

## Dr. Jenike Makes a Compelling Case for Funding Research

Hello,

It is time once again for me to perform my yearly ritual. The one where I beg, implore, and plead for your support for the OC Foundation Research Fund. Through its Research Fund, the Foundation supports research into the causes and treatment of OCD. We are also hoping that the new Genetics Collaborative that the Foundation has recently set up will discover innovative treatment approaches in the near future. The OCF has been able to raise money to support many of its programs (the newsletter, website, annual conference, Behavior Therapy Institutes, just to name a few) from various sources. But it depends entirely on you – people with OCD, family members, treatment providers and friends – to be able to fund its Research Awards Program.

Continued publicity about OCD and related disorders has greatly heightened awareness of these conditions, but only the sufferers and their families can understand

the true pain and disability that they cause. Every day I talk with patients who are suffering unrelenting, unspeakable anguish. I don't know of any other disorder where the sufferer experiences such excruciating mental pain.

As I have noted each year, the only way we are going to devise new and more effective treatments is through creative research. There are a finite number of talented researchers working on neuropsychiatric disorders. Out of necessity, they gravitate towards disorders where there is research funding available. Many young researchers throughout the world continue to approach me about whether or not significant funds will be available to help them study OCD and related disorders. They are interested in OCD; but they tend to go into areas where research funds are more easily obtainable. If we can provide funds for young investigators early on in their careers, they will then be able to

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## Relationship Between Body Dysmorphic Disorder and Social Phobia: Two Very Debilitating Disorders

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Body dysmorphic disorder (BDD) is characterized by an intense preoccupation with an imagined (or, if real, slight) bodily defect in a person with a normal appearance. Unfortunately for many professionals as well as for the general public, BDD is conceived of as a trivial or inconsequential disorder. This is far from the truth. BDD affects every aspect of one's life. The person is often very

depressed due to his limitations. BDD involves the shell of the individual (the body); and, therefore, one cannot run away from it. You carry your body with you at all times. The perceived defect typically involves the face (e.g., vascular markings, asymmetrical eyebrows, color or shape of teeth, elongated chin, shape of nose, etc.), skin blemishes, size of various body parts, muscularity, deformity of primary or secondary sex characteristics, etc. This preoccupation often leads to persistent checking behaviors (e.g., examining one's reflection in mirrors frequently or for lengthy

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## From The Foundation

Dear Friends,

It's the first week of November and we're in the midst of our move to New Haven. My office is even more of a maelstrom than it usually is. I'm milking the situation. For every important paper I've lost, misplaced phone number and unpaid bill (including those from my own homestead), I'm blaming it on the move. My answer to everything is: It's already packed up, including my phone. And, I'll be sealing myself up in a box soon. So, no, I won't be getting you whatever I promised you on time.

Besides being a colossal pain, moving gives you an excuse to look back. It's sort of a Proustian experience. Rather than the smell of Madelines bringing back memories, it's the stuff you retrieve from the bottom of desk drawers and behind the credenza that takes you back.

Yesterday, Jeannette found a folder that held a copy of our Application for Recognition as a 501 (c) (3) corporation. It was strange to see my distinctive scrawl all over it. I had completely forgotten that I had prepared it. A lot has happened since the group's first meeting in the Nurses Lounge at the Connecticut Mental Health Center on November 1, 1986. But the need that brought us together then is still the primary focus of the Foundation: finding effective treatment for everyone with OCD.

By the time, you're reading this, we will be settling in at 676 State Street in downtown New Haven. It's a homecoming of sorts. Our original place of business, besides the trunk of Ritchie White's car, was in New

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## Bulletin Board For Research Studies

### RESEARCH STUDY OF CBT FOR OCD AT THE ANXIETY DISORDERS CLINIC AT THE NEW YORK STATE PSYCHIATRIC INSTITUTE (NYSPI)

The Anxiety Disorders Clinic at the New York State Psychiatric Institute (NYSPI) invites you to participate in a research study of cognitive-behavioral therapy for OCD. Eligibility for participation in the research study includes: 1) currently diagnosed OCD; 2) current use of a medication for OCD; 3) some benefit from an adequate trial of this medication. Study participants will receive at no charge: 1) Exposure and Ritual Prevention Therapy or Stress Management Therapy (therapy will occur 2 times per week for 2 months at the NYSPI in Manhattan); and 2) Medication and Psychiatric visits. Responders will enter a 6-month maintenance phase after therapy. For more information and a confidential screening, please call: 212-543-5367 (IRB#3697).

### DO YOU HAVE OCD AND LIVE IN OR NEAR NYC?

If you are not on psychiatric medication, you may be eligible for a brain scan research study. The study's aim is to examine whether brain serotonin receptors are different in OCD patients than in those without OCD. The serotonin receptors will be measured using two investigational drugs and a special camera called PET. An MRI scan is also done. Subjects are compensated \$400 for their participation and offered two months of free treatment as needed. Please call the Anxiety Disorders Clinic at the New York State Psychiatric Institute for a confidential screening: 212-543-5367 (IRB#14729).

### OCD AND DEPRESSION

The Mayo Clinic OCD/Anxiety Disorders Program is seeking adults with OCD who are also depressed to participate in a treatment study. The purpose of this research is to examine the effectiveness of a comprehensive cognitive-behavioral therapy (CBT) program that addresses both depressive and OCD symptoms simultaneously. Participants will undergo a 16-session (twice-weekly sessions for 8 weeks) treatment program and receive follow-up assessments. Participants will be partially reimbursed for their participation.

**Who is eligible to participate?** If you are between the ages of 18 and 70 and suffer from OCD along with depression, you may be eligible. You also must be able to attend 16 sessions over 8 weeks at Mayo Clinic in Rochester, MN.

**Benefits for participants:** You may not receive any direct benefits from participating. However, it is possible that your OCD and depressive symptoms may improve from the CBT you'll receive. There is good evidence that CBT is helpful for both OCD and depression.

**Contact information:** The study is being conducted by Jon Abramowitz, Ph.D. and colleagues. Further information is available by contacting Dr. Abramowitz at 507-284-4431, or via e-mail: [abramowitz.jonathan@mayo.edu](mailto:abramowitz.jonathan@mayo.edu). This study has IRB approval and is being funded by the OC Foundation.

### OCD NEUROIMAGING STUDY

The Mayo Clinic OCD/Anxiety Disorders Program is seeking adults with OCD for a study on the effects of cognitive-behavior therapy on brain functioning. Eligible participants will receive 16 treatment sessions over 8 weeks (twice-weekly) and have "pictures" of their brain taken with an MRI scan before the first treatment session and following the last (16th session). Participants will also receive compensation for their participation.

**Who is eligible to participate?** If you are between the ages of 18 and 70 and suffer from OCD, you may be eligible. You also must be able to attend 16 sessions over 8 weeks at Mayo Clinic in Rochester, MN.

**Benefits for participants:** You may not receive any direct benefits from participating. However, it is possible that your OCD symptoms may improve from the CBT you'll receive. There is good evidence that CBT is helpful for OCD. You can also obtain a "picture" of your brain from the MRI scan.

**Contact information:** The study is being conducted by Drs. Stephen Whiteside, Jon Abramowitz and Jonathan Port. Further information is available by contacting Dr. Whiteside at 507-284-4431, or via e-mail: [whiteside.stephen@mayo.edu](mailto:whiteside.stephen@mayo.edu). This study has IRB approval and is being funded by the OC Foundation.

### GENETICS AND OCD

The Mayo Clinic OCD/Anxiety Disorders Program is seeking adults who have received successful or unsuccessful medi-

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**This newsletter is underwritten in part by a grant from Pfizer Pharmaceuticals, Inc.**

A COPY OF THE OFFICIAL FLORIDA REGISTRATION AND FINANCIAL INFORMATION OF THE OBSESSIVE COMPULSIVE FOUNDATION, A CONNECTICUT NON-PROFIT CORPORATION, MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE WITHIN FLORIDA 1-800-435-7352 OR 1-850-488-2221 IF CALLING FROM OUTSIDE FLORIDA. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE OF FLORIDA. THE OCF FLORIDA REGISTRATION NUMBER IS SC-09749. THE OCF DOES NOT HAVE A PROFESSIONAL SOLICITOR. ONE HUNDRED PER CENT OF EVERY CONTRIBUTION IS RECEIVED BY THE OCF. DONATIONS WILL BE USED TO UNDERWRITE THE OCF'S PROGRAMS, ACTIVITIES AND OPERATIONS AS WELL AS FOR RESEARCH.

## OCD NEWSLETTER

The OCD Newsletter is published six times a year.

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The Obsessive Compulsive Foundation (OCF) is an international not-for-profit advocacy organization with more than 8,000 members worldwide. Its mission is to increase research, treatment and understanding of Obsessive Compulsive Disorder (OCD). In addition to its bi-monthly newsletter, OCF resources and activities include: an annual membership conference; popular website; training programs for mental health professionals; annual research awards; affiliates and support groups throughout the United States and Canada; referrals to treatment providers; and the distribution of books, videos, and other OCD-related materials through the OCF bookstore; and other programs.

**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 or treatments mentioned with your treatment provider.



# All Tangled Up: When OCD Has Multiple Layers

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Multiple layers of OCD, or OCD that involves obsessing about the OCD treatment, is a phenomenon I see frequently. It contributes to patients' difficulties in treatment, yet often goes unrecognized.

Most readers of this article are well-acquainted with the reinforcement cycle that maintains OCD and the treatment interventions that disrupt the cycle. The reinforcement cycle consists of a "what if" obsessional thought followed by avoidance and neutralizing thoughts or acts that give fleeting relief but strengthen the anxiety-laden "what if." OCD treatment consists of cessation of neutralizing thoughts or acts, called Response (or Ritual) Prevention, and the challenging of behavioral avoidance, called Exposure. Treatment also emphasizes the acceptance of uncertainty about the obsessional "what if."

In addition to these concepts, there are fundamental assumptions about treatment that patients grapple with before engaging in a challenging treatment program. These fundamentals include assumptions about accuracy of diagnosis, best treatment options, and clinician competence. The second layer, or what I call the "meta layer," of obsessive worry focuses on these basic assumptions that are necessary for a patient to engage in treatment.

What follows are lists of common "what if" worries comprising the meta layer of symptoms. Obsessive worries regarding treatment outcome and the treatment itself include the following: What if therapy does not work? What if this is not the right medication? Is a behavioral or cognitive approach better? What if I am doing the exposure assignments incorrectly? What if I cannot do the treatment? What if I forget or misunderstand what the therapist said? Particularly challenging obsessive worries about the outcome of treatment include the following: What if I become suicidal from treatment? What if I do not get better? What if I have to live like this forever?

Obsessive worries about the accuracy of the diagnosis include the following: What if I am diagnosed with OCD erroneously? What if it (e.g., the contamination) is "real" (not OCD)? What if this time it is not OCD? What if my OCD is different? What if this ordinary behavior is OCD? Obsessive worries about the therapist include: What if the therapist does not have enough experience? What if he or she does not really care about me? What if the therapist does not really understand me, my symptoms, my situa-

tion, my culture, my religious beliefs, etc.? These lists are not exhaustive, but are some examples of the meta layer of obsessive worry.

Neutralizing thoughts and behaviors reinforce the "what if" worries about the assumptions necessary for treatment. Compulsive note-taking reinforces worry about forgetting what the therapist said. Patients directly or indirectly elicit reassurance about the correctness of their diagnosis and treatment approach and about the qualifications of their clinician. Patients scrutinize therapist behavior for evidence of genuine concern. Compulsively trying medication after medication can reinforce worry about taking the wrong medication. Patients struggle to perform exposure exercises perfectly. They analyze approaches to therapy, see several therapists simultaneously, and shop from therapist to therapist in an effort to find the right therapy. Self-reassurance, advice-seeking, and analyzing also reinforce obsessive worry about the assumptions necessary for treatment.

One reason the meta layer of obsessive worry goes unnoticed is that these concerns are reasonable. In contrast to the dramatic presentation of most obvious OCD symptoms, which patients usually experience as irrational or excessive, patients experience these worries and efforts to neutralize as reasonable. Clinicians also experience these questions from their patients as reasonable and respond with information intended to alleviate the patient's concerns. Unfortunately, by responding in this way without considering the obsessive nature of the worry, the clinician unwittingly reinforces the obsessive worry.

Another reason the meta layer is reinforced inadvertently is that clinicians are eager to explain and justify their treatment recommendations. They might also be eager to promote the superiority of their own skills, training, or approach. Although sometimes helpful, such explanations can reinforce a meta layer of obsessive worry about the adequacy of the treatment approach or about the competence of the clinician.

Even when the clinician recognizes the presence of a meta layer, she may find it uncomfortable to respond in a way that disrupts the cycle of obsessive worry. For example, imagine a patient who has obsessive worry that he will never have relief from severe symptoms. In order not to reinforce the worry, the therapist would need to resist the inclination to reassure the patient. Rather, the therapist would need to say something difficult, but honest, such as, "There is a chance that you will never have the relief that we both want you to have."

Another reason for difficulty in recognizing the meta layer is that the patient may not be disclosing this layer of symptoms. For example, the patient may fear insulting the clinician by expressing doubt about the treatment or about the clinician's qualifications. Because only the obvious OCD symptoms were the reason for seeking treatment, the patient may not recognize these worries as appropriate to discuss in treatment. Rather, the patient may be reassuring himself or seeking information or advice about the worries outside of therapy.

I give extra consideration to the possibility of a meta layer if my patient's symptoms are not improving or are getting worse no matter what exposure exercises we try. This can arise when the meta layer includes the compulsive need to perform the exposure exercises in exactly the right way. Sometimes, this need is associated with obsessive worry about not getting better. The problem here is that the exposure exercises for the obvious OCD symptoms have become a way of neutralizing the meta layer of obsessive worry about not getting better. In other words, the treatment of the obvious layer of symptoms is reinforcing the meta layer of symptoms.

I also consider the presence of a meta layer if both patient and therapist are trying hard but are feeling frustrated. When working as intended, Exposure and Response Prevention are not frustrating for the therapist or the patient. Therapy might feel frightening, upsetting, challenging, or exhilarating; but rarely frustrating. Frustration is a feeling that comes from engaging in the endless cycle that maintains OCD and obsessive worry. When the patient and therapist are feeling frustrated, the therapist may be unintentionally neutralizing the meta layer, causing the therapy to get all tangled up.

The general idea in therapy is to disrupt the reinforcement cycle of the meta layer of symptoms, together with the cycle of the obvious layer. A clear understanding of the reinforcement cycle shared by the therapist and patient is vital. "What if" worries and efforts to avoid and neutralize associated with the meta layer are identified. Identification of other "what if" worries that may be present is also helpful. The patient and therapist agree not to reinforce the obsessive worries. The therapist points out examples of reassurance questions and other efforts to neutralize, as they arise. The therapist will need to remind the patient gently of the importance of learning to accept uncertainty and of the reasons the therapist is not providing comforting, neutralizing responses. This cessation of neutralizing is Response Prevention for the meta layer of obsessive worry about the treatment. Making decisions about one's own treatment in spite of uncertainty is Exposure for this layer.



# BDD & Social Phobia

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time periods), camouflaging (e.g., attempting to hide the perceived defect from others by covering the facial "defect" with one's hair, or elaborately arranging one's clothing, covering mouth, etc.) and avoidance of social situations in which others might observe one's perceived flaw.

## Understanding Body Dysmorphic Disorder

While BDD is currently categorized as a somatoform disorder, both theory and research suggest that BDD might be better conceptualized as an obsessive-compulsive (OC) spectrum disorder (Neziroglu & Yaryura-Tobias, 1993). This conceptualization was an outgrowth of similarity of symptoms between OCD and BDD and similar cognitive behavioral and pharmacological treatment response. However, recently there has been more evidence for the link between BDD and OCD based on a morphometric magnetic resonance imaging (MRI) study (Rauch, Phillips, Segal et al., 2003). The study involved comparing regional brain volumes in eight women with BDD and eight healthy participants. The BDD group exhibited a relative leftward shift in caudate asymmetry and greater total white matter versus the comparison group. These findings in regard to the caudate nucleus are consistent with both conceptualization of BDD as an obsessive compulsive spectrum disorder, and the striatal topography model of OCD.

Although the community prevalence rate of BDD is still a matter of debate, data seem to suggest that BDD affects approximately 2% of the general population (Rich, Rosen, Orosen, & Reiter, 1992). Moreover, reports from mental health settings suggest that BDD is present in 5% to 40% of those presenting with an Anxiety or Depressive disorder (American Psychiatric Association, 2000). Studies show that BDD appears to be distributed equally among men and women. Although it seems to usually develop during adolescence, BDD can arise anytime dur-

ing the life cycle, occasionally manifesting itself after failed plastic surgery.

BDD is often comorbid with OCD, social phobia, major depressive disorder (Phillips, Gunderson, Mallya, McElroy, and Carter, 1998), and personality disorders. In fact, Perugi et al. (1997) claim that BDD is almost never experienced in isolation from other psychological disorders. One fairly recent study (given the slow development of the literature) suggests that OCD may be present in 94% of patients displaying BDD (Neziroglu, McKay, Todaro, and Yaryura-Tobias, 1996). These authors further suggest that social phobia may be present in approximately 18% of BDD patients. While treatments for OCD have been applied to BDD, current treatments have not typically taken patients with both BDD and social phobia into account.

## Understanding Social Phobia

Social phobia (SP) is a pattern of excessive concerns that typically are related to the fear of scrutiny by others and/or social interactions, as well as a habitual avoidance of social situations. Individuals with SP often miss important social occasions (e.g., weddings, business meetings, etc.) due to their concerns. Mattick and Clarke (1998) suggest that SP consists of two dimensions. The first is a fear of social scrutiny (i.e., an intense fear of what others might think about one's presentation, style, appearance, etc.). The second dimension, according to Mattick and Clarke, is a fear of social interactions (e.g., feeling unable to properly carry on a conversation, a date, etc.). People suffering from SP may display difficulties in only one dimension or in both. BDD sufferers often display similar concerns, particularly in regard to social scrutiny.

## Distinctions Between BDD and Social Phobia

As stated above, BDD and SP often present as comorbid conditions. Nevertheless, distinctions can be

made between the identifying markers of each disorder. Although patients suffering from BDD and/or SP often verbalize similar concerns (e.g., "I'm not good enough," "Everyone will notice my deformity or inabilities."), some evidence has accumulated to distinguish between the two conditions. Both current research (e.g., Veale, Kinderman, Riley & Lambrou, 2003) and clinical experience seem to suggest that the core concerns of social phobics and patients with BDD differ. It is reasonable to suggest that patients displaying BDD are concerned with social scrutiny by others, particularly in regard to their "defect." However, BDD patients are more concerned with satisfying their own internal demands of "perfection" and "beauty" than they are of winning other people's approval. This last statement may seem counter-intuitive to the family and friends of BDD sufferers, because BDD patients tend to often seek reassurance from others that their particular "defect(s)" are "OK" or "not too noticeable." Yet, such reassurance does little for the BDD sufferer, other than reinforce their future reassurance-seeking behavior. That is, because the BDD sufferer is truly concerned about measuring up to his or her own ideal, no amount of reassurance from family or friends can ever be enough. Rather, reassurances by family or friends merely abate the BDD sufferer's anxiety about his or her appearance for a short time and in the end leave him or her more likely to seek such assurances in the future. (Author's [MR] note: I have found a particularly effective response to reassurance-seeking questions about appearance to be, "You look like you did yesterday" and in response to further concerns, "You look exactly like you will tomorrow.") If this does not work, you can always just tell the person that you will not reassure since it merely perpetuates the disorder and you want to help. Just a brief reminder: SP may appear as a condition comorbid with BDD.

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# The Newsletter Interviews the Info Specialists at the Obsessive Compulsive Information Center

*An interview with Maggie Baudhuin, M.L.S., and Bette Hartley, M.L.S., information specialists, about the Obsessive Compulsive Information Center at the Madison Institute of Medicine.*

## NEWSLETTER: What is the Obsessive Compulsive Information Center?

**OCIC:** The Obsessive Compulsive Information Center, which we refer to as OCIC, is a comprehensive resource for information on OCD and related disorders. Currently, the Center has over 20,000 references on file and we add approximately 1,000 new references each year. Information is available on all aspects of OCD. You can think of us as a clearinghouse for OCD information. We collect the information, archive it for future use and disseminate it.

## NEWSLETTER: When was the OCIC started?

**OCIC:** Founded in 1990, the OCIC was modeled after our Lithium Information Center. That Center began in 1975, soon after lithium received FDA approval as a treatment for bipolar disorder (manic depression). In recent years, we have expanded our services to include information on all treatments of bipolar disorder; and currently there are over 35,000 references on file with our Lithium and Bipolar Disorders Treatment Information Centers.

All three of our Centers, as well as other activities of the Madison Institute of Medicine, are the inspiration of our founders, Drs. John Greist and James Jefferson, who, along with Dr. David Katzelnick, are also the Centers' Directors.

## NEWSLETTER: How have Drs. Greist, Jefferson and Katzelnick been involved in the field of OCD research and treatment?

**OCIC:** Together, our directors have authored more than 300 papers on OCD and its treatment. OCD, as well as other anxiety disorders, has been a main area of interest of theirs for many years. Highlights of their research include drug treatment studies and the development and application of computer programs in the assessment and treatment of OCD. Both Drs. Greist and Katzelnick have presented at the OCF Annual Conference in the past; and Dr. Greist was the keynote speaker at the Conference in St. Louis in 1998.

## NEWSLETTER: What kinds of information about OCD does the OCIC offer?

**OCIC:** Information is available on all aspects of OCD including diagnosis, prevalence, possible causes, comorbidity with other illnesses, and treatments including medication, behavior therapy, cognitive therapy, neurosurgery and combined treatments. We have information on OCD in different age groups – young children, ado-

lescents, adults, and the elderly. These are well-researched topics that we have substantial information on. We also have information on more obscure and less-researched topics, such as, hypnosis, yoga and nutritional supplements in the treatment of OCD, and information on OCD with other illnesses, such as, Huntington's disease, Lyme disease and epilepsy.

## NEWSLETTER: Does the OCIC have information on the OC spectrum disorders?

**OCIC:** We do collect information on disorders considered by many to be part of the OC spectrum. These disorders include trichotillomania, body dysmorphic disorder, hypochondriasis, compulsive shopping, and compulsive skin picking. We attempt to collect all information about the disorders that are considered to be part of the spectrum.

Many other disorders are often considered to be related to OCD, based on obsessive or compulsive features of the disorder. Examples include compulsive exercise, compulsive gambling, compulsive sexual disorders, and certain impulse control disorders. If an article on any of these disorders makes a reference to a compulsive or obsessive feature or behavior, we will add the article to our database. We also include articles about compulsive, repetitive behaviors in patients with Tourette's Syndrome, autism, and eating disorders. Thus, we have some information on certain related disorders; but we do not have complete literature collections on them.

We do attempt to collect all information about Obsessive Compulsive Personality Disorder (OCPD) and do have a comprehensive collection of literature on this particular personality disorder.

## NEWSLETTER: What types of reference material are in the OCIC database?

**OCIC:** Any and all information we can locate on OCD and spectrum disorders is collected. We are not limited to specific journals, languages or formats. Our database includes references to articles from medical journals, newspapers, Internet sources and popular magazines, and to books, book chapters, government documents, meeting proceedings, unpublished manuscripts, pamphlets and other sources. All references are entered into our database and can be searched and retrieved by author name, title, abstract or key words (index terms), publication name and year of publication.

## NEWSLETTER: Can you explain more about the information you have available on medications used to treat OCD and OC spectrum disorders?

**OCIC:** We collect literature on medications and combinations of medications that are commonly

used to treat OCD. For instance, we have articles on clinical trials of medications, including trials that were used to gain FDA approval of the medications. We have many articles on file that review the various anti-obsessional medications currently available, and many case reports involving medication use. We have articles discussing medication side effects and possible ways to manage these side effects. Also, we collect information on non-approved, newer medications that are currently being studied in the U.S. and other countries and on nonprescription, over-the-counter products that have been tried, such as, inositol and St. John's wort.

## NEWSLETTER: Does the OCIC have research material on behavior therapy for OCD?

**OCIC:** Since behavior therapy is a very well-researched and proven effective treatment for OCD, it is not surprising that we have well over 3,000 references on file on this topic. A list of 3,000 plus references is not very helpful for most individuals. But we can limit a search on behavior therapy to any subtopic or specific aspect of this treatment. For instance, we can quickly locate information on optimal session length, individual versus group therapy, and self-help techniques. We can also limit any search to the most recently published articles on a topic. In addition to behavior therapy alone, we have many articles on combined cognitive-behavioral therapy and also articles that discuss the use of cognitive therapy alone.

## NEWSLETTER: Tell us more about the kinds of OCD related questions your staff can answer?

**OCIC:** Any question related to OCD or an OC spectrum disorder can be directed to us. Often we can answer questions over the phone or by e-mail. Sometimes we will need time to research an answer to a question; and then we can either return a call or send information by mail, fax or e-mail.

Examples of commonly asked questions are information about OCD in general (how it is diagnosed, how common it is, how it is treated), and OCD in different age groups, such as, very young children or elderly patients. We also receive many questions about OCD subtypes or spectrum disorders, such as, hoarding, scrupulosity, body dysmorphic disorder, trichotillomania and compulsive skin picking. We can answer questions related to any reported treatment for OCD including specific medications. Any question, be it very specific or general, can be directed to us at the OCIC.

## NEWSLETTER: What advantages do you offer over other database searching, such as, the National Library of Medicine's MEDLINE?

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# Research Digest

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

*The following is a selection of the latest research articles on OCD and related disorders in current scientific journals.*

## Obsessive-compulsive symptoms in pregnancy and the puerperium: a review of the literature

*Journal of Anxiety Disorders, 17:461-478, 2003, J.S. Abramowitz, S.A. Schwartz, K.M. Moore et al.*

Studies and reports of OCD beginning or worsening during pregnancy or during the time immediately following childbirth (also referred to as postpartum or puerperium) are reviewed. The literature suggests OCD occurs at a higher than expected rate in the postpartum period. Interestingly, content of obsessions tends to vary. Women developing OCD symptoms during pregnancy tend to report contamination obsessions, while women developing OCD symptoms after childbirth tend to report obsessions of harming the child. Obsessional thoughts of harming the newborn are also common for women with postpartum-onset depression. The differences between OCD and postpartum depression or postpartum psychosis are discussed. Although little researched, the recommended treatments for postpartum OCD are the same as for OCD occurring at other times – serotonin reuptake inhibitors (SRIs) and/or cognitive-behavioral therapy (CBT).

## Connections among symptoms of obsessive-compulsive disorder and posttraumatic stress disorder: a case series

*Behaviour Research and Therapy, 41:1029-1041, 2003, B.S. Gershuny, L. Baer, A.S. Radomsky et al.*

The relationship between traumatic events, posttraumatic stress disorder (PTSD) and OCD is explored. Case reports of 4 individuals having both PTSD and treatment-resistant OCD are presented. In these cases, traumatic experiences occurred before the onset of OCD and there was a relationship between symptoms of both disorders. When symptoms of OCD lessened, symptoms of PTSD increased and vice versa. Behavior therapy (BT) is an effective treatment for both disorders. However, exposure-based BT for one disorder did not generalize to the other disorder in these patients. Exposure therapy for OCD tended to worsen the trauma-related fears and habituation to the OCD-related obsessions did not occur. Researchers recommend an assessment of trauma history and PTSD for patients referred for OCD treatment.

## Cyclothymic OCD: a distinct form?

*Journal of Affective Disorders, 75:1-10, 2003, E.G. Hantouche, J. Angst, C. Demonfaucon et al.*

Surveying 175 outpatients from a psychiatric clinic and 453 of their members, a French OCD Association explored the frequency with which individuals with OCD also experienced mania, hypomania or depression. Bipolar disorder (manic-depression) was identified in 11% of these OCD patients. These patients with comorbid bipolar disorder were termed cyclothymic OCD patients. Based on information collected in the survey but unconfirmed by face-to-face interviews, a comparison was made between cyclothymic OCD and non-cyclothymic OCD. Cyclothymic OCD patients had a greater severity of disease (based on a greater number of psychiatric admissions), higher risk of suicide attempts and a greater number of manic or hypomanic episodes. Most importantly, the cyclothymic OCD patients had a less favorable response to serotonin reuptake inhibitor (SRI) medications, along with a higher rate of mood switching (manias induced by the SRIs). Early recognition of cyclothymic OCD is important because this will help in selecting medications. Mood stabilizers and/or atypical neuroleptics could be used along with SRIs to protect against mania.

## Obsessive compulsive disorder in the workplace: an invisible disability

*Women and Therapy, 26:169-178, 2003, A. Neal-Barnett and L.L. Mendelson*

Interesting case studies, including a court case, are used to illustrate points in this discussion of OCD, women and jobs. Lower job performance, absenteeism and other difficulties often occur for those with untreated OCD. Even though OCD is a treatable mental disorder, it is still classified as a disability according to the Americans with Disabilities Act. Even with treatment, other support and job accommodations may be needed for successful employment. The authors conclude "If a woman with OCD knows what type of work she wants to do, what type of work she loves, and has insight into her OCD, with support, appropriate accommodations, and a sense of empowerment, she will succeed."

## WCA recommendations for the long-term treatment of obsessive-compulsive disorder in adults

*CNS Spectrums, 8(suppl 1):7-16, 2003, J.H. Greist, B. Bandelow, E. Hollander et al.*

Based on proceedings from the World Council

of Anxiety meeting held September 2000 in Italy and on published literature through October 2001, recommendations for the treatment of OCD were compiled. Both psychotherapy and drug therapy, separately or combined, are recommended. For psychotherapy, experts recommend the combination of behavior therapy (exposure and ritual prevention) and cognitive therapy. For drug therapy, experts recommend starting with selective serotonin reuptake inhibitors (SSRIs), i.e., fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), sertraline (Zoloft) or citalopram (Celexa). A minimum of 1-2 years of drug therapy is recommended before a very gradual withdrawal of medication is considered.

## Approaches to common obstacles in the exposure-based treatment of obsessive-compulsive disorder

*Cognitive and Behavioral Practice, 10:14-22, 2003, J.S. Abramowitz, M.E. Franklin and S.P. Cahill*

Suggestions are given for handling common problems during behavior therapy (BT) for OCD. In particular, suggestions are made to help gain patient acceptance of and compliance with exposure and ritual prevention. Patient education helps: it is normal to have intrusive thoughts – 90% of the general population has unwanted thoughts; confronting thoughts will lessen anxiety – *suppressing thoughts* actually causes an *increase* in the thoughts; learn to be comfortable with uncertainty as in non-OCD situations – 100% certainty is not possible; and thoughts are not equal to actions – thinking a bad thought will not cause it to happen. Issues and ways to manage excessive reassurance-seeking behavior are addressed, e.g., when and how to appeal to experts about safety issues. Lastly, tips for implementing BT and use of both specific homework exercises and general everyday opportunities for exposure and ritual prevention are discussed.

## Cognitive-behavioral group therapy in obsessive-compulsive disorder: a randomized clinical trial

*Psychotherapy and Psychosomatics, 72:211-216, 2003, A.V. Cordioli, E. Heldt, D.B. Bochi et al.*

Forty-seven patients with OCD were randomly assigned to either 12 weekly cognitive-behavior therapy (CBT) sessions or a waiting list (control group). Group treatment was used, both because it has been suggested to enhance adherence to CBT and because it is a less cost-



## Research Digest

ly format. Hopefully, if group CBT was found effective, it could become more available to a greater number of patients. In addition to studying the effectiveness of group CBT, a secondary goal was to study its effectiveness in reducing the intensity of overvalued ideas and improving quality of life. CBT improved OCD in 69.6% of patients. The improvement was maintained and an additional reduction in symptoms was observed during the 3-month post-treatment follow-up period. Additionally, CBT in a group setting was effective in reducing the intensity of overvalued ideas and improving quality of life. Only one patient dropped out of the CBT group, a lower than expected number of dropouts. Researchers speculate that the group format may increase patients' motivation to do behavior therapy and adhere to treatment.

### Telephone-administered cognitive behavior therapy for obsessive-compulsive disorder

*Cognitive Behaviour Therapy, 32:13-25, 2003, S. Taylor, D.S. Thordarson, T. Spring et al.*

Cognitive behavior therapy (CBT) is an effective treatment for OCD. However, many individuals with OCD do not have access to CBT because of a shortage of therapists who provide CBT and because most of these few therapists work in urban areas. This study evaluated an alternative method of delivering CBT, using the telephone. Along with a treatment manual, 33 individuals with OCD received 12 weekly 45-minute telephone-administered sessions of CBT. Response was similar to that reported with face-to-face behavioral treatment. Patients with major depression were excluded from the study, so it is unknown if it would also be effective for individuals suffering both OCD and depression. These results suggest that telephone-administered CBT is effective for individuals with OCD and would be an alternative method to deliver CBT for people living in more remote regions or for whom it is impractical to get to a therapist's office.

*This result is not surprising as the benefit from exposure and ritual prevention, the key elements of CBT, occurs not because of office visits with a therapist. Rather, the benefit comes when patients carry out exposure followed by ritual prevention for their obsessions and rituals in the settings where obsessions and rituals occur outside therapists' offices! (JHG)*

## Ridding The Home of OCD

**William M. Gordon, Ph.D.**  
**Private Practice, Upper Montclair, NJ**

OCD rituals and compulsions often are most severe in the privacy of one's own home. While they occur throughout the day in many different situations, the home turf is often the most problematic. Hair pullers, for example, usually do the most damage at home – not at work. Likewise, many symmetry, repeating, and checking rituals occur more frequently at home than anywhere else.

What is it about the home that allows for more ritualizing? Although some families do engender high stress, for most people the home environment is less stressful than work or other situations. Yet the OCD is worse at home.

I believe that certain characteristics of the home environment inadvertently facilitate obsessive symptoms. We often feel that our home is our castle. At home we can do whatever we like. We don't have to worry about how others view our behavior. We can do bizarre things without feeling embarrassed. No one's watching, except maybe other family members. And who cares what they think? They already know about our idiosyncrasies.

Additionally, time constraints and responsibilities often are less at home. Especially for single people, there is far less accountability at home than at work. Chores can be put off. Time can be wasted. Rituals can then be indulged in.

This relative lack of accountability and increased privacy allow OCD rituals to run unchecked. OCD gobbles up free time. It turns free time into OCD time. Some OCD sufferers may feel that they have earned the right to ritualize after a hard day's work. They may just want to relax and let it all out. We know, though, that a little ritualizing only produces more ritualizing and ultimately more stress. As with addictive behaviors, performing a few rituals usually increases, rather than decreases, the desire to do more. (Delaying the ritual, though, is an effective way of lowering the urge to do it.)

We are faced with a dilemma. A warm, indulgent home environment allows OCD to flourish, which then turns our cushy castle into a hellish prison. How do we deal with this situation? How do we maintain a warm, relaxed home environment without giving a green light to OCD? The answer lies in learning how to be loving and firm with ourselves. Dr. Tamar Chansky addresses this issue for parents of children with OCD in her excellent book, "Freeing Your Child From Obsessive Compulsive Disorder." How, though, can we apply this firm, loving attitude towards ourselves in our own homes?

A good place to start is to get accurate data on how much time you spend ritualizing at home. Buy a stopwatch. As soon as your OCD kicks in, start the watch. When you stop obsessing, turn it off. At the end of the day, record the

total amount of time you spent obsessing at home. Do this for a week. You'll be amazed at how much time you wasted. Think about specific things you could do with that extra time. *P.S. Don't give time estimates. Using the watch increases self-awareness, which is the necessary first step in changing behavior.*

Next, schedule in a 20-30 minute block of time when you can do your exposure and response prevention (ERP) exercises. Reward yourself by engaging in some pleasant activity after you complete the exercises, e.g., watch a favorite TV show or listen to some music. Remember that ERP only works if you do it. Building in incentives helps you to do it consistently.

Try to isolate OCD in a small area of the house or apartment. For example, if you obsess a lot, do it only in one room. (Pick a room that's not too comfortable.) Establish other areas in the house that are OCD-free zones. Never obsess in these areas. Gradually expand the OCD free zones. Isolating the OCD will reduce your desire to engage in it.

Notice which activities trigger OCD. For example, some people obsess and ritualize a lot while talking on the phone or watching TV or laying in bed. Whenever you obsess on such occasions, interrupt the activity. If you catch yourself ritualizing during a TV show, turn off the TV for one minute, stop ritualizing, and only then turn it back on. Repeat this process whenever necessary. If you obsess in bed, get out of bed briefly, stand for a minute without obsessing, and then return to bed. One patient of mine has a compulsion to run in the house from one location to another. Whenever this happens, he now has to either crawl back to the starting point or else run a block outside. All of these tactics penalize the OCD. They also uncouple the association between the activity and the tendency to ritualize. Neuroscientists note that "neurons that fire together, wire together." We want to break those neural connections between OCD and certain places and activities.

Invite friends and coworkers to your house often. Their presence might inhibit your ritualizing. Establishing some precedent for being in the house without ritualizing might make it easier to avoid ritualizing even when they are gone. Make a commitment to avoid ritualizing for at least 10-20 minutes after they leave. Then make it longer.

Finally, plan your free time so that you do rewarding, enjoyable activities. Don't sit around the house doing nothing. OCD loves a behavioral vacuum. Pleasant activities, especially with other people, improve your mood and prevent OCD from infringing on your time. If you are not working, consider a part-time job, volunteer work, or classes at a local college or adult school. By filling your day with meaningful activities, you help to crowd out OCD. All of these tactics help to minimize OCD and make your home life more rewarding.



## OCIC Interview

(continued from page 5)

**OCIC:** To begin with, we try to locate everything in the literature that pertains to OCD. In addition to the technical and research literature you can find in large bibliographic databases such as MEDLINE, we reference things that are often not found in other databases including books, book chapters, pamphlets, patient information materials, meeting proceedings, and articles from newspapers, newsletters, and popular magazines. We include all clinical and research materials we are able to locate and do not limit what we collect to only certain medical journals. It is important to note that we reference articles from the OCD Newsletter, which we feel are some of the most useful patient-oriented materials available.

Index terms used by large bibliographic services are often too general when dealing with a specific subject area. We index articles using very specific terms that are generated by information requests. For example, people are often looking for reports that relate directly to their specific obsessions or compulsions, so we make a point of adding specific key words that will help us quickly retrieve such reports. Thus, our index terms include: "AIDS, obsessions with," "Electrical accidents, obsessions with," "Computers, compulsive use of," and so on — terms you would never find in a larger, more general database.

There are also subtypes of OCD that cannot be easily identified in larger databases. We add keywords that allow us to quickly locate papers on specific subtypes, such as, "obsessions without compulsions," "cognitive rituals" and "sub-clinical OCD." Our indexing is also more current; and we can quickly create new index terms as needed. Examples include "PANDAS" (pediatric autoimmune neuropsychiatric disorders associated with strep) and "Deep Brain Stimulation."

To summarize, our services are designed to help the user find the specific information that is needed in an efficient manner by maintaining a comprehensive literature collection in which very specific subtopics are easily located.

**NEWSLETTER:** What other services does the OCIC offer?

**OCIC:** In addition to answering information requests on any OCD-related topic, we maintain therapist, specialty clinic and support group referral lists. We have referral listings for physicians, psychologists and behavior therapists in most of the 50 states and some locations in Canada and other countries. In addition, we keep a listing of available patient support groups and try to update it on a regular basis. Anyone looking for a therapist or support group can contact us for referrals.

We have a Literature Update Service available to clinicians, researchers and anyone else want-

ing to keep up with the latest publications on OCD. For an annual subscription fee, the user is provided with a monthly listing of all new references added to our OCIC database within that time period.

At national and local meetings we set up educational exhibits for consumers and professionals. Also, our directors give presentations around the U.S. to clinician and patient advocacy groups. These are some of the ways we strive to educate the public and get up-to-date information into the hands of those who need it.

**NEWSLETTER:** Do you publish any books?

**OCIC:** We do publish a number of patient information booklets on various disorders and treatments. Currently we have 17 booklets in our series that are revised and updated on a continuous basis. The series includes Obsessive Compulsive Disorder: A Guide by John H. Greist, MD, Obsessive Compulsive Disorder in Children and Adolescents: A Guide by Hugh F. Johnston, MD and J. Jay Fruehling, MA and Trichotillomania: A Guide by Jeffrey L. Anders, MD and James W. Jefferson, MD. We have also published booklets on ADHD, Depression, Panic Disorder, Posttraumatic Stress Disorder and Social Anxiety Disorder. A complete listing can be found on our website: [www.miminc.org](http://www.miminc.org).

**NEWSLETTER:** For whom do you do searches and provide information? Can a layperson request a search or information?

**OCIC:** Anyone is welcome to contact the Information Centers. Originally, we believed that healthcare providers would be the largest group seeking information. Instead, we find that requests come in almost equally from laypersons and healthcare professionals. Often the information we send out is very technical, so we encourage patients to discuss the information with their clinician or therapist.

Physicians, psychologists, researchers, social workers, nurses, pharmacists, and attorneys, and patients and their families and friends are examples of some of the individuals who contact us.

**NEWSLETTER:** Are there charges for your services? What are they?

**OCIC:** As part of a not-for-profit organization, the OCIC depends on nominal user fees and contributions for support. A minimum fee of \$10.00 is charged for each computer search, with most searches costing between \$10.00 and \$20.00. There is no charge for quick reference questions answered by phone or e-mail, or for referrals. Single copies of articles (subject to copyright law) are available for 25 cents per page, plus postage. The current annual fee for our Literature Update Service is \$75.00 (e-mail) and \$150.00 (U.S. mail).

**NEWSLETTER:** Who does the research and answers the questions?

**OCIC:** We (Maggie and Bette) conduct literature searches and answer questions. Also, all papers entered into our library database have been read and indexed by the two of us.

Together we have over 40 years of experience working at the Information Centers.

Micki Thren oversees all patient booklet orders and Trudy Lorandos handles literature acquisition and bibliographic database entry for our Centers.

You might speak with any of us if you call, since we all answer basic questions involving our services, referrals, book orders, etc. Technical research questions are referred to Maggie and Bette.

**NEWSLETTER:** What is Madison Institute of Medicine's (MIM) mission?

**OCIC:** By providing the most up-to-date information and promoting the education of patients, families and healthcare professionals, we at MIM work to improve the recognition and treatment of mental health disorders.

**NEWSLETTER:** Do you offer information on the Internet?

**OCIC:** Our website, [www.miminc.org](http://www.miminc.org), provides information about our organization, its services and publications. This site can also be used to order materials from us.

Since 2000, we have been developing another website, [www.FactsForHealth.org](http://www.FactsForHealth.org). At this time, the site has information on Alzheimer's Disease, Posttraumatic Stress Disorder, Premenstrual Dysphoric Disorder and Social Anxiety Disorder. The site is free to the public and has been developed exclusively with the support of grants to the Madison Institute of Medicine. Highlights include in-depth information on each disorder, on-line diagnostic screening tests and searchable referral databases.

With additional financial support we would like to expand this website to cover other disorders, such as, OCD, Generalized Anxiety Disorder, Depression and Bipolar Disorder, and continue to apply for grants that will help us reach these goals. Developing and maintaining subject-specific information centers such as our OC Center is a huge undertaking and very costly. Our FactsForHealth website provides another, less expensive, but extremely useful way of disseminating important information to those in need. We certainly plan to maintain our current information centers, but also plan to expand our web-based services.

**NEWSLETTER:** How can someone contact your Center to obtain information or learn more about your organization?

**OCIC:** To talk with an information specialist, request a literature search or order patient information booklets, we can be reached by phone between 8:30 a.m. and 5:00 p.m., Central Time, Monday-Friday. Requests for information can also be mailed, faxed or emailed to us at: Information Centers, Madison Institute of Medicine, 7617 Mineral Point Road, Suite 300, Madison, Wisconsin 53717; Phone: 608-827-2470; Fax: 608-827-2479; E-mail: [mim@miminc.org](mailto:mim@miminc.org); Websites: [www.miminc.org](http://www.miminc.org); [www.factsforhealth.org](http://www.factsforhealth.org).



## A Review of "Treatment of OCD in Children and Adolescents: A Cognitive-Behavioral Therapy Manual" by Aureen Pinto Wagner, Ph.D.

Review by Martin Franklin, Ph.D.

*Dr. Franklin is a researcher and clinician at the Center for the Treatment and Study of Anxiety, University of Pennsylvania School of Medicine.*

One of the most serious problems facing the mental health field today is that cognitive-behavioral treatments (CBT) for pediatric and adult mental illnesses remain difficult to find outside academic research settings despite strong evidence for their efficacy. Moreover, even when they are accessed, the treatments as delivered in some clinical contexts often do not resemble the carefully constructed and theoretically driven manuals used in randomized controlled trials (RCTs); and thus, the efficacy of these treatments may be attenuated. This unfortunate situation is certainly evident in the treatment of OCD, where many patients who are ostensibly receiving CBT do not receive an adequate theoretical rationale for the chosen treatment procedures, are given insufficient guidance in constructing and working through a hierarchy of feared thoughts and situations, are provided with vague instructions regarding response prevention, and are not carefully educated about the importance of identifying and refraining from mental rituals, among other acts of omission and commission.

Indeed, on more than a few occasions in over a decade devoted to clinical practice and research on the treatment of adult and pediatric OCD, I have interviewed patients who, in the context of their CBT treatment, were asked to snap a rubber band on their wrist every time they experienced an obsession in order to drive away feared thoughts and images. This approach is more likely to induce rather than reduce obsessional distress; and, in the wake of this sort of frustration, I have often wished that the tried and true procedures of exposure and response prevention could be disseminated more readily to mental health professionals who encounter OCD patients in their clinical practices.

It is also imperative that CBT materials designed for dissemination should be made as accessible and easy-to-use as possible, since one of the major barriers to their use in real-world clinical settings appears to be the time and labor intensity of translating research-oriented manuals for use with OCD patients in general, but with children and adolescents especially.

Aureen Pinto Wagner's newest volume, "Treatment of OCD in Children and Adolescents: A Cognitive-Behavioral Therapy Manual," addresses many of these critical needs and has the potential to improve significantly the delivery of CBT for pediatric OCD in the community. Her extensive clinical experience and previous work in creating materials for children and adolescents with OCD and for their families are clearly evident in this therapist manual, which may be used in concert with these other books.

The most obvious and immediate advance is that this manual provides therapist and patient forms on CD ROM, an attractive and sturdy version of

the Feelings Thermometer which children and adolescents will be asked to use during and between treatment sessions, and sufficient detail in the description of treatment procedures that are clearly the product of the author's wealth of experience and knowledge in treating children and adolescents with OCD. The provision of these materials goes a long way towards promoting compliance with treatment procedures and keeping therapist, patient, and parent on the same page as the therapy progresses. The thought and care that went into their creation also sets an obvious tone about treatment for the patient. It says to him that the serious use of these handsome materials is important in helping him to achieve his goal of reducing OCD symptoms.

The manual is divided into fourteen chapters, the first four of which are devoted to the nature and maintenance of OCD symptoms, a description of the theoretical rationale for CBT procedures, and a discussion of the particular challenges of using CBT with children and adolescents. In this latter section, the author discusses treatment readiness issues, which often arise in the very early stages of assessment and thus are essential to address immediately. She also reminds us that OCD affects and is affected by family issues, and that it is important to properly prepare the family to assist the child and the therapist before CBT is implemented. Her suggestions about how best to accomplish this are likely to be especially helpful. Throughout these chapters and, indeed, in the volume more broadly, Dr. Wagner cites the scientific literature to support her assertions. She is also liberal with clinical pearls and cogent examples gathered through her extensive experience with pediatric OCD.

The heart of the volume is devoted to what Dr. Wagner refers to as the Four Phases: 1) Biopsychosocial Assessment and Treatment Plan; 2) Building Treatment Readiness; 3) The RIDE Up and Down the Worry Hill; and 4) After the RIDE. The cultivation of treatment readiness is appropriately emphasized throughout the volume. It is made clear to therapists that effective treatment cannot proceed until the child is fully on board with the plan and has explicitly agreed to go forward. In placing this strong emphasis here, the volume goes above and beyond many of the excellent CBT manuals that have preceded it. In doing so, it makes a very important contribution to the growing clinical literature on pediatric OCD.

Child-friendly metaphors are used in the service of conveying these important points; and the protocol devotes two to four 50 minute sessions to this essential work. Stabilization is the first step, and involves psychoeducation about OCD as a biopsychosocial illness and presents an opportunity for children and families to speak about OCD's impact upon the family. The second stage, labeled Communication, describes the maintenance factors of OCD in greater detail and prepares everyone for the third stage, Persuasion, in which the therapist encourages children and families to see the necessity, possibility, and power

of change. The techniques of motivational interviewing (e.g., consideration of the pros and cons of living with OCD) are liberally used. Each is used in the service of encouraging the child to commit to the treatment program. The last stage, referred to as Collaboration, is designed to clarify how the treatment will be done and to install the child as the team's leader. This arrangement is intended to minimize the temptation to push harder at first than the child is willing to go and to promote the child's active participation in the process.

The material in these sections is presented in a clear, logical, and concise fashion. The fact that several sessions are explicitly devoted to "Collaboration" emphasizes its importance to therapists and families, each of whom might be tempted to move ahead quickly in view of the negative impact OCD has had on the child and family system. Dr. Wagner emphasizes throughout the book that this is both understandable and unwise. In doing so, I believe has done a considerable service for children and adolescents who will be treated using these materials.

Assuming that the preparation has gone well and the implementation of ERP is now at hand, Dr. Wagner uses the term "RIDE up and down the worry hill" to guide the implementation of ERP and to track progress. RIDE is an acronym for: Rename the thought; Insist that YOU are in charge; Defy it by doing the opposite, and Enjoy your success by rewarding yourself. The first two steps can be conceptualized as preparatory because these steps are designed to encourage the child to do what needs to be done, which is to resist OCD's demands to avoid situations and thoughts and/or to engage in compulsions. The final step reminds the child to reinforce his/herself for successful use of the steps. And, throughout the volume, families are vigorously encouraged to do so as well. Several cards are provided with the manual for the child to use during and after his/her exposure practices. Here again, the formality and attractiveness of the presentation is designed to convey a message about its importance and thereby promote compliance.

The RIDE acronym helps to break down ERP into concrete, finite steps that structure and clarify the treatment process. The purpose is to foster endurance of the anxiety until habituation takes place. This latter point is a critical one, and therapists using the RIDE protocol must remain alert to whether or not children understand that the first two steps are not intended to reduce obsessional distress, but rather to encourage the child to tolerate the anxiety associated with planned and unplanned ERP tasks. Dr. Wagner's specific examples of how the RIDE cards should be used underscore this important point; but, nevertheless, it bears repeating throughout the treatment. Dr. Wagner's Phase 4 section discusses preparing the patient and family for the transition, maintenance visits, booster sessions, realistic expectations, and strategies for managing the inevitable slips that will arise. This is an important concept that when



## Book Review

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totally internalized will go a long way in preventing "abstinence violation effects" or panicking when common problems do indeed arise.

One of the real difficulties in creating a treatment manual for pediatric OCD is the heterogeneity of patient presentations limits the degree to which general rules and examples can be provided. In Chapter 12, Dr. Wagner addresses this issue by providing more specific information about various OCD subtypes, such as, patients with reassurance rituals that involve family members, mental rituals associated with "bad thoughts," hoarding, etc. Her examples of how to use the Fear Ladder and RIDE cards to work with these particular presentations are especially helpful. It behooves the clinician to read this chapter carefully before beginning CBT with any child or adolescent with OCD.

In Chapters 13 and 14, Dr. Wagner also addresses typical problems that sometimes occur in the context of ERP, such as, limit setting, appropriate use of rewards and punishment, managing explosive behavior, and treatment reluctance that occurs during treatment. The citations at the end of the volume are thorough and up-to-date. They provide a guide for readers who encounter OCD more frequently and/or wish to create a subspecialty practice. Dr. Wagner also provides a list of support organizations that will be helpful for the practicing clinician to have at the ready.

Clearly, my review conveys a great deal of enthusiasm for the purpose and content of this manual and the accompanying materials. I strongly believe that it fills a critical gap in the armamentarium of practicing clinicians who treat OCD. It distills information about the nature and treatment of OCD in a clear and logical manner. And, the author is to be lauded for paying particular attention to the practical constraints that make CBT for pediatric OCD sometimes difficult to learn and deliver in clinical settings.

Of course, there are always tradeoffs that have to be made when writing such a book. Dr. Wagner's conscious choice to emphasize ease of use occasionally comes at the expense of providing more detailed information about the theoretical framework on which ERP is built and about current controversies in the field (e.g., whether the habituation model that is strongly emphasized here is sufficient to explain changes in OCD symptoms and how best to integrate informal cognitive techniques, including the discussion of objective risk and responsibility) about ERP. That said, I think Dr. Wagner's newest volume is a significant advance that will assist clinicians interested in providing high-quality CBT in a manner that is consistent with the constraints of clinical practice. Clinical researchers interested in dissemination of CBT for pediatric OCD should also take heed: Herein lies a manual that can be readily tested in clinical settings, perhaps with and without expert supervision, in order for us to learn whether CBT for pediatric OCD can be successfully disseminated well beyond the academic research context.

## Dr. Jenike Makes A Case For Funding OCD Research

(continued from page 1)

gather sufficient pilot data to be eligible for federal grants. In this way, our initial relatively small investment in them may pay enormous dividends for the OCD community for decades to come.

Unfortunately, there is another problem for OCD researchers. The federal government through the National Institute of Mental Health does not give anywhere near as much funding to OCD research as it awards to other mental illnesses, namely, schizophrenia, major depression and bipolar disorder. OCD is underrepresented in grants that are competitively awarded.

This is in some ways a direct result of a relatively small number of OCD investigators applying for such grants. We are soon going to meet directly with Dr. Thomas Insel, the Director of the National Institute of Mental Health, to advocate for more funding for OCD research. Our case will be dramatically helped if we can say the OC Foundation is raising significant money and is funding young researchers who will eventually apply for federal funding. Dr. Insel was one of the early pioneer researchers in the field of OCD and is sympathetic to our cause.

I heartily thank those of you who responded in the past. In 2000, we raised \$168,050. In 2001, we raised \$198,613. In response to last year's letter, which went out to over 15,000 people who have OCD or their family members, only 734 responded which is fewer than 5% of you. However, in only a two-month period (December 1, 2002 to January 31, 2003), we raised \$102,646. During the rest of 2003, we raised another \$68,140 for the OCF Research Fund and an additional \$40,821 specifically targeted for the OCF Genetics Collaborative. When you think that OCD affects over 6 million people in the US alone, this still seems like a trivial amount. As I have noted in the past, if we raised only one dollar per patient, we should have many times this amount. Any amount you can spare would help us greatly.

With the money that is raised, the OC Foundation funds research proposals that are submitted by researchers from all over the world. Members of the OC Foundation's Scientific Advisory Board rank the proposals to be sure that the finest are funded. The only thing holding us back from progress in these disorders is a lack of research funding. We have skilled researchers submitting projects for funding. Unfortunately, these talented people will have to look elsewhere and

work on other disorders if we do not rise to the challenge.

Now that the Foundation has set up the OCF Genetics Collaborative, we need to raise research money to fund the research being done by the members of the Collaborative. We have enlisted the world's finest researchers in the field of OCD genetics; and we need to make sure we have the funds to support this crucial work. If genes can be identified for OCD and related disorders, researchers can eventually figure out what these genes do and perhaps correct the deficits. It would also help identify children, who may be at high risk for developing OCD.

Organization, such as, NARSAD, Tourette's Syndrome Association, and the Alzheimer's Association each raise many hundreds of thousands to millions of dollars to support research into their respective areas of interest. Many of the world's best researchers decide to study particular disorders based on the availability of funds. The OCF needs money to compete with these organizations to attract the best researchers to our cause. If we are going to push OCD research to the forefront, we will need to be able to offer more research dollars to investigators.

We need your help to assist us in finding the causes of OCD and in developing new and more effective treatments. Please help!

Sincerely,

Michael A. Jenike, MD  
Professor of Psychiatry  
Harvard Medical School  
Chair, OCF Scientific Advisory Board

**Please  
Contribute  
to the OCF  
Research  
Fund**



# From The Foundation

(continued from page 1)

Haven at the mental health center where all the original members were taking part in a SSRI treatment trial. Our address back then was a post office box in Vernon, CT that Debbie Maguire had opened. The thousands of letters that flooded in there after Kathleen Page so bravely starred in the "20/20" segment on OCD hosted by John Stossel also roused the suspicion of the local postmaster. He approached Debbie and Gert Trudel on one of their weekly runs and suggested, "He was watching them. And, whatever they were doing better not be some sort of scam."

He wasn't the only one who was watching us then. There were others, but it was more protectively. Dr. Dennis Charney, now chief of the Mood & Anxiety Disorders Research Program at the National Institute of Mental Health, was the Principal Investigator of the SSRI treatment trial we were all participating in. He was the head of the research program in which all the founding directors were involved and he's the one who allowed us to meet every Saturday afternoon at CMHC. It was actually Dr. Wayne Goodman, a young researcher at Yale at the time, who brought all the original members of what became the OCF together. This wasn't the only thing he did to advance the treatment of OCD. At the same time, he was introducing the future directors to one another; he was inventing along with Dr. Steven Rasmussen of Brown the YBOCS.

After Kathleen appeared on "20/20," we got a phone to answer the thousands of calls from people with OCD who diagnosed themselves through the information on the program. Ciba Gige gave us the phone and \$250 to cover the charges. The phone started out in Fran Sydney's house and migrated. We used up the \$250 within days of the program, returning calls to people who just wanted to talk with someone else with OCD.

The response to that show changed the direction of the Foundation. The show generated thousands of inquiries from people, who recognized their symptoms from what Kathleen and the other "stars" were describing. These people were amazed to find out that what they had been suffering from was an actual disorder, it had a name and that they were not alone in their experiences. They wanted to know where they could go to get the treatment and relief promised by Kathleen's story. We decided in response that we would devote ourselves and our resources to getting people information about OCD and referring them to doctors and programs that could provide

them with effective treatment.

There were very few treatment options in 1987. There were 22 research centers around the U.S. where investigators were testing the new SSRIs. These were the only places you could get these new drugs because none of them had FDA approval yet. And CBT was just emerging as an effective treatment for OCD. The "20/20" segment also looked at the work Dr. Edna Foa was doing, treating patients with OCD with CBT.

I remember one Saturday afternoon that spring. We had unloaded sacks and sacks of mail on to my dining room table. Armed with slips of paper with the addresses and number of those 22 treatment centers where the SSRIs were being tested and a very rudimentary sense of the geography of the U.S., all of us – the original directors – matched inquirer to the nearest (some times that was more than a thousand miles) university site, inserted the address slip and a "Q&A" brochure that we had hastened into print into an envelope that as often as not had a battered but used stamp steamed off a self-addressed envelope sent along with the inquiry. We noticed right away that people with OCD were self-reliant and scrupulous about paying their own way.

Our first tax returns were in the same folder. The entries brought back many memories. Now who would ever have thought that a tax return would be a source of pleasant memories? The notation under "indirect public support" reminded me of the generous donations we started to receive that enabled us to rent our own space in North Haven and start hiring a professional staff. We got our first executive director in 1989. You can tell because that's the year we have our first entry under "Compensation of officers....".

There's a line under Expenses for "Conferences, conventions and meeting." I remember our first American Psychiatric Association conference in 1988. Norm Black, the board's Harvard MBA, had patiently explained to some of the skeptics on the board (I was one of the worse) that the OCF needed to have a presence at these events. He was right. Here at our booth in the APA Exhibit Hall, we started talking to treatment providers about OCD and the new treatments. It was revelatory. The thinking at the time among practitioners was that there was very little OCD and there was absolutely no way to treat it. I like to think the Foundation used its first exhibit to start changing that attitude. We literally reached out and grabbed everyone who

ventured down the aisle where our booth was. Drs. Charney and Goodman at their presentations told their audiences about the Foundation and urged them to visit our booth. They did and they stayed and they talked and they shared and they learned. Even the emissary from the Conference staff, who was sent down to warn us not to harass the doctors, went away with wearing a button saying "Obsessive People do it over and over" and a referral for his sister who he firmly believed had OCD. The experience manning that booth taught us that the Foundation really had an important role to play in educating even professionals about OCD and its treatment.

When I was untacking layers of yellowed notes from my bulletin board (I decided this had to be done before I could draft the agenda for the directors meeting), I discovered a list of free prescription programs sponsored by the pharmaceutical companies that manufacture some of the drugs used to treat OCD. It was old and tattered and there were lots of lines and number crossed out and written over. Some of the lines were crossed out and there was no replacement information. This meant that these companies had abandoned their free prescriptions plans. This realization brought me out of my pleasant reminiscing very abruptly. It reminded me that there was still so much more work to be done. So, I smoothed out that page and put it on top of the box containing my most important papers. I want it to be the first thing I unpack and put up when we get to New Haven. I want it to be there to remind me that we have so much more to do before we have secured effective treatment for everyone with OCD.

Ciao!

*Patricia Perkins*

**A very big (Texas-sized)  
thank you to  
Linda Jayaram and  
David Barish.  
They held a Casino Night  
Fundraiser in their home  
on September 20, 2003  
and raised  
\$3,000.00 for the  
OC Foundation.**



# From the President

Dear Friends,

One of the best things about being president of this Foundation for the last four



years has been to oversee the growth and development of our research programs. While it is satisfying to me personally, it should be rewarding to all of you as well. You have helped and encouraged us to move

these efforts to a new level. As you read this newsletter issue, you will see that we are launching our annual Research Fund Campaign with Dr. Michael Jenike's appeal letter. Therefore, I thought that it would be timely to share with you the first quarter progress reports received from the recipients of the 2003 OCF Research Awards. You can then see for yourselves how important supporting the OCF Research Fund is for those who suffer from OCD. The reports demonstrate not only the important research goals of each study, but also the day-to-day problems that face the various research teams. Research is an arduous but rewarding effort.

## "GABHS Induced OCD (PANDAS): Analysis of Clinical and Neurobiological Response to Antibiotic Treatment"

This is a study to find the cause of one type of OCD – a type that strikes children after they have experienced a strep infection, has a sudden onset and appears to resolve when the child is treated with antibiotics.

Marie Lynd Murphy, M.D., Elmwood Pediatric Group  
Eileen Lynd-Balta, Ph.D., Saint John Fisher College

In the first three months of our grant, we have started preparations for the clinical study itself. Research nurses are being trained to collect patient data using standardized instruments. We have revised our Informed Consent documents and have submitted them for approval to the local Investigational Review Board.

Now, we are investigating possible options for analyzing the blood samples we obtain in batches after the clinical phase of the study has been completed. We are arranging the logistics of medication purchase and reimbursement now before the start of the winter strep sea-

son when we will begin recruiting new patients.

We are presently analyzing the serum samples that we collected last winter. We have discovered the optimal dilutions of antisera to use in looking at the serum samples. We are using immunocytochemical techniques to identify the presence of antineuromal antibodies in the serum samples. This technique will allow us to map the location of staining in discrete brain nuclei that will help elucidate the scientific basis of this disorder, providing more than a temporal link between the strep infection and OCD. Knowledge of the neural pathways and neurotransmitters involved may guide treatment and medication decisions for this type and other types of OCD.

## "T-cell characterization after Streptococcal M-protein inoculation and superantigen administration for superantigens in neuropsychiatric disorder"

In this study, the investigators are exploring the effects of Strep infection on the antibodies that form in the basal ganglia in response to a Strep infection.

Kyle A. Williams  
Third-year medical student  
University of Minnesota Medical School  
Suck Won Kim, M.D.  
Associate Professor  
University of Minnesota Medical School  
Patrick M. Schlievert, Ph.D.,  
Professor  
University of Minnesota Medical School  
Jon E. Grant, J.D., M.D.  
Brown University

For the last three months, we have been isolating streptococcal antigen genes from the M18 strain of Group A Streptococcus and expressing them in E. coli cells to generate purified, recombinant toxins that will be used to immunize mice. We have completed the cloning and purification on all of the superantigens; and we are in the final stages of verifying the cloning of the streptococcal M protein. This is the final virulence factor that must be generated and inoculated into the mice. We anticipate that this will be completed in mid-November. After that, we will begin generating the volume of streptococcal protein needed to immunize the mice. These studies will take about two months to complete. Then, we will begin our immunological assays and data preparation.

Our study has generated considerable

interest at the University of Minnesota and we are now in the planning stages of designing multiple adjacent studies which we will be able to complete at no extra cost. The local publicity that we received from being named OCF Research Award winners has resulted in PANDAS patients contacting our research group and we anticipate submitting a request for an NIMH grant within the next six months based on this work.

## "Clinical and Genetic Studies of OCD With and Without Tics"

This is an investigation of whether there are clinical or genetic differences between patients with OCD who have tics and those who do not

Karen Weissbecker, Ph.D.  
Assistant Professor  
Tulane Health Science Center and the  
Hayward Genetics Program  
Humberto Nicolini, M.D., Ph.D.  
Head, Division of Clinical Research  
Instituto Mexicano de Psiquiatria

In this study, Drs. Weissbecker and Nicolini are hoping to investigate whether there are clinical or genetic differences between OCD patients with and without a comorbid tic disorder. They are trying to determine whether properly accounting for these differences may affect the results of genetic association studies between OCD and several candidate genes.

Since the grant began, we have entered the data from the YBOC checklists of 43 probands and are in the process of checking the data entry and cross-referencing this information with the previously entered demographic and diagnostic information. These data will be used for a factor analysis of symptoms to assess whether there are differences in the types of obsessions or compulsions experienced by OCD patients with and without comorbid tic disorders. These data will also be used to test hypotheses regarding differences in severity, age-of-onset, family history, and other clinical features between OCD patients with and without tics.

DNA has been isolated for 51 OCD patients and their parents for use in tests of association. Dr. Nicolini's lab has been working on the genotyping analysis of candidate gene markers. They have recently completed the genotyping of three candidate genes: 1) the 5HT1DB Serotonin receptor gene, 2) the 5HTT



Serotonin transporter gene, and 3) the mu receptor gene. These data will be sent to Tulane where we will perform the association analyses.

#### "Brief Consultation to the Families of Treatment Refusers: A Pilot Outcome Study"

Brief Consultation to Families (BCF) is a program that was developed by the Saint Louis Behavioral Medicine Institute clinical team to help families refocus their efforts on the things that they can change rather than on changing the person with OCD.

Melanie M. VanDyke, Ph.D.  
Anxiety Disorder Center  
Saint Louis Behavioral Medicine Institute  
C. Alec Pollard, Ph.D.  
Director, Anxiety Disorder Center  
Saint Louis Behavioral Medicine Institute  
Professor, Department of Community and Family Medicine  
Saint Louis University School of Medicine

During this initial phase, we have worked to complete the IRB proposal for conducting our study and have focused on the ethical issues that must be resolved to achieve our scientific goals. In order to get IRB approval, we had to take a new Internet course in ethics required for all researchers at Saint Louis University. We have both completed the course.

We have also been completing the two family consultation protocols we will be following in this study, the Education and Supportive Intervention (ESI) and the Brief Family Consultation (BFC). These are the two alternative interventions families in this study will receive.

We have hired a research assistant for the study and have started a waiting list for potential participants. While we are waiting for final IRB approval before starting recruitment, we have designed a plan to inform family members about the study and have received a number of inquiries.

#### "Multi-Site Study of CBT Treatment Failures"

This is a multi-site study into why some patients with OCD do not have a positive response to cognitive and behavioral treatments.

Sabine Wilhelm, Ph.D.  
Assistant Professor  
OCD Clinic, Massachusetts General Hospital  
Harvard Medical School  
Gail Steketee, Ph.D.

Professor  
School of Social Work, Boston University  
Our project is a multi-site study. We are gathering existing data from several different OCD clinics to examine why some patients with OCD fail to benefit from cognitive and behavioral treatments that have a high rate of efficacy for most patients.

During the first three months, we obtained IRB approval and hired a Post-doctoral fellow. We also obtained data from the original eight sites that had agreed to contribute existing data sets from studies employing manualized CBT treatment. In addition to the data collected at our OCD Clinic, we received data from Drs. Jonathan Abramowitz (Mayo Clinic, Rochester, MN), Jean Cottraux (France), Michael Kyrios (Australia), Neil Rector (Toronto, Ontario, Canada), Debbie Sookman (Montreal, Quebec, Canada), David Tolin (Institute of Living, Hartford, CT) and Maureen Whittal (Vancouver, British Columbia, Canada). We also recruited an additional site: Dr. Kieron O'Connor from the Centre de recherche Fernand-Seguin in Montreal.

So far, we have ensured that all the data sets include a range of measures and variables that can be studied as possible predictors and/or mechanisms of treatment outcome, including symptom assessment tools, cognitive measure specifically related to OCD and demographics. Right now, we are combining the data from all sites in a master file. We have met several challenges in compiling the data. For example, all the data from Dr. Cottraux in France had to be translated from French into English before we could add them to the master file. Our goal is to create a master data file that includes the raw scores of the individual items of the measures instead of summed questionnaire scores. Such comprehensive data sets will enable us to perform more elaborate and informative statistical analyses.

#### "Effectiveness of Intensive Residential Treatment for Severe and Treatment-Refractory OCD"

In this study, the investigator is examining the effectiveness of Intensive Residential Treatment from an intent-to-treat sample of patients with severe and treatment-refractory OCD.

S. Evelyn Stewart, M.D.  
OCD Research Fellow  
Harvard Medical School

OCD is the fourth most common psychiatric illness. Although recent decades have brought new and more effective treatments for it, full remission is uncommon and partial remission remains the norm, leading to many refractory cases. Intensive Residential Treatment (IRT) has recently been developed as a promising treatment approach for persistent, severe and refractory OCD. In this outcome study, I am examining the effectiveness of IRT in 487 patients admitted to the OCD Institute in Belmont, MA between February 1999 and June 2003.

The sample of participants treated at the OCD Institute were 58% male, with an average age of 33 years. The length of stay ranged widely between 1-640 days, with an average of 61 days. OCD severity at initial assessment measured by YBOCS scores was 26.3, indicating a high mean level of severity. At the time of discharge (including participants who left prematurely), the mean YBOCS total was 19.3, ranging between 0 and 40. The mean YBOCS decrease was 26.9%, and self-reported Patient Global Improvement scores indicated significant improvement. Measures of comorbid depression and psychosocial functioning also improved.

In summary, at this point in our analysis, it is clear that there is a clinically and statistically significant improvement of OCD symptoms, depression symptoms and psychosocial functioning following IRT for severe and previously treatment-refractory OCD patients.

In the upcoming months additional variables will be added to the database, which will permit regression analyses to determine predictors of outcome following IRT admission. Also, we will be conducting factor analysis to determine whether certain symptom dimensions are associated with treatment response and non-response. I am presently writing up the above data for publication.

I am certain that everyone will agree that our research award recipients are moving closer to the Foundation's goal of "Effective Treatment For Everyone with OCD." Please read with special attention, Dr. Jenike's letter highlighting the need for OCD research on page 1, and consider joining me in making a contribution to the OCF Research Fund for 2004.

Best regards,  
Janet Emmerman  
President  
OCF Board of Directors



# My OCD Notebook

## Families Working Within The Transition Zone

By Constantina Boudouvas, L.C.S.W.  
The Menninger Clinic  
Houston, TX

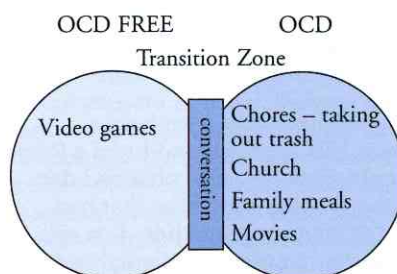
Obsessive Compulsive Disorder is a neurobiological disorder whose symptoms play themselves out in the interpersonal realm of peoples' lives. For family members of loved ones struggling with the intense anxiety of this disorder, it is often found that their families' routines and culture are dominated and entangled in OCD rules, thereby disrupting family functioning and causing extreme distress. Families vary widely in their response to OCD symptoms. Either they find themselves accommodating the symptom by changing the environment or being antagonistic towards their loved one in response to their own frustration about the disorder. At times family frustration can become so intense that conflict is the prevailing currency exchange in families. This happens when the symptoms may be life threatening and there is an intense sense of powerlessness.

Below are some steps and tools that we use at our Family Day Workshop at the Menninger Clinic, and that were presented at the OCF Conference in Nashville.

### Step One: Defining the Transition Zone

Behavior contracting begins with externalizing OCD from the person who has the disorder. This process allows for the development of a transition zone which serves as a base for further family interventions. Using the narrative theory of "externalization," which means separating the problem from the person, patient and therapist collaboratively work with their families to create a "working area" or "transition zone" in which symptoms and triggers will be identified at the same time that the client makes a commitment to change his/her response to those triggers and enlists family support in response prevention.

The task and focus when working with families in defining the transition zone is to identify what areas of family life have become saturated with OCD symptoms and what family routines/relationships are OCD-free. John March and Karen Mulle in "OCD in Children and Adolescents: A Cognitive-Behavioral Treatment Manual" developed and discussed this concept of creating a zone that identifies the OCD symptoms that the OCD sufferer and therapist will challenge in their work together.



It is strongly advised that family members do not reduce all reassurance giving and accommodating unless there is an active plan for change among patient, therapist and family members. This method of mapping and contracting is predicated on an understanding of the neurobiological component of the illness and on a recognition of the intense anxiety that underlies symptoms.

### Step Two: Behavior Contracting

Identifying the transition zone provides a context from which a behavior contract can be drafted. This behavior contract gives everyone a map of how family members will respond to OCD triggers, rituals and behaviors. The contract takes specific items identified in the transition zone and clearly defines the family members' response to a symptom as well as the OCD sufferer's response. The contract also identifies what family members will do if the OCD sufferer is not able to use response prevention with the identified trigger/symptom.

Because most family cultures become entangled with OCD rules, individual family member's lives may become so focused on the OCD sufferer that they often times report neglecting activities/responsibilities that they once enjoyed or in which they were able to participate. In our practice, we encourage family members to give this some thought and place in the transition zone such activities. Research has shown that family members, who can respond to OCD symptoms in a non-reactive manner, are more able to effectively help the OCD sufferer in his/her recovery. Since there is a high correlation between self-care and a person's ability to have "low expressed emotion" (i.e., non-reactive responses to anxiety), we encourage family members to reengage in activities they may have abandoned. These may include spiritual practices, exercise routines, social activities and interests among other things. By making

some of these activities part of the behavior contract, family members can identify specific behaviors they are responsible for managing in the same way that the OCD sufferer is selecting behaviors to target through E&RP. The fact that everyone is committing him or herself to accomplish or overcome something makes the therapy more of a collaborative effort.

### Step Three: Families need Habituation tool!

Families living with the chronic stress and anxiety of OCD in their household at times become hypervigilant themselves about the environment in order to "protect" their loved one or themselves from trigger situations. Living with these kinds of symptoms can produce a repetitive cycle of unpredictable outbursts and a corresponding sense of helplessness for the family or the development of repetitive maladaptive family response in the face of such anxiety.

Family recovery involves a habituation process, i.e., watching their loved one interface with the environment without ritualizing or getting rageful. Involving family members in exposure and response prevention, whether directly in the session or by gaining permission from the patient to have family members aid in blocking rituals, is critical with both children and adolescents as well as with adults. This also allows for them to become accustomed and habituate to their loved one's nonanxious response to triggers that he or she is working on.

### Step Four: Becoming Familiar with Cognitive Domains

Frequently, persons who suffer with very severe OCD lack the capacity to reflect on their obsessive thoughts or to question the validity of their perceptions. Through extensive cognitive behavior therapy, persons with OCD begin to gain some capacity to identify irrational aspects of their obsessive thoughts fears, and become more able to tolerate uncertainty.

This creates the opportunity for conversations with family members about the "cognitive domains" that OCD hijacks. If this can occur in the presence of a mediator, such as, a therapist, families can openly discuss the conflict and confusion that arises in the presence of such irrational thinking and behavior. Educating family members on the cognitive domains of OCD can give families a language to help the OCD sufferer challenge the OCD in the midst of difficult exposures.



# Bulletin Board For Research Studies

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cation treatments for OCD. The purpose of this research is to examine the genetics of treatment response to serotonin medication in patients with OCD. It may be possible to use genetic screening to predict who will respond to these kinds of medicines and who will experience side effects or no improvement. Participants will undergo a clinical evaluation, blood draw, and urine screen and be reimbursed for their participation.

**Who is eligible to participate?** If you are between the ages of 18 and 65 and have received serotonin reuptake medication for OCD (these medications include: Anafranil, Zoloft, Paxil, Celexa, Prozac, Luvox, among others), you may be eligible. Participants must also be able to commute to Mayo Clinic in Rochester, MN.

## Risks and benefits for participants:

There are no direct benefits from participating in this study. The study includes a blood draw to obtain a sample of blood, which may cause short-term discomfort. You will also be asked to provide a urine sample.

**Contact information:** The study is being conducted by Stefanie Schwartz, Ph.D., John Black, M.D., and Jon Abramowitz, Ph.D., at Mayo Clinic. Further information is available by contacting Dr. Schwartz at 507-284-4431, or via e-mail: schwartz.stefanie@mayo.edu. This study has IRB approval and is funded by the OC Foundation.

## THE NEW YORK STATE PSYCHIATRIC INSTITUTE SEEKS PARTICIPANTS FOR MAGNETIC RESONANCE IMAGING STUDY

This study seeks to learn more about the causes of various neuropsychiatric disorders including OCD. The study involves taking an MRI image of the brain. MRI is a safe, painless, radiation-free way to "take a picture" of the brain. It also involves responding to questions about medical and psychological histories and completing various neuropsychological assessments. By comparing the MRI data from individuals with disorders to that from healthy control subjects, the study will help further our understanding of the neurological basis behind disorders such as OCD.

**Who is Eligible?** Individuals with OCD, Tourette's Syndrome, ADHD, anxiety disorders, affective disorders, and/or disruptive behavior disorders as well as healthy controls between the ages of 6 and 65 are eligible.

Participants will be compensated \$80 for their time.

**Contact:** Victoria Stein  
The New York State Psychiatric Institute  
Unit 74, Rm 2301  
1051 Riverside Drive  
New York, NY 10032  
(212) 543-6287  
steinv@child.cpmc.columbia.edu

## RESEARCH: THE HOPE FOR TOMORROW

Families with Obsessive Compulsive Disorder are invited to help scientists learn more about the causes of OCD.

A team of scientists at six academic institutions is investigating genetic factors which may increase the susceptibility to OCD. Recent advances in molecular biology and statistical genetics make it possible to identify and describe specific genes that may cause complex diseases such as OCD. We are seeking families with OCD to help us conduct these studies.

## YOU CAN HELP!!

If at least two members of your family are diagnosed with OCD or exhibit symptoms, your family might be eligible for this nationwide study. Participation includes a confidential interview and a blood sample. The interview will be scheduled at a time and place convenient for the participant. Participants will be compensated.

## YOUR HELP COUNTS!!

Each participant's help is vital and DOES make a difference. Families may be referred by a clinician or may contact us.

To learn more about the study, please contact (collect calls accepted):

\* Rhode Island region  
Anthony Pinto (401)-455-6299  
apinto@butler.org

\* Boston region  
Michelle Wedig (617)-726-5594  
mwedig@partners.org

\* New York region  
Jessica Page (212)-543-5355  
pagejes@pi.cpmc.columbia.edu

\* Los Angeles region  
Amanda Pearlman (310)-825-4132  
apearlman@mednet.ucla.edu

\* Washington DC and other regions  
Diane Kazuba  
Local: (301)-496-8977  
Toll-free: 1-(866)-644-4363  
kazubad@intra.nimh.nih.gov

\* Maryland and all other regions  
Krista Vermillion (410)-575-7326  
jacks@jhmi.edu

OCD Collaborative Genetics Study includes Brown University, Columbia University, Johns Hopkins University, Massachusetts General Hospital, National Institute of Mental Health and UCLA

## UNIVERSITY OF CALIFORNIA LOS ANGELES (UCLA) IS CONDUCTING A NUMBER OF STUDIES ON OBSESSIVE COMPULSIVE DISORDER

### PET/Paxil Study

This is a 12-week study for people with Obsessive Compulsive Disorder who are not taking medication. This study is researching changes in brain glucose metabolism of people with OCD treated with the medication Paxil.

For the participant, this study involves having a PET scan of the brain prior to commencing a 12-week regimen of Paxil and then a second PET scan at the end of the regimen. It also involves having an MRI scan of the brain before and after treatment with Paxil. Participants will be closely monitored for side effects and efficacy of the medications by their study doctor.

For more information on this study please call (310) 794-7305.

### PET/Paxil Hoarding Study

This is a 12-week study for people with Obsessive Compulsive Disorder, and more specifically those people who have the hoarding/packrat/clutter syndrome who are between the ages of 18-65 years. This study is researching changes in brain glucose metabolism in people with the hoarding problem when treated with the medication Paxil.

For the participant, this study involves a PET scan of the brain prior to commencing a 12-week regimen of Paxil and then a second PET scan at the end of the regimen. It also involves having an MRI scan of the brain before and after treatment. Participants will be closely monitored for side effects and efficacy of the medications by their study doctor.

For more information on this study please call (310) 794-7305.

### PET/CBT/Neurocognitive Testing Study

This 4-week study for people with Obsessive Compulsive Disorder involves having a PET scan of the brain and a 2-



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hour battery of neurocognitive tests prior to 4 weeks of intensive Cognitive Behavior Therapy (CBT). Participants will also have an MRI of the brain before and after treatment. CBT involves daily (Mon-Fri) 90-minute sessions with a therapist. Participants will receive a second PET scan of the brain and a shortened battery of neurocognitive tests at the end of treatment.

This study is looking at changes in brain metabolism before and after treatment with CBT. It is also looking at changes in neurocognitive functioning before and after treatment.

For more information on this study please call (310) 794-7305

### NEUROIMAGING STUDIES OF FRONTAL LOBE PATHOLOGY IN OCD

The purpose of this research study is to examine which parts of the brain may play a role in the neurobiology of obsessive-compulsive disorder. Participants are administered comprehensive neuropsychological, clinical, and diagnostic assessments. In addition, a magnetic resonance (MR) imaging scan of the brain will be obtained. MR imaging takes pictures of the brain and is noninvasive. It is hypothesized that individuals with OCD will demonstrate both structural and functional abnormalities in key brain circuits perceived to play a role in the neurobiology of the disorder. Research study participants are compensated for their time. This research study does not include any treatment. It is hoped that these data will ultimately be able to inform treatment strategies for this disorder. To learn more about this research study please contact the Obsessive-Compulsive Disorder Clinic at the Zucker Hillside Hospital at (718) 470-8157.

Principal Investigator: Philip R. Szeszko, Ph.D., Assistant Professor of Psychiatry, Albert Einstein College of Medicine

### ESCITALOPRAM IN THE TREATMENT OF INTRUSIVE THOUGHTS IN PATIENTS WITH OCD

Current theory regarding OCD (Steketee & Frost, 2002) stresses the importance of the role that thoughts or cognitions play in OCD. In fact, DSM-IV criteria (American Psychiatric Association, 1994) highlights how intrusive thoughts or images may be diagnostic of OCD or may function as a stimulus for anxiety reducing rituals. Only

a limited amount of attention has been given to how treatment may influence the role that intrusive thoughts play since it has been far easier to assess the reduction of behavioral rituals (e.g., whether there is a decrease in time spent washing). One potential explanation for why treatment outcomes as they relate to intrusive thoughts have not been investigated is that until recently, there has not been a consolidated measure of intrusions available.

In order to provide researchers and clinicians with a unified measure, The Obsessive Compulsive Cognitions Working Group (OCCWG) has developed a measure, the Interpretation of Intrusions Inventory (III) (Obsessive Compulsive Cognitions Working Group, 1997, 2001, 2003), the purpose of which is to ascertain the degree of importance that individuals attach to their intrusive thoughts. Thus, to the degree that treatment is effective, OCD sufferers will attach progressively less importance to intrusive thoughts/obsessions and subsequently be less distressed by the intrusions.

The objective of this study is to determine whether pharmacological treatment with escitalopram (Lexapro) will decrease the importance individuals suffering from OCD associate with intrusive thoughts. We are looking to investigate whether as a result of the medication, subjects will have less intense intrusive thoughts. All subjects will be asked to participate in a 12 week clinical trial and will complete a diagnostic clinical interview along with several questionnaires.

**Exclusion/Inclusion Criteria:** Subjects diagnosed with OCD who have been treated with citalopram (Celexa) will be excluded from the study unless the medication was discontinued due to side effects. Individuals who are concurrently prescribed other anxiolytic or anti-obsessional medications or who are involved in cognitive behavioral treatment for OCD will also be excluded. Adults between the ages of 18 - 60 who are fluent in English will be included. Eligible patients will: be between 18-60 years of age and suffer from OCD as defined by DSM-IV criteria for at least the past year. We will exclude individuals who are: currently taking Lexapro, suffering from organic mental disorders; psychotic mental disorders including delusional disorder, somatic type; affected by mental retardation or developmental disabilities; diagnosed with substance or alcohol abuse within the past 6 months; are suffering from primary major depression, OC spectrum disorders (i.e., trichotillomania, hoarding, etc.), factitious

disorders, dissociative disorders, personality disorders sufficiently severe to interfere with cooperation with the study; those with a history of bipolar I or II disorder; taking other psychotropic medications; taking medications that may interact with escitalopram; are pregnant, intend to become pregnant, or are breastfeeding; or unable to complete self-report forms that are in English.

If you are interested in finding out more about the study or are interested in participating, please contact Dr. Cheryl Carmin at the University of Illinois at Chicago at 312-413-2633.

### MULTI-CENTER TRIAL OF ZIPRASIDONE (GEODON) AUGMENTATION IN SEROTONIN REUPTAKE INHIBITOR-RESISTANT OBSESSIVE COMPULSIVE DISORDER (OCD)

This study will investigate the safety and efficacy of adding ziprasidone (Geodon) to a serotonin reuptake inhibitor (SRI) in patients with treatment resistant OCD. Patients will be randomly assigned to receive 8 weeks of augmentation treatment with either ziprasidone or placebo.

#### To be eligible, patients must:

- be between 18-65 years of age
- have a primary diagnosis of OCD
- have had between one and three adequate trials (adequate dose for 12 weeks or more) of an SRI with unsatisfactory response, and must CURRENTLY be on one of these SRIs.

If someone is interested in participating in this study, whom should they call?

Emily Smith, MSW  
Study Coordinator  
Stanford University Medical Center  
650-498-5644  
emilyhs@stanford.edu

Bettina Knight, CCRC  
Study Coordinator  
Emory University  
404-727-8964  
bknight@emory.edu

Chantal Hebert  
Study Coordinator  
University of Florida  
904-292-2773  
chebert@psych.med.ufl.edu

Lisa Sharma  
Study Coordinator  
Mt. Sinai Hospital  
212-659-8732  
lisa.sharma@mssm.edu

Lauren Kerwin  
Study Coordinator  
Pacific Institute of Medical Research  
310-825-0860  
lkerwin@mednet.ucla.edu



# **THE OCF'S VIDEO PRESENTATION**

## **"OCD IN THE CLASSROOM"**

### **IS NOW AVAILABLE**

"OCD in the Classroom" is the OCF's newly revised program to educate educators about the effects of OCD on a child's performance in the classroom. The program contains two videos: "Jake's Story and the Kids' Panel" and "How to Recognize and Respond to OCD in School Age Children," a "Presenter's Manual," containing a tightly written script and transparencies that outline a presentation on OCD and the effects that it has upon a child's ability to study and learn, the updated edition of "School Personnel: A Critical Link in the Identification, Assessment and Treatment of OCD in Children and Adolescents" by Gail Adams, Ph.D., and the pamphlet, "Obsessive Compulsive Disorder in Children & Adolescents," by Dr. Hugh F. Johnston and J. Jay Fruehling, M.A.

This program to "educate the educators," which is packed in an easy-to-tote box, is available from the OC Foundation at a cost of \$15.00 plus shipping and handling for OCF members and \$25.00 plus shipping and handling for non-members. There are only 500 copies of this program available at this reduced price. This is because the project was underwritten by the Lupin Foundation, the Perakis Family Foundation, Bernie and Edna Bahr and everyone who bought a raffle ticket at the Annual Conference. Once these initial sets are sold and we reorder, the price will increase to reflect the actual cost to produce it.

To order, call Leslie at 203-401-2070, Ext. 14, or email her at: [capezzone@ocfoundation.org](mailto:capezzone@ocfoundation.org).

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# THE OBSESSIVE COMPULSIVE FOUNDATION ANNOUNCES ITS CALL FOR PROPOSALS FOR THE 2004 OCF RESEARCH AWARDS

The Obsessive Compulsive Foundation invites investigators to submit applications for the 2004 OCF Research Awards.

**THE SUBMISSION DEADLINE IS JANUARY 30, 2004.**

## TOPICS OF INTEREST

The OC Foundation is committed to finding and promoting "Effective Treatment for Everyone." To further this mission the Foundation is interested in funding research into the brain, its chemistry, structure and functioning; basic neurobiology as it relates to OCD and the OC Spectrum Disorders; the genetics of OCD; its epidemiology; and any aspect of OCD or OC Spectrum Disorders that will lead to prevention and treatment advances. For more insight on the types of projects funded, please read the quarterly reports from the 2003 OCF Award Winners in "From the President" on pages 12 and 13 of the NEWSLETTER.

## HOW TO APPLY

For more information on how to apply for the 2004 OCF Research Awards, please contact Jeannette Cole, OCF deputy director, at 203-401-2070, ext. 18, or email her at: [cole@ocfoundation.org](mailto:cole@ocfoundation.org), or go to the OCF website at [www.ocfoundation.org](http://www.ocfoundation.org) and download the application.

## Affiliate News

### Stanford/OCFSFBA OCD Conference

*by Scott Granet, LCSW  
President*

*San Francisco Bay Affiliate of OCF*

On November 1, The Stanford University Medical Center OCD and Related Disorders Research Program and the Obsessive-Compulsive Foundation of the San Francisco Bay Area jointly sponsored a half-day conference entitled, "Modern Approaches to OCD, BDD, and Impulse Control Disorders."

One hundred and twenty-five patients, family members, professionals, and concerned others heard a variety of presentations about OCD and related disorders offered by several local experts.

President of the OCFSFBA, Scott Granet, LCSW, opened the program by welcoming the attendees, and later spoke on Body Dysmorphic Disorder. He was followed by Dr. Alan Ringold, who presented on medications; and then Dr. Lorrin Koran spoke about Stanford's current research, as well as those studies that have been completed. He also invited patients to consider volunteering to be part of a research study, and spoke of the great benefit to all in doing so. Dr. Margo Thienenmann presented on OCD in Children; Dr. Herbert Gravitz spoke on OCD and the Family; and the day's final presentation was on impulse control disorders, by Dr. Elias Aboujaoude.

Scott Granet also spoke of the many wonderful resources offered by the national OCF, and invited all to participate in the local support groups. In addition, he spoke of the need for people interested in joining the OCFSFBA board of directors so that the organization can expand the resources it offers to the area's OCD community.

While the day's event was undoubtedly a great success, there are many more people with OCD and related disorders who did not attend the conference, and who need help. The conference was just one of many ways the OCFSFBA hopes to provide support to its community in the months and years ahead. Many thanks to all whom participated in making this a very special day.



## Rare Gene Mutation in Uncommon Familial Form of OCD

By Dennis Murphy, M.D.  
Laboratory of Clinical Studies  
National Institute of Mental Health

Prior research has shown that several gene variants are more common in individuals with Obsessive Compulsive Disorder (OCD) than other patient groups or controls, but the differences are not specific to OCD.

Investigations of a new, uncommon coding region variant, 1425V, in the serotonin transporter gene in 112 OCD patients and 271 patients with eating disorders, depression, along with controls found this new variant only in two families with OCD. In this multi-generational study, six of the seven family members who had the mutation had either OCD (5) or obsessive-compulsive personality disorder (OCPD) (1). The seventh individual in these two families with the mutation was not psychiatrically evaluated. The seven other family members of the 14 total who did not have the mutation did not have OCD.

The individuals in the two families who had OCD also had multiple other diagnoses including tic disorder (3), anorexia nervosa (2), Asperger's Syndrome (2), alcohol problems (4), social phobia (3), depression (3) plus ADHD and PTSD and were generally treatment-resistant. This suggests that OCD in these two families is complicated and severe.

The mutation is rare; and so far has been identified in a total of 7 of 833 individuals (in this study and a prior study) who have been genotyped for it. While more individuals need to be studied utilizing both clinical evaluations and DNA, it may be estimated that 2% or less of individuals with OCD may have the 1425V mutation.

The mutation is unusual in that in cell culture studies the uptake of serotonin is markedly stimulated. This occurs by a change in the way the serotonin transporter is regulated by cell signals. The research was published recently in the journals *Molecular Psychiatry* (November) and *Molecular Pharmacology* (August) by investigators at the NIH, Yale University and the University of Pittsburgh.

## BDD & Social Phobia

(continued from page 4)

### Treatment Approaches

There have been many reports of successful treatments of BDD using pharmacological approaches (e.g., Fernando, 1988; Hollander, Liebowitz, Winchel, Klumker, & Klein, 1989; Phillips, McElroy, Keck et al, 1993; Phillips, Albertini, Rasmussen, 2002, etc.). Hollander et al (1989) report success in five patients using a variety of serotonin reuptake inhibitors (SSRIs). These authors particularly suggest clomipramine and fluoxetine as the treatments of choice for the pharmacological treatment of BDD. However, the direct mechanism(s) responsible for the amelioration of BDD symptoms has not yet been explicitly identified.

Cognitive-behavioral therapy (CBT) is suggested as a treatment of choice for BDD and body image dissatisfaction. An illustrative example of such an approach has been provided by Schmidt and Harrington (1995). They report the successful treatment of one BDD patient using a short-term cognitive-behavioral treatment program. The patient presented with concerns regarding hand-size, believing that he had exceptionally small hands. The patient, therefore, attempted to keep his hands concealed, especially around women, who he believed would assume that his small hands were indicative of his masculinity. Using nine sessions of a collaborative-empiricist cognitive therapy approach and behavioral homework assignments (e.g., comparing his hand-size with others), clinically significant success was achieved.

Similarly, a series of studies undertaken by Neziroglu and colleagues at the Bio-Behavioral Institute in Great Neck, NY, demonstrated effective results for the treatment of BDD using primarily exposure and response prevention (ERP) augmented with cognitive restructuring. Neziroglu and Yaryura-Tobias (1993) reported success in four out of five

patients using such a method. Similar success has been demonstrated by Neziroglu, McKay, Todaro, and Yaryura-Tobias (1996), as well as McKay et al (1997). Moreover, Veale and colleagues (1996) reported similar success in a randomized wait-list control study using cognitive-behavior therapy.

Group therapy has been suggested as a means of augmenting individual and psychopharmacologic therapy for BDD and body dissatisfaction (Rosen, Reiter, and Orosan, 1995; Rosen, Saltzberg, and Srebnik, 1989; Wilhelm, Otto, Lohr, and Deckersbach, 1999). We have found that groups are also helpful in reminding patients that they are not alone. In our current groups, it does not seem to matter that different people are affected by different aspects of their appearance. In OCD groups, there have traditionally been problems when there are vast differences in the symptoms. For a more in-depth review of treatment studies, the reader is referred to Neziroglu and Khemlani-Patel (2002; 2003).

### Summary

BDD is a debilitating disorder characterized by preoccupations regarding perceived bodily anomalies and frequent checking behaviors (e.g., considerable grooming procedures, examination of 'defect[s],' etc.). BDD often causes considerable distress to the sufferer and his or her family and friends and seems to be related to other OC spectrum disorders. Yet, effective treatments have been shown to exist, particularly a combination of pharmacological and behavior therapy approaches. New treatments are being tested as this article is printed. With the correct therapeutic interventions, BDD sufferers can receive the best currently available treatments for their concerns.

**For a complete list of references, please contact OCF at 203-401-2074.**



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