their worries and behaviors as a shameful secret. Efforts are being made to increase awareness and recognition of this treatable illness within schools and in the general population.

## OCD symptoms

OCD presentation is very similar across children, adolescents and adults. People with OCD have repetitive thoughts or images that they can't control, and the anxiety caused by these thoughts leads to impulses or actions that are distressing, time-consuming or limiting to normal functioning. Of special note, the insistence on repetitive or 'just right' behaviors that occurs during the 'terrible twos' stage in toddlers is distinct from illness-related OCD symptoms. These serve as a part of normal child development, in contrast with OCD symptoms, which impair function and distract the child from learning normal developmental tasks.

One way that childhood/ adolescent OCD differs from OCD in adults is that youngsters may not always realize that their thoughts, worries or behaviors are excessive. For example, while an OCD-affected adult may recognize that stopping a superstitious ritual is desirable, an OCD-affected child may view the ritual as a literally protective act (e.g. a child who doesn't want to stop being afraid of germs or to stop repetitively washing, compared with an adult who desperately wants to be able to stop and to lose the worries).

A second distinction between OCD symptoms across age groups is the content of the disabling obsessions and compulsions. All categories of adult OCD symptoms may appear in children and adolescents, including sexual, aggressive and religious obsessions. However, rates of these symptom types tend to differ by age. Religious and somatic (body or health-related) symptoms appear to be more common in child versus adolescent or adult groups and ordering and hoarding symptoms more common in child/ adolescent versus adult groups. There are also symptoms that are particularly noted in children, including 'just right'

obsessions, compulsions involving other persons such as parents, and superstitious rituals. Another OCD symptom in childhood is the intense fear or avoidance of a 'contaminated' sibling, leading to marked disruption of family functioning. Across the lifespan, OCD patients often experience more than one symptom type at one time, and symptoms also frequently change over the long-term course.

There are groups of symptoms that tend to go together (these symptom groups are also known as symptom dimensions or factors). This is true for children, adolescents and adults. Although a person's symptoms may change over time, it appears that they often stay within the same symptom group for a given individual. There are four groups commonly described, that include: 1) contamination and cleaning symptoms, 2) hoarding obsessions and compulsions, 3) symmetry/ ordering/ repeating symptoms and 4) aggressive/ religious/ sexual/ somatic and checking symptoms.

It is presently unclear whether childhood and adult-onset OCD differ significantly in terms of their long-term course. In the longest OCD study to date on adults, after an average time of 47 years from initial assessment, 20% of patients had no symptoms and 28% had some symptoms but not full OCD. A child OCD long-term outcome meta-analysis (an analysis of combined past studies) found that 40% had no OCD symptoms and 19% had some symptoms but not full OCD when they were seen at long-term follow-up.

## Potential causes of OCD in children and adolescents

OCD is believed to result from a combination of genetic, biological and environmental risk factors that combine within a specific individual at a certain time point to trigger onset of the illness. Biological or environmental triggers may include a child's

immune system response to illnesses such as strep throat. This occurs in a reported OCD subgroup of childhood-onset cases called PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders associated with Streptococcus). Among children, genetic causes are thought to contribute approximately 45-65% of the risk for developing OCD. Studies have suggested that children often have differing OCD symptoms from their parents. This argues against the notion that OCD running in families is a pure result of children imitating their parents' OCD symptoms.

Having a family history of OCD is currently one of the strongest risk predictors for developing OCD. However, this does not mean that every child of an OCD-affected adult will develop this illness. Despite progress in the study of OCD genetics, no single 'OCD gene' has been identified as a major cause of OCD. From twin studies and family studies, genetics appear to play a larger role (having higher heritability rates) as a cause of childhood-onset versus adult-onset OCD. For example, relatives of adults with OCD possess a four-fold increased risk of developing the disorder (8%), whereas relatives of those with childhood-onset OCD have a five- to eight-fold increased risk of developing it (10-17%).

## Treatment for OCD in children and adolescents

One of the first and most central aspects of OCD management for children is education. Both the child and family should be reassured that symptoms are in keeping with a known and treatable illness, rather than signaling 'odd habits,' misbehavior or defiance. When lasting symptoms cause significant distress or impair family, school or social functioning, they can no longer be attributed to a passing phase. Frequently, learning that these symptoms are part of a known illness

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## Research Digest

Selected and abstracted by Bette Hartley, M.L.S. and John Greist, M.D.  
Madison Institute of Medicine, Inc.

*This **Research Digest** again emphasizes studies of cognitive behavior therapy (CBT) for OCD because CBT is often twice as effective as serotonin reuptake inhibitor (SRI) medications in the short-term, and most patients maintain gains for years after effective CBT. The studies reviewed found CBT effective for children as young as five, for adolescents, and also for adults with poor response to medications in high dose. One preliminary study suggested value in specific motivational techniques combined with CBT. Another confirmed benefit lasting to 10 years. Finally, D-cycloserine, a medicine used to treat tuberculosis, offered promise of speeding benefit from CBT. There is a rub in this positive picture: qualified CBT therapists are hard to find.*

### **A randomized, controlled trial of cognitive-behavioral therapy for augmenting pharmacotherapy in obsessive-compulsive disorder**

*American Journal of Psychiatry, 165:621-630, 2008, H.B. Simpson, E.B. Foa, M.R. Liebowitz et al.*

Serotonin reuptake inhibitors (SRIs) are antidepressants with proven effectiveness in treating OCD. While SRIs typically reduce OCD symptoms, many responders continue to have distressing OCD symptoms that cause dysfunction in their lives. This study examined the benefit of adding cognitive-behavioral therapy (CBT), specifically exposure with ritual prevention, to on-going treatment with adequate doses of SRIs for patients who had little benefit from the medications. Conducted at two academic outpatient clinics in Philadelphia and New York, a comparison was made between augmenting SRIs with exposure and ritual prevention (56 patients) or with another form of CBT, stress management training (55 patients). Participants received 17 sessions of CBT (either exposure and ritual prevention or stress management training) twice a week while continuing SRI drug therapy. Exposure and ritual prevention was superior to stress management training in reducing OCD symptoms, with more patients reaching responder status (74% versus 22%). These results are consistent with earlier research showing stress management training had little effect on OCD symptoms. Exposure and ritual prevention augmentation of SRI medications was an effective strategy for reducing OCD symptoms. Currently, treatment guidelines for OCD do not recommend combining SRIs and exposure and ritual prevention for all patients. The combination of treatments may be especially helpful for patients not responding to SRI medications alone.

### **Treatment of obsessive-compulsive disorder: personal follow-up of a 10-year material from an outpatient county clinic**

*Nordic Journal of Psychiatry, 62:39-45, 2008, T. Olsen, A.H. Mais, T. Bilet et al.*

Most OCD treatment studies have been at academic centers. This study was conducted at a

psychiatric outpatient clinic of a general hospital in Norway. The clinic systematically offered a combination of exposure with ritual prevention and serotonin reuptake inhibitor (SRI) medications to OCD patients. This paper presents their treatment model and the treatment outcome of the first 25 OCD patients treated at the clinic. Obsessions, compulsions and depression were significantly reduced after treatment and further improvement occurred during the follow-up (1-10 years after treatment). Before treatment only 11 patients were employed and at follow-up 18 were employed. This study demonstrated that a general outpatient psychiatric clinic can successfully utilize methods that have previously been shown to be effective in highly specialized treatment settings.

### **Quality of life in obsessive-compulsive disorder: an evaluation of impairment and a preliminary analysis of the ameliorating effects of treatment**

*Depression and Anxiety, 25:248-259, 2008, M.M. Norberg, J.E. Calamari, R.J. Cohen et al.*

Pre- and post-treatment quality of life was evaluated in 188 OCD patients receiving treatment at specialty OCD clinics—Rogers Memorial Hospital in Wisconsin and Rosalind Franklin University of Medicine and Science in Illinois. All patients received cognitive-behavioral therapy (CBT) and most also received medications. The Quality of Life Inventory was used measuring life satisfaction and importance in 16 areas: health, self-esteem, goals and values, money, work, play, learning, creativity, helping, love, friends, children, relatives, home, neighborhood, and community. Substantial pretreatment quality of life impairment was found across all life domains, as has been found in other studies. Results were interpreted separately for responders, partial responders and non-responders to treatment. Interestingly, some OCD patients experienced significant OCD symptom reduction but little improvement in quality of life. These individuals may need additional interventions, such as vocational rehabilitation and social skills training, to maintain treatment response.

### **Adding motivational interviewing to exposure and ritual prevention for obsessive-compulsive disorder: an open pilot trial**

*Cognitive Behaviour Therapy, 37:38-49, 2008, H.B. Simpson, A. Zuckoff, J.R. Page et al.*

Behavior therapy, specifically exposure and ritual prevention, is an effective treatment for OCD. However, some individuals refuse treatment, others begin but drop out, still others do not fully follow procedures well, and not all individuals who complete treatment maintain their gains. Researchers explored combining motivational interviewing techniques with exposure and ritual prevention to help OCD patients more fully participate in behavior therapy. Motivational interviewing is a goal-oriented method for increasing motivation to change by working on patients' ambivalence (uncertainty or indecisiveness) about the treatment. Motivational strategies used for six patients are described. Five of these individuals responded to the combination treatment, with three achieving an excellent response. Researchers suggest that integrating motivational interviewing with standard exposure and ritual prevention is a promising method to increase and maintain patient engagement with behavior therapy. They are currently conducting a controlled study comparing the combination of motivational interviewing and exposure and ritual prevention and exposure and ritual prevention alone.

### **Augmentation of behavior therapy with D-cycloserine for obsessive-compulsive disorder**

*American Journal of Psychiatry, 165:335-341, 2008, S. Wilhelm, U. Buhlmann, D.F. Tolin et al.*

D-cycloserine (Seromycin), a medication approved to treat tuberculosis, has been shown to increase extinction learning (or habituation) involved in exposure therapy to reduce fear. This study examined the effects of combining D-cycloserine and behavior therapy. In a double-blind trial with 23 OCD patients, D-cycloserine augmentation of behavior therapy was compared to placebo augmentation. All participants received 10 behavior therapy sessions, conducted twice weekly. One hour before each session, participants received D-cycloserine, 100 mg, or a placebo. The D-cycloserine augmentation group's OCD symptoms were significantly more improved at mid-treatment than the placebo augmentation group. At the end of treatment and 1-month later, the differences in OCD severity were no longer significantly different. The improvement in OCD symptoms occurred earlier, or more quickly, with the addition

of D-cycloserine. Additionally, the D-cycloserine augmentation had positive effects on co-occurring depression. Although findings need to be replicated and questions remain about dosing, this study showed that D-cycloserine augmentation may accelerate the benefit of behavior therapy for OCD. If D-cycloserine produces a faster response, patients might be more motivated to continue behavior therapy.

#### **Early childhood OCD: preliminary findings from a family-based cognitive-behavioral approach**

*Journal of the American Academy of Child and Adolescent Psychiatry, 47:593-602, 2008, J.B. Freeman, A.M. Garcia, L. Coyne et al.*

Behavior therapy, specifically exposure with ritual prevention, is the therapy of choice for OCD in children. However, studies have not adequately evaluated the effectiveness of exposure with ritual prevention for young children. This study compared the effectiveness of family-based cognitive-behavioral therapy (CBT) to family-based relaxation treatment (RT) for children ages 5 to 8 years with OCD. The CBT program was adapted to the younger age group, such as using child-friendly examples, and by an awareness of a young child's dependence on parents. Younger children rely on parents more than older children, and parents may be more likely to reinforce or actively accommodate a young child's rituals. Throughout treatment, parents were trained as coaches for their children. Forty-two children were randomized to receive 12 sessions of family-based CBT or family-based RT. In the CBT group, 69% of children achieved a clinical remission compared to 20% in the RT group. The finding that some children in the RT group improved, although not to the degree of children in CBT, was similar to other studies' findings that active control conditions may have some benefit. The RT program was not only a control, but also meant to provide some general anxiety management skills to children and their families. Overall, the 49% greater chance of remission makes CBT the clear choice for children with early-onset OCD when CBT is adapted to their developmental needs.

#### **Five-day intensive treatment for adolescent OCD: a case series**

*Journal of Anxiety Disorders, 22:495-504, 2008, S.P. Whiteside, A.M. Brown and J.S. Abramowitz*

Access to behavior therapists with expertise in exposure and ritual prevention for OCD is very limited. Families are often forced to travel to specialized OCD clinics, creating problems due to time away from home, school and work as well as increased living costs for long stays

away from home. Based on the authors' clinical experience, 5 days is a manageable length of time for many families to be away from home for treatment. They adapted a traditional cognitive-behavioral therapy (CBT) program, primarily using exposure plus ritual prevention, to a 10-session program over five days. Additionally, they increased parent involvement in the program to help continue treatment in the home environment. Although this is a small case series, only 3 adolescents treated, it importantly demonstrated that a brief, intensive treatment may be an effective method of delivering CBT for some adolescents with OCD who have geographic or other barriers to receiving treatment at specialized OCD clinics.

#### **The use of computers in the assessment and treatment of obsessive-compulsive disorder**

*Computers in Human Behavior, 24:917-929, 2008, C.W. Lack and E.A. Storch*

Research on computer-administered assessment and cognitive-behavioral therapy for OCD is reviewed. Need for computer delivery is discussed—at least 2.2 million people in the U.S. have OCD; many primary healthcare providers are unfamiliar with OCD and computerized screening tests would be beneficial; many with OCD do not seek treatment because of cost of treatment and shortage of trained professionals. Computer-based assessments and treatments for OCD could be less costly and more available than traditional methods. A computerized version of the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) was shown to be as good as a clinician-administered Y-BOCS for measuring OCD symptoms. Equally accurate was an interactive voice response (IVR) Y-BOCS in which telephone callers interacted with the computer through a voice menu. As of 2006, there were only eight published studies using computer-based treatment approaches for OCD. The first program published was called OC-CHECK (Baer et al., *American Journal of Psychiatry*, 1987), a behavior therapy support program delivered on a handheld, portable computer. OC-CHECK reminded patients of behavior therapy instructions and tracked information on intensity and frequency of symptoms. The second program published was BT STEPS, an IVR behavior therapy program that was effective in a randomized controlled trial (Greist et al., *Journal of Clinical Psychiatry*, 2002) for OCD. Currently these programs, OC-CHECK and BT STEPS, are not available. Importantly though, research has shown computer-administered assessment and treatment for OCD works. The authors make recommendations for future use of computers, such as converting programs such as BT STEPS into Internet programs. ■

## **My Personal Story**

*(Continued from page 4)*

with this without the help of medicine. After all, shouldn't the insight into understanding OCD have caused the thinking and behaviors to go away?

Finally, there are some things I have learned/accepted along the way that have made a significant difference in handling this very formidable foe:

1. Perhaps the most powerful three words I have found are "I don't know". The certainty that we try to obtain through our obsessive thoughts and compulsions is unattainable. It's a bit of a cliché, but "living with uncertainty" is what ultimately makes OCD tolerable for me. It's incredibly difficult to get to this point, but essential for living with OCD.
2. If you choose to share with others that you have OCD, don't expect people to immediately empathize or even have minimal understanding of what you're going through. It's a bizarre and misunderstood disorder and difficult for others to relate to. The few individuals I have chosen to share this with are surprised, uncomfortable with the information, and don't understand how someone who may outwardly appear "normal" in most situations could possibly experience the thoughts and behaviors of OCD.
3. OCD can be a source of humor and even creativity at times. I firmly believe that at least some of my sense of humor has origins in OCD thoughts.
4. Look OCD straight in the eye. Every day I'm challenged to do things that would be easier to avoid, because I finally understand that accommodating your OCD thoughts in an attempt to get rid of the immediate anxiety is deadly in the long run. I spent years believing that resolving the OCD thought of the moment would prevent the next one from coming. Think of them as buses that run 24 hours a day—you don't have to get on every one that comes by.
5. Practicing mindful meditation works. Focusing on what you're doing in the present and trying to fully experience it tends to limit the impact of my OCD thoughts. It helps to slow things down, which makes it easier to simply experience/observe the OCD thought without needing to do something about it.
6. Most importantly, you are not your OCD. It certainly can be a constant companion at times and isn't going to suddenly leave like an unwanted guest. Let it stick around, but on your terms and realize that you are defined in many different ways besides your OCD. ■

## Message from the President

(Continued from page 1)

to serve as an additional National Spokesperson for the Foundation, augmenting the wonderful work that Elizabeth McIngvale has done and continues to do to raise awareness about OCD. Our reinvigorated *What Does OCD Look Like?* Campaign will be re-launched later this year, featuring Jeff alongside Elizabeth, with future “faces” to come.

I’m also glad to report that our founder and past executive director, Patti Perkins, will join the Board in August. Patti continues to work tirelessly to help people with OCD, and her years of experience and expertise are invaluable assets to the Foundation, especially as we continue the transition to a new office and staff. It is especially appropriate that Patti is being honored at this year’s Annual Conference. While we celebrate her past contributions, we can rest assured that she will continue to champion and help lead our cause.

Our outreach efforts are critically important. As you know, most people who suffer from OCD do not seek or gain an accurate diagnosis—the first step to effective treatment—until well after the onset of the disorder. We can change that with greater awareness.

Indeed, when OCF’s contact information was included in a “Dear Abby” column earlier this year, hundreds of people called the office to get information. We saw a similar phenomenon when Dr. Michael Jenike was interviewed on the *Today Show* this spring; web traffic soared on the morning of the show, and in the following days. Similarly, a recent *Oprah* show dedicated to OCD and featuring Dr. Jonathan Grayson prompted many visits to our website. People are hungry for information and help, and we need to provide it.

With this in mind, we also need to strengthen our outreach to current and potential treatment providers, with the goal of increasing the number and quality of providers so that people with OCD and their families get the help they want and need. As part of that effort, we will be continuing our acclaimed Behavior Therapy Institutes—with three scheduled for 2009 in various parts of the country. Targeted funding by generous donors has helped decrease the tuition for the BTI’s significantly, making them increasingly affordable for even more treatment providers to attend.

We continue to provide resource and referral information via our website, over the telephone and by mail to those who seek it. Indeed, thousands of people with OCD, family members and treatment providers turn to OCF each year for information and advice, and we will strengthen this vital part of our work.

Again, I’m delighted to help lead OCF efforts as we move forward and work to fulfill our mission. Together, we can ensure that all people with OCD get the support and treatment they need.

*Diane Davey*

## Mark’s Ride—May, 2008

75 people gathered at Marymoor Park in Redmond, Washington to bike the Sammamish River Trail while raising \$2,700 dollars for the Obsessive Compulsive Foundation. Mark’s Ride was started three years ago by friends and family as a way to remember a young man who was strong, gentle and faithful beyond his years and who still ‘lives in spirit’. If you are interested in participating in next year’s ‘Mark’s Ride’, please contact John Nelson at [john.r.nelson@comcast.net](mailto:john.r.nelson@comcast.net)



## Austin Center OCD Treatment

(Continued from page 1)

*One to three weeks (for adults) or four days (for children) sounds like a very short time. Is that really long enough?*

An adult coming for treatment shouldn’t expect to be anywhere near symptom-free after such a relatively short stay. But it is possible to achieve a 50% drop in YBOCS (Yale-Brown Obsessive-Compulsive Scale) symptom severity in that time, and that’s what we shoot for. We don’t always achieve that; sometimes we don’t even achieve a 25% drop. Our intensive treatment is meant to be a major push, a jump-start, toward treatment that will then continue on an outpatient basis. In many cases, the progress achieved after the intensive phase is greater than that achieved during the intensive phase. With children, there may be significant progress in symptom reduction or hardly any at all, but we intend to teach everyone in the family how the treatment works, and to a large degree how to do it. Of course, they will still need professional guidance after they get home, but we hope to increase their knowledge, confidence, and commitment so that everyone can follow through when they get home. We still aim for a 50% reduction in symptoms over the following several weeks or months.

### *What does the therapy consist of?*

It’s very similar to what we do in the regular outpatient treatment of OCD, except that it’s more intensive. The cornerstone of our approach is cognitive behavior therapy (CBT), and the most common CBT technique we use is exposure and ritual prevention (ERP). We also evaluate for medications and can make recommendations for their use (starting, adjusting, or discontinuing), but medications usually take several weeks to take effect, so we don’t depend on medications to have an effect during someone’s stay here.

Typically, an adult coming for treatment would meet with me or another senior therapist for two hours of individual therapy each morning, Monday through Friday, and then for

up to four more hours of individual therapy each afternoon with a doctoral student intern. Some of the therapy takes place in our office, and some takes place “in the field”, at shopping malls, for example, or outdoors, as is most appropriate and effective for the treatment. Our interns, from the University of Texas clinical psychology PhD program, are well trained in this kind of “in vivo” therapy, and of course we work closely with them and supervise them. The family members also have the opportunity to meet with each of these therapists and also with our family specialist, Vicki Easterling, during their stay with us. Although people rarely come to our center for intensive treatment if compulsive hoarding is their primary issue, if it’s part of the picture of their OCD, they can also work with our hoarding specialist, Dr. Irene Tobis, during part of their stay. We have a team approach, and patients and their families are important members of that team.

In the case of children and adolescents, there is considerable flexibility in the therapy schedule and participant involvement, depending on the age and needs of the child or adolescent, and which parents or family members are present. In general, the daily schedule consists of individual therapy for the child or adolescent, family sessions, ERP sessions with and without parents, and educational and coaching sessions for parents. At the end of each day, family members leave with homework assignments that are reviewed the following morning in order to build knowledge, skills and confidence. ERP sessions are done both in and out of the office, where clients can confront real-life triggers and practice their new skills.

#### ***Are family members always present during therapy sessions?***

No, not always. We provide opportunities for each patient to speak alone with each of their therapists throughout their stay, and they might meet one-on-one with a therapist most of the time. In some cases there is a great deal of family participation, and in other cases much less. It all depends on the individual situation.

Family and relationship issues are extremely important, which is a major reason we recommend that even adult clients come with a family member. OCD is obviously hard for the OCD sufferer to live with, but individuals with OCD can also be hard to live with. Anger and resentments build up. We try to get everyone on the same page and working together. Friends and family members, of course, typically (and quite naturally) have tried to reassure the client about their obsessive concerns, but reassurance is rarely helpful and usually makes the OCD worse. We train family members how to be supportive without providing reassurance about obsessive concerns. We also encourage the family to move toward healthy and enjoyable activities, without having OCD be the centerpiece of their interactions with each other, and to practice this during their stay with us.

#### ***What would determine family participation?***

There are a number of reasons why we might want more family participation, such as when family members have been sucked into the person’s OCD world, say, by providing excessive reassurance, or by going along with OCD-driven requests, for example that everyone needs to shower and change clothes whenever they come into the house. Also, the client and the family may prefer more family involvement. And, of course, with a child, the family needs to be very involved with treatment. There are also times where the family is over-involved and needs to back off. Vicki Easterling, our therapist I mentioned earlier who specializes in treating children and adolescents, has a lot of experience in family therapy. In addition to being lead therapist when the case is a child or adolescent, she may participate in treating cases where there are significant family dynamics.

#### ***How young a child would you see for intensive treatment?***

We don’t have a fixed rule on the age of the child. Remember, we see families with children with OCD. The younger the child, the more crucial it is to have family participation in the

treatment. Even children and adolescents who are highly motivated still require that their parents or caregivers be well educated in OCD and fully prepared to act as coaches and cheerleaders in their ongoing endeavor to get and keep OCD under control. Family involvement and participation greatly increase the odds of short and long term success. In our experience some cognitive-behavioral strategies are unlikely to be helpful for children younger than six, but counseling the parents and caregivers of even younger children can still be very helpful. Of course, adolescents’ need for privacy and independence is taken into account and respected in assessing and planning for parental involvement.

#### ***What kinds of cases work well in intensive treatment, and what kinds don’t work well?***

Most types of OCD work well, including what used to be known as “pure O” (for pure obsessional) or “primarily O”. Body dysmorphic disorder (BDD) cases often do well in intensive treatment. The cases that don’t work well are ones that are tightly bound to the client’s home situation. Someone who obsesses about things not being right with their house, for example, may find those concerns disappear when they move away from home temporarily. Hoarding is also difficult to treat away from the settings in which the behavior occurs. Hairpulling (trichotillomania) and skin-picking are also not recommended for intensive treatment.

#### ***Is group therapy part of your treatment?***

No. Although we do offer outpatient group therapy, it’s not part of our intensive treatment. We’re a small facility, and we see only one intensive treatment patient or family at a time, so there is no group for them to meet with. Sometimes it feels like group therapy when the senior therapist, the student intern, the family therapist, the client and family members are all in the room!

#### ***What about follow-up?***

Follow-up is crucial. We prepare for follow-up (often called discharge planning) even before the person

## Austin Center OCD Treatment

*(Continued from page 9)*

arrives. Tremendous progress can occur while they're here with us, but intensive treatment in any facility must be followed up with continued outpatient therapy after the person leaves, or any gains made will almost certainly be lost. This can be difficult if there are no trained OCD therapists near the person's home, which is in fact a common reason for people to come to our center. Consequently, we often wind up providing continued outpatient therapy by telephone.

### *Is that legal?*

Yes, it's legal and ethical and remarkably effective. Obviously, it's better to have face-to-face meetings, where you can see people's facial expressions and other non-verbal behavior, but it's not necessary. There are blind therapists who are very competent. Insurance may not reimburse for telephone sessions, however.

### *What is your success rate?*

That's difficult to compute. Some of the best treatment centers in the world, like the OCD Institute at McLean Hospital in Belmont, MA, have only modest success rates, since they often treat the very toughest cases. If someone has never had good CBT/ERP before, our success rate is very high. But if they've seen several competent therapists with

little or no success, we may have to find an approach that the others had missed. Sometimes we do and sometimes we don't.

I remember one intensive treatment case that I thought was a dismal failure. We just couldn't get anywhere; it was like pulling teeth. We simply couldn't find a way to get the client to do any of the exercises we recommended. We terminated treatment after one week, because it would have been a waste of time and money to continue. Then a year or two later I got an email from the mother, thanking us, saying that when her daughter got home from Austin, she began to do the ERP we'd recommended and got much better. The mother reported that she was now entering graduate school and doing great. So, even though we measure gains at the end of the intensive treatment phase, once a person gets back home with new tools and confidence, we expect to see continued growth and success.

### *How much does your program cost?*

We charge \$700 for the first day and \$500 for each additional day. We provide treatment for up to five days (Monday-Friday) a week for adults, and four days (Wednesday-Saturday or Thursday-Sunday) for children and their families. We're considering including followup phone calls into an up-front cost, since we think those are so important, but so far those are charged separately, at our usual hourly fees (we offer reduced rates for our student therapists).

### *Is your intensive outpatient treatment covered by insurance?*

Sometimes. It's important to arrange this ahead of time. After the treatment is already paid for, insurance companies have less incentive to approve it. We don't belong to any HMO networks or panels, and people generally get reimbursed less for going "out of network" to see us. But one person came to us from out of state, going out of network, of course, and his insurance company reimbursed him all but a \$25-a-day copayment. He may have had exceptional negotiating skills, or maybe he was able to talk to someone at the

insurance company who realized that it would save them money in the long run to get it treated properly than to pay for years of ineffective treatment. We have provided some tips on how to get insurance companies to pay for treatment on our website, <http://austinoed.com>.

### *How does your intensive outpatient treatment differ from an inpatient or residential treatment program? Why would someone choose one over another?*

All forms of intensive treatment, whether outpatient, residential, or inpatient, are obviously going to be intense. We generally offer more individual therapy – up to 6 hours a day – and less in terms of groups, than inpatient or residential programs. And because we don't need a large support staff, such as 24-hour nurses, laundry, cafeteria, groundskeepers, etc., we can charge a lot less. A residential or inpatient setting would be a better choice if the person has significant potential for suicide or violence, or if they have a complicated medical or psychopharmacological picture that needs to be closely monitored over a long time.

Our children's program doesn't separate the child from their family, and focuses more than most other programs on training parents to deal effectively with their child's OCD.

One advantage to the outpatient nature of the AustinOCD program is that it allows people to enjoy their visit to Austin at the same time they're making progress in treatment. Even if someone is highly motivated to make a lot of progress, there's a limit to how much therapy anyone can do in any one day. Most people don't do the full 4 hours each day with the student intern; instead, they usually take only 2 1/2 to 3 hours. But then they might find some interesting places around town to do their homework exercises. We encourage people to take breaks from their therapy every day and on the weekends just to enjoy Austin, which is a college town, of course, also known as the Live Music Capital of the World, so there's always a lot going on for just about anyone's interests. ■

## Don't Forget!

## 15<sup>TH</sup> ANNUAL OCF CONFERENCE

August 1-3, 2008

Renaissance Boston Waterfront Hotel, Boston, MA

There will be workshops, presentations, support groups led by clinicians, investigators and people with OCD and family members. This Conference is designed for people with OCD, including children, adolescents and young adults, family members, and treatment providers.

For more information, go to [www.ocfoundation.org](http://www.ocfoundation.org)

## HELP THE OCF EXPAND GLOBAL OUTREACH

By Elaine Davis, Ph.D.

Email and the World Wide Web have made instant correspondence between individuals and organizations across the globe an everyday occurrence. The Obsessive Compulsive Foundation is no exception and our website widens our presence as it serves as an authoritative source of information on OCD for people around the world.

Our global presence became quite apparent to me when I had the privilege of helping to answer the foundation email last winter during the move from New Haven to Boston. It was gratifying to help people find resources and treatment providers or simply letting them know they were not alone in their struggle with OCD. However, there was one aspect of this task that I found frustrating: Many correspondents explained how grateful they were to find information about the correct medication protocols and the importance of ERP in effectively treating OCD, but they were often at a loss as to how to find treatment providers offering expert care in the country where they lived. In most cases, I was unable to guide them beyond providing advice on which questions to ask therapists in their local area to hopefully find one familiar with specialized OCD treatment techniques.

The medical literature makes it clear that there is a dedicated international group of researchers working to improve the quality of treatment for OCD. We can infer that treatment providers dedicated to treating people with OCD do exist in other countries. We have continued evidence that there are people seeking help from these mental health providers. We want to help bring these groups together for their mutual benefit by expanding the international list of OCD treatment providers.

We need your help. If you are aware of treatment centers or individual providers in foreign nations who provide specialized care for people with OCD, please forward any contact and related information to [info@ocfoundation.org](mailto:info@ocfoundation.org). OCF staff will reach out to these people to inform them about our organization and promote OCF membership. Any information that you can provide is greatly appreciated. With your help the OCF will take a big jump down the path of becoming a truly international organization. ■

### Bulletin Board

(Continued from page 2)

#### Key Exclusion Criteria:

Current medical or neurological problem that would make participation hazardous

#### Who is this study for?

For people with OCD who are not on psychiatric medications and who would like to help us answer the scientific question of whether their brain differs in this way from people without OCD.

#### Would you like to help understand the causes of OCD?

We are looking for people to participate in a study sponsored by the NATIONAL INSTITUTE OF MENTAL HEALTH.

The study will create a DNA collection from over 2,000 people to permit scientists to search for OCD-related genes. Identifying genes that contribute to OCD may lead to the development of better treatments for OCD.

#### YOU ARE ELIGIBLE FOR PARTICIPATION IF:

- You are between the ages of 18 and 60.
- You have been told by a doctor or other health professional that you have obsessions and compulsions.
- Both of your biological parents are alive and might be interested in also helping with the study.

#### IF YOU VOLUNTEER AND ARE ELIGIBLE:

- You will be interviewed about your personal and family mental health history. Interviews can be completed in your home or at our medical center.
- You and your parents will be asked to give a blood sample for DNA. This can be done in your home or at our medical center.
- Confidentiality is protected for you and your parents.
- Compensation is \$75 for a 2-3 hour interview and a blood draw

#### FOR MORE INFORMATION:

Please contact us at (212) 543-5364 or CUOC-GAS@gmail.com. If emailing, please include a phone number where we can reach you.

#### Maximizing Treatment Outcome in OCD IRB# 5188

Principal Investigator: Dr. H. Blair Simpson

To schedule a confidential screening, contact:

Jose Hernandez #212-543-5367 or Jessica McCarthy #212-543-5380

#### Overview of Study:

This study compares the effectiveness of two proven treatment strategies for OCD patients who are currently on a serotonin reuptake inhibitor (SRI, i.e., clomipramine, fluoxetine, fluvoxamine,

paroxetine, sertraline, citalopram, or escitalopram) but still have residual symptoms. Participants remain on their current medication and receive either cognitive-behavioral therapy (CBT) consisting of exposure and ritual prevention or an additional medication (risperidone). The goal is to compare these two augmentation strategies, each of which has been found effective in prior studies. All treatment is at no charge. Note: Patients who do not improve after 8.5 weeks of treatment will be offered at no-cost the treatment they did not initially receive (either the CBT or the add-on medication).

#### Key Eligibility Criteria:

- 18-70 years; both genders

#### Key Inclusion Criteria:

- OCD is the primary problem
- On a stable dose of a serotonin reuptake inhibitor

#### Key Exclusion Criteria:

- Medical or psychiatric conditions that would make study participation hazardous
- Patients who have already had an adequate trial of these augmentation strategies while on a serotonin reuptake inhibitor

#### Who is this study for?

OCD patients on medications who still have bothersome symptoms and who have not previously received an adequate trial of these proven augmentation strategies. ■

## Dissociative Disorder

(Continued from page 1)

She has no idea what happened to her except that one day she woke up and she did not feel herself. She questions her existence and wonders why everything seems so different. She obsesses over the way she feels all day long and although she can go through her day and do what she needs to everything is an effort.

John is a 40 year old man who has had feelings of depersonalization and derealization for years but episodically. The feelings could last from days to weeks to months and he does not know what triggers them. He suspects that it is usually preceded by extreme anxiety over various issues in his life. Every day is a struggle when he has these feelings of dissociation. He describes them as numbness, going through the day faking and not connecting to others or your environment. He similar to Jamie obsesses all day about how he feels and whether the feelings will go away. He behaves like a robot, doing the right things with extreme effort, but not really experiencing feelings of anger, sadness, happiness or for that matter any emotion. He only feels anxious and depressed over being dissociated and not being himself. His body and mind do not seem to belong to him. He can not think and his mind seems almost empty. He questions the meaning of his life.

Depersonalization disorder is characterized by persistent or reoccurring feelings of being detached from one's mental processes or bodily sensations. A disturbed sense of reality is often reported, with subjective experiences including: difficulty concentrating, feeling "spacey," difficulties with perceptual integration, doubt of autonomy of action, and detachment from private experiences (feelings, thoughts, urges, sensations, etc.). Intact objectivity and reality testing, in addition to organized thoughts/speech, distinguish symptoms of DPD from psychosis. Therefore, abnormalities of experiential integration cause a great deal of distress, as individuals with DPD are able to acknowledge disturbances and reflect

on previous functioning. Endless contemplation of the depth of current failures, as well as the possibility of chronic depersonalization preoccupies individuals diagnosed with DPD. Obsessive tendencies also relate to the philosophical and spiritual implications of DPD diagnosis. Predominantly obsessive individuals with OCD are more likely to have dissociative symptoms than less obsessive individuals. This supports a potential overlap in pathogenic processes. Cognitive tendencies of the typical DP disordered individual includes philosophical obsession, common to patients with OCD, and rumination on distress, associated with more depressive syndromes.

### Philosophical Obsessions

Philosophical obsession, a common symptom of OCD, is characterized by persistent, intrusive focus on the meaning of existence, theological issues, or personal purpose. Individuals with obsessive philosophical thoughts may muse over their own mortality, often communicating inner-turmoil related to some sort of existential dilemma. Content of philosophical obsessions is frequently very negative (e.g., "what is the purpose of living?" "why do we go on if we are simply going to die?" etc.), and thoughts reoccur in a relentless, nagging manner. This symptom is also commonly found among individuals with DPD, manifesting intellectual focus on distressing topics related to philosophical and existential concerns. A synthesized syndrome was proposed by Torch (1978), which identified qualities of the "intellectual obsessive depersonalization syndrome." This was originally observed among highly intellectual individuals, with a tendency to ruminate on the intrinsic meaning of things. Among individuals with DPD, the content of obsessions relates to symptoms of depersonalization, but also addresses greater philosophical matters (e.g. musings about the existence of a human soul; whether the depersonalized individual is lacking crucial components of the "self"; whether a person can thrive with a permanent sense of personal and spiritual emptiness, etc.). Clinicians and researchers

have acknowledged philosophical obsessions and other overlapping symptoms of OCD and DPD for over 50 years. However, a cohesive cluster of common symptoms has not been empirically-evaluated.

Reoccurring negative thinking is also used to describe cycles of rumination, but a distinction between rumination and philosophical obsession is made with regard to how the thinker responds to negative thoughts; individuals who are ruminating are troubled by the content of the thoughts, but rarely feel powerless to the thoughts, themselves. Individuals who are experiencing philosophical obsessions are very troubled by the persistence of negative thoughts, and often engage in some sort of mental or behavioral compulsion in order to neutralize the anxiety caused by the obsessions. This may also involve engaging in exhaustive efforts to answer existential questions, and this is something that negative ruminators are less motivated to do.

### Rumination on Distress

Again, philosophical obsession and rumination share qualitative similarities, with distinguishing characteristics relating mainly to response to and reflection on reoccurring thoughts. Both tendencies represent distinct contributions to the clinical profile of DPD. Rumination is understood to be a cognitive process of examination and reexamination of a distressing issue. While at first this process does not appear to be an avoidant, in nature (as the ruminating individual is actively acknowledging troubling matters), it is considered to be experientially avoidant (as contact with the present moment is lost). Ruminative distress is observed among individuals with DPD. High self-report of depersonalization was found to be associated with increased avoidance coping, increased use of passive coping behaviors, and increased rumination. It seems counterintuitive that an individual with impaired emotional/perceptual processing (and likely, feelings of "numbness") would be unable to abandon focus on discomfort. Many individuals with DPD report a loss of contact with their

emotions and the emotional weight of typically-evocative imagery. Similarly, a lack of certainty about their mood in the present moment is often acknowledged, as is impaired ability to recall emotions in previous situations. However, depersonalized individuals never lose an awareness of their faulty information-processing. The feelings of “emptiness” or “loss of soul” associated with this awareness is often a tragic point of focus, and rumination on this state is common. Thoughts such as, “I cannot live the rest of my life like this,” or, “this is so uncomfortable; I cannot tolerate this sensation much longer,” may characterize the ruminations of an individual with DPD.

Because depersonalization represents a learned aversion to strong emotions/sensations, individuals with DPD are preoccupied with experiential monitoring. However, a simultaneous discomfort is associated with the learned response, which is characterized by a disruption/misperception of experiential factors (short-term memory, sensory integration, sense of time, etc.). Therefore, obsessive focus is also devoted to acknowledgement of symptoms of depersonalization. Ultimately, this results in inordinate attention to internal information, representing a source of distress in and of itself. The individual with severe DPD is left with an almost chronic internal preoccupation and the ironic complaint that they cannot “feel.” Therefore, subjective characterization of cognitive elements of DPD may include ‘restlessness’ in addition to ‘numbness’. Relentless efforts to understand are distinctly obsessional, while preoccupation with negative thoughts relates more to rumination on distress. Therefore, it is important for clinicians to be aware that this profile of cognitive symptoms may be related to primary or comorbid feelings of depersonalization.

Fugen Neziroglu, PH.D. is a board certified cognitive behavioral psychologist who has written extensively on obsessive compulsive spectrum disorders for the past 25 years. She is Clinical Director of Bio-Behavioral Institute in Great Neck, NY and runs the intensive outpatient and inpatient OCD Spectrum Program. She is on the scientific board of the obsessive compulsive foundation. For further questions she can be reached at 516-487-7116. [www.bio-behavioral.com](http://www.bio-behavioral.com).

Katherine Donnelly, MA. is a psychology intern at Bio-Behavioral Institute in Great NY, and a doctoral student at Hofstra University, Hempstead, NY. She works under the supervision of Dr. Neziroglu and has been writing and treating individuals with obsessive compulsive spectrum disorders. She is currently running an OCD group utilizing Acceptance Commitment Therapy (ACT). She too can be reached at 516 487-7116. ■

## OCD Genetics Collaborative Update

*(Continued from page 3)*

been sent to the laboratory at MGH and are currently undergoing quality control prior to being genotyped at the Broad Institute. A brief update of this work was provided to the total group Friday evening and two of the five working groups met to work out the details of the analyses of the genotypic and phenotypic data. As a result of these working groups, some changes were made to the design of the GWAS that will be implemented immediately. Specifically, additional control samples will be added to the genotyping project to facilitate the ability to carefully match cases to controls from diverse ethnic backgrounds. Thus, approximately, 4,000 DNA samples will be genotyped for this GWAS and more than 3,000 control genotypes available from public databases will be used for the association analyses.

The final presentation on Saturday was by Dr. Robert Bilder, Chief of Medical Psychology – Neuropsychology at the Jane & Terry Semel Institute for Neuroscience and Human Behavior and Professor of Psychiatry & Biobehavioral Sciences and Psychology at UCLA. The title of Dr. Bilder’s presentation was “Phenomics: The Phinal Phrontier”. His presentation focused in the need to apply some of the same bioinformatics methods to understanding the complex psychiatric phenotypes that had been used in mapping the human genome. He provided a comprehensive overview of the software packages available at UCLA and funded as part of the NIH roadmap initiative.

On Sunday morning, the entire group met together to hear reports from each of the working groups. Each of the groups presented an outline of their discussions and a plan for continuing to work together throughout the year. Regular conference calls will be scheduled and it is anticipated that several “white” papers will be written to articulate what is needed to move research on OCD forward.

The final presentation was a proposal to create a rapid replication working group that would provide a forum to quickly replicate new findings in the literature. Membership in the group would require at least 50 full trios at the site. Altogether, 8 sites agreed to continue discussing the structure of this group and how it would work together.

As initiated last year, a poster session was held so that attendees could formally present their research to the group. Altogether, 20 posters were available for viewing and discussion.

### Significance

Several new collaborative groups have formed over the course of last year and the entire OCGC is continuing its work on the Whole Genome Association Scan. Clearly, the meetings have lead to additional collaborative work on the genetics of OCD and related conditions.

### Plans

Next year a similar conference event will be hosted by individuals at the University of Southern California. We will once again, bring together experts from around the world to discuss and plan the research on obsessive compulsive disorder. At least one guest speaker will be invited who can provide perspective and insight into methods of studying the disorder. The topics of the conference will be dependent upon the progress throughout the year and the status of the projects, but we anticipate focusing much of the time on the progress/results of the genomewide association study. All attendees will continue to give updates on their research via the poster session. We also expect to spend additional time discussing how to move projects forward expeditiously through continued collaboration. ■

## Effects of Hormones

(Continued from page 3)

The third case involved a 56 year old middle aged woman whose OCD first appeared 14 years ago shortly after undergoing a hysterectomy during which both ovaries were removed for the purpose of treating difficult migraine headaches. The onset of OCD was instant and severe following her hysterectomy, causing her to become homebound. For the past 14 years, she hasn't carried a pen for fear of harming others.

We have been treating patients with OCD for 16 years and are seriously dedicated to the best possible outcome while returning people to the fully functional level. Following this approach, both Professor Alexander Bystritsky, a fellow researcher, and I felt that the immediate involvement of Dr. John O'Dea, a Los Angeles-based endocrinologist, was essential in keeping with our progressive approach. Dr. O'Dea is a physician who thinks outside the traditional box and appreciates the wide impact of hormones on the mind and body. He took carefully timed blood samples from the three patients and discovered predictably low levels of estrogen and an exaggerated impact from the masculine hormones. And that is how it came about that these three people finally began to respond to therapy, as hormonal modification was introduced. These women had been seriously disturbed with OCD symptoms for years despite aggressive, even heavy-handed treatments with psychotropic medications along with cognitive-behavioral therapy and response prevention. Prior to this, their response to treatment has been minimal but now, working hand in hand with Dr. O'Dea, we discovered a huge difference in the response to the therapeutic process and the outcome of the treatment.

In one of the above cases no psychotropic medication was changed, in another one there was no psychotropic used at all (patient refused), and in one case the medication was slightly increased. In all three cases, intensive cognitive-behavioral exposure and response prevention techniques were implemented including writing and exercising mindful awareness.

All of the three cases improved during the 4-6 weeks of treatments, showed tremendous improvement in functioning up 90% with OCD symptoms bothering them only minimally by the end of the treatment. This is not to say that because of the hormonal interventions alone all of the cases were so greatly improved. Our

empirical research shows that our CBT program has overall success rate of 69% across the board. This experience may shed light that will allow us to approach each case individually and holistically rather than in a compartmentalized fashion. Just like snowflakes or diamonds, each case is unique, and needs a special approach and custom tailored treatment program for each individual, with re-assessment and changes to the program on the daily basis if necessary.

This short report looks only at three patients who are all due back for follow-up in six months. The emphasis of this report was to raise awareness about the importance of treating each individual client from multi-dimensional perspective. It is important to conduct a thorough medical history intake with every OCD client to make sure that no stone is left unturned and that an extensive team of multi-disciplinary specialists are assembled, and well fitted with each client. ■

## OCD in Children & Adolescence

(Continued from page 5)

brings relief to both the child and family, by 'demystifying' the symptoms. Since OCD tends to worsen during times of stress, the relief associated with receiving an accurate diagnosis and treatment plan alone may lead to decreased symptom severity.

Central tenets of OCD treatment are similar for childhood/adolescent and adult illness. These treatments include individual and family education, cognitive-behavioral therapy, cognitive therapy and medication management. Psychoeducation about OCD should include encouragement to minimize ritual frequency, family accommodation of symptoms and avoidance of places or activities that may trigger OCD symptoms. Although not formally studied, it is likely that families with OCD-affected children may be more inclined to attempt to 'rescue' the child from symptoms. Such behavior may include conducting rituals for the child, allowing the child to avoid triggers, and responding to excessive reassurance-seeking. Unfortunately, all of these actions lead to worsening rather than improvement of OCD.

The management steps beyond diagnosis and family education are to initiate cognitive-behavior therapy (CBT) and/or a serotonin reuptake inhibitor (SRI) medication trial. Sadly, a majority of OCD-affected children due not receive CBT as an initial part of their treatment plan. This

is likely due to the limited community and hospital availability of CBT clinicians who are experienced with OCD. Most children who do begin CBT treatment are able to complete this approach (75%), and up to 70% of those doing CBT experience at least some improvement. Of note, treatment with either relaxation training, or 'talking' (psychodynamic) psychotherapy alone have not been shown to improve OCD.

Serotonin-reuptake inhibitors, including selective serotonin-reuptake inhibitors (SSRI's), and clomipramine are effective OCD treatments for children/adolescents. Between 60-70% of patients have a satisfactory response during the first two SRI trials. This form of treatment frequently leads to decrease in symptom severity rather than a 'cure' from symptoms, however. In addition, recent suggestions that these medications may lead to suicidal thinking in a small group of children require that special monitoring takes place, especially when starting or increasing dosage. Predictors of good response to initial OCD treatment in children (with CBT and/or an SRI) include awareness of having OCD, fewer obsessions and compulsions, less severe obsessions, lower academic and functional impairment, lower accommodation-related parental stress and absence of disruptive behavior disorders.

## Summary

Obsessive-compulsive disorder is a mental illness that frequently affects children and adolescents. It may be under-recognized by parents, teachers and other caregivers due to the secretive nature of the disorder and its associated shame. Prompt diagnosis of OCD among affected children and adolescents is necessary to limit suffering directly resulting from OCD, in addition to the distraction from normal childhood development that this illness brings. Fortunately, progress is being made in understanding the genetic and biologic underpinnings of the disorder. These advances will ideally lead to improved approaches for preventing, treating and, eventually, potentially curing this common childhood disorder. ■

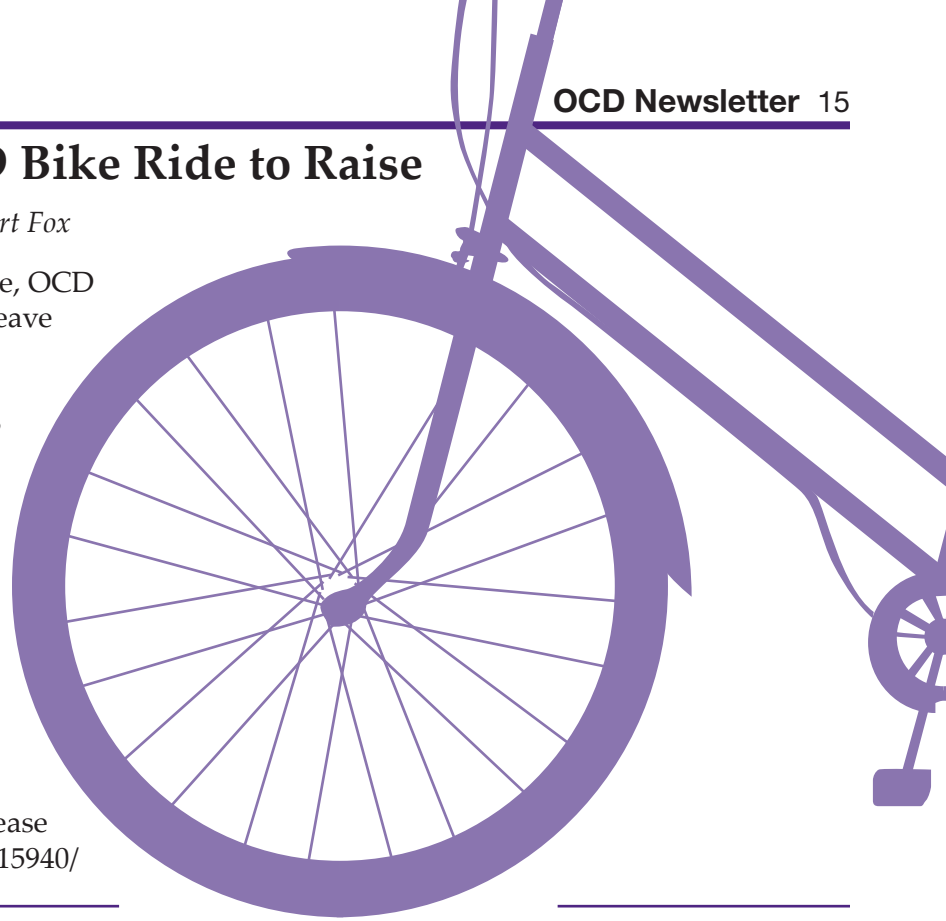
*SPECIAL NOTE: Researchers are very grateful to families who are willing to contribute to studies that aim to find the causes and best treatments for OCD. Some studies currently looking for interested OCD families (adults or children) include: the McIngvale MGH Longitudinal OCD At-Risk Study (1-800-CURE-OCD; 1-800-287-3623), the Genetic Family Study at MGH (1-800-471-2730) and the Obsessive-Compulsive Genetic Association Study (at U.S. centers in Baltimore 410-614-4942, southern CA 323-442-2542, L.A. 310-206-1350, N.Y.C. 212-543-5372, Providence R.I. 401-455-6608 and Boston 617-724-9505). Our coordinators welcome your questions and involvement!*

## Boston's First Annual OCD Bike Ride to Raise Awareness and Funds *By Robert Fox*

As you likely know from your own experience, OCD can be a very debilitating condition that can leave you sometimes feeling extremely frustrated, misunderstood and alone. Don't suffer in silence! Join us on Sunday, September 7, 2008 in Boston for this powerful opportunity to make a statement by coming together as ONE as we pedal our way to raise awareness and funds at this first ever event!

All pledges you obtain will go directly to the OCF to continue the critical research needed to help treat this condition. Volunteers are very much needed so even if you don't ride your help will be just as important!

To learn more, and to sign up for the Ride, please visit: <http://bike.meetup.com/207/calendar/8015940/>



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