

OCD Newsletter

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OCD GENETIC RESEARCH ADVANCES WITH LARGEST SINGLE GRANT EVER AWARDED BY THE OBSESSIVE COMPULSIVE FOUNDATION

NEW HAVEN – The Board of Directors of the Obsessive Compulsive Foundation has voted to give members of the OCF Genetics Collaborative, chaired by David Pauls, Ph.D., professor at Harvard Medical School, and head of the Psychiatric & Neurodevelopmental Genetics Unit, a \$100,000 grant, matched by The McIngvale family of Houston, Texas, in honor of their daughter, 19-year old Elizabeth McIngvale, the national spokesperson for the Obsessive Compulsive Foundation.

In a groundbreaking collaborative effort between nine universities headed by Dr. Pauls' team at Harvard, and the team of Gerald Nestadt, M.D., Principal Investigator of the OCD Collaborative Genetics Study, and co-Director of the Obsessive Compulsive Disorder Clinic at Johns Hopkins Hospital, this \$200,000 grant will, according to Dr. Nestadt, support the investigation of "candidate genes in regions on specific chromosomes identified in our genome-wide scan of OCD."

More than 1600 research candidates have been selected for genotype sampling, however, more OCD families are needed to participate in this study. According to Dr. Pauls, "It takes large numbers of families to allow the identification of susceptibility genes in complex genetic disorders like OCD. It is only with the cooperation of individuals with OCD, and their families, that this work can move forward."

MANAGEMENT OF SUBSTANCE USE DISORDERS IN OBSESSIVE COMPULSIVE DISORDER

By Jon E. Grant, JD, MD, MPH, and Suck Won Kim, MD Department of Psychiatry University of Minnesota Medical School Minneapolis, MN

Although research on OCD has improved treatment for individuals suffering from this disorder, relatively little attention has been paid to the influence of substance use disorders (SUDs) in this population and how best to treat individuals when both disorders co-occur. Rates of lifetime SUDs (abuse and/or dependence) in a recent sample of 293 individuals with primary OCD found that 25.6% had a lifetime substance use disorder (23.2% with a lifetime alcohol use disorder and 13.3% with a lifetime drug use disorder) (Pinto et al., 2006).

The reasons for the high rate of lifetime SUDs among OCD subjects are unclear. One possibility is the very high levels of distress reported by individuals with OCD. On average, OCD patients report unusually poor quality of life, which correlates highly with OCD symptom severity (Eisen et al., 2006). Use of alcohol and drugs may therefore be a means of self-medicating this distress. This self-medication hypothesis has been examined in affective and anxiety disorders as a possible explanation for the increased rates of comorbidity with SUDs (Carpenter & Hasin, 1999). Some support for this hypothesis comes from a small study of 85 individuals with OCD. Twenty

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Message From the President

Dear Friends.

By the time you read this, the 13th Annual Obsessive

Compulsive Foundation Conference will have come and gone. I hope that your time was well spent and that you were able to learn more about how to cope with OCD and how to help those



who suffer with the disorder.

While you were there, you may have been fortunate enough to meet Dr. Michael Jenike and Diane Davey, members of the OCF Board of Directors who work hard to care for those with OCD. They work at the OCD Institute (OCDI), which was the first residential treatment program for OCD patients in the country. The Institute is located on the campus of McLean Hospital in Belmont, Massachusetts and is affiliated with Massachusetts General Hospital.

Diane Davey, a graduate of Boston College with a degree in Nursing, began her career at McLean Hospital on an inpatient Cognitive Behavioral Therapy (CBT) Unit, working primarily with patients diagnosed with Eating

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Bulletin Board

OCD TREATMENT STUDY FOR CHILDREN AND ADOLESCENTS

If your child or teen (ages 7-17) is suffering from Obsessive-Compulsive Disorder he or she may be able to participate in a research study at the National Institute of Mental Health in Bethesda, MD. We are investigating the medication riluzole which has been reported to benefit adults with OCD or depression. We expect that riluzole will decrease Obsessive-Compulsive symptoms in children and adolescents.

Children with a primary diagnosis of OCD, who reside within commuting distance of Bethesda, MD, may be eligible. Children will receive a one-day comprehensive psychiatric and medical evaluation, and follow-up visits every two weeks for 3 months, and at 4, 6, and 12 months. There is no charge to participate; travel assistance is provided.

Dr. Paul Grant, MD, a child and adolescent psychiatrist, is the Principal Investigator. For further information please contact Lorraine Lougee, LCSW-C at 301-435-6652 or Matthew Hirschtritt at 301-496-5323, or email OCDNIMH@intra.nimh.nih.gov.

National Institute of Mental Health, National Institutes of Health, Department of Health and Human Services.

PERCEPTUAL STUDY IN BDD, OCD AND CONTROLS

At the Bio Behavioral Institute we are studying how accurately OCD and BDD patients perceive their appearances. A computerized program is utilized in this study. As part of the study, participants who are interested in finding out how they think, feel and perceive their looks, would be photographed at the Institute and will have to answer a few questions. It will require about 30-60 minutes of their time. Feedback will be provided. Anyone interested please call Natalie, Great Neck, Long Island (516) 487-7116.

DECIDING BETWEEN RIGHT AND WRONG

What is your moral sense? Researchers at Harvard University are interested in how people decide between right and wrong. Your participation is very important to this project. If you wish to participate or just learn more, please log on to:

http://www.harvardcogevlab.org/MST/OCF/demographics1.php

OCD AND HOARDING STUDY

The Institute of Living in Hartford, CT and

The School of Social Work at Boston University are conducting research to understand the features of obsessive compulsive disorder and compulsive hoarding. The study compares people with hoarding problems to those who have obsessive-compulsive disorder (OCD). It is not necessary for participants to have hoarding problems or clutter to participate. The researchers hope to learn more about why hoarding and obsessive-compulsive symptoms develop, how these problems are related to other psychiatric disorders and how best to assess these problems. This information may be helpful for identifying effective treatments in the future. Researchers are looking for people age 18 or older who have (1) problems with excessive clutter or (2) obsessive-compulsive disorder and, (3) live within forty minutes of the greater Hartford or Boston area. The study consists of a 4-hour diagnostic interview about anxiety and mood symptoms followed by a 4-hour interview about clutter and acquiring. These interviews take place at the clinics. Additionally, the study will include a 1-hour visit to the participant's home where the participant will take part in an experimental task about removing clutter and another task about acquiring new items. Participants will also have a chance to take part in a discarding and acquisition task. Participants will be paid \$20/hr for their time and can make up to \$180.

If you are interested in participating and have any questions, please contact Jessica Rasmussen, B.A., at Boston University at (617) 358-4213 or (617) 353-9610 or Buck Brady, B.A., at The Institute of Living in Hartford, CT at (860) 545-7574.

NEW HOARDING THERAPY GROUP

Are you not able to part with anything, including the most useless junk, telling yourself, "I might need it someday?"

Does your home resemble a warehouse?

Have you pretty much given up hope in obtaining help for your problem?

Are you really motivated to do something about your hoarding?

A Hoarding Therapy Group provides both support and treatment. Individualized treatment plans are tailored to the needs and capabilities of each participant; de-hoarding assignments are manageable. Feelings relevant to the hoarding experience are explored. Guest speakers will be periodically scheduled.

For further information, contact Stacie Lewis, LCSW, at (212) 568-9570 (Manhattan, NYC location).

FREE COGNITIVE BEHAVIORAL TREATMENT FOR CHILDREN AND ADOLESCENTS WITH OBSESSIVE COMPULSIVE DISORDER IN THE SAN FRANCISCO BAY AREA!

We are seeking children and adolescents aged

7 to 17 with OCD who have not had cognitive behavioral therapy (CBT) for OCD before.

- Our study will test a new way to learn and do CBT using technology.
- There are no charges for the therapy or being in the study.

If you are interested, please contact Margo Thienemann, M.D., at mthiene@stanford.edu or 650 723 5383 or Sarah Forsberg at sarah523@stanford.edu.

For further information regarding questions, concerns, or complaints about research, research related injury, and questions about the rights of research participants, please call (650) 723-5244 or call toll free 1-866-680-2906 or write the Administrative Panel on Human Subjects in Medical Research, Administrative Panels Office, Stanford University, Stanford, CA 94305-5401.

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OCD NEWSLETTER

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The Obsessive Compulsive Foundation (OCF) is a not-for-profit organization. Its mission is to increase research into, treatment for and understanding of obsessive compulsive disorder (OCD). In addition to its bi-monthly newsletter, OCF resources and activities include: an annual membership conference, web site, training programs for mental health professionals, annual research awards, affiliates and support groups throughout the United States and Canada. The OCF also sends out Info Packets and Referral Lists to people with OCD, and sells books and pamphlets through the OCF bookstore.

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

SUBSTANCE USE DISORDERS

(continued from page 1)

percent had a lifetime substance use disorder and 77% of those individuals reported onset of OCD prior to developing the substance addiction (Hamel et al., 2004). So, not only are SUDs common among OCD subjects, but OCD may also be a precipitating factor in the development of substance addiction.

It is interesting that the substances most often abused by OCD subjects (alcohol and cannabis), while often abused in the general population, may be more likely than other substances to alleviate anxiety (Carrigan & Randall, 2003; Bukstein et al., 1989), which appears to be high in individuals with OCD (Pinto et al., 2006). It is also possible that the relationship between OCD and SUDs is more complex (e.g., that they share the same causal factors) or that there is not a causal relationship between them. Further research is needed to explore the relationship between OCD and SUDs, including the extent to which each disorder may contribute to the other disorder's development and maintenance.

Some reports posit that comorbid SUDs are associated with more severe psychiatric symptoms and poorer functioning in patients with other disorders. Recognizing comorbidity with SUDs in OCD is important because identifying and treating the SUD may significantly improve the prognosis of the OCD. This may be particularly important in individuals with OCD, because case reports in other disorders suggest that certain psychoactive substances, such as cocaine or methamphetamine, may exacerbate obsessional symptoms (Satel & McDougle, 1991; Koizumi, 1985). On the other hand, other substances, such as opiates, may be enticing for patients because they may potentially alleviate obsessional symptoms (Koran et al., 2005). Conversely, to the extent that OCD may potentially contribute to the development or maintenance of a SUD, it is also important to recognize and treat the OCD, which is often an underrecognized and inadequately treated disorder (Blanco et al., 2006).

Treatment

There is no data regarding whether to treat the substance addiction or OCD first or to treat both simultaneously. What we know concerning the neurobiology of both OCD and SUDs, however, is that there appears to be two different mechanisms

involved when these disorders co-occur. Evidence suggests that there is increased activity in cortico-basal ganglionic-thalamic circuitry underlying OCD symptoms. Addictions appear to be mediated via the ventral tegmental area and nucleus accumbens circuit which process reward via dopamine activity within the ventral striatum. Given these differences in neurobiology, effective treatment for OCD may differ substantially from treatment for a SUD. Although different treatments are involved, in our clinical experience we have found that patients with OCD and SUDs can be treated effectively for both disorders simultaneously.

It is well established that the pharmacological first-line treatment of choice for OCD is a serotonin reuptake inhibitor (SRI) (for example, clomipramine, fluvoxamine, fluoxetine). The data regarding the efficacy of SRIs in the treatment of addiction are mixed, with some studies showing a beneficial effect; but in many others there is no difference between active drug and placebo (Pettinati, 2001). In contrast to their role in OCD, SRIs do not have FDA approval for the treatment of addiction and are largely thought only to be helpful for targeting cooccurring disorders or symptoms in addictions.

Unlike the treatment of OCD, a range of treatment modalities are available for substance abusers and different modalities are appropriate at different phases of recovery. Detoxification is the first phase of recovery; and medications are often required to reduce symptoms of withdrawal. Longer acting benzodiazepines are typically used in alcohol withdrawal. Opioid withdrawal can be effectively managed using methadone, clonidine, naltrexone or buprenorphine.

The second phase of recovery is active treatment provided in settings ranging from weekly outpatient counseling, to ambulatory day programs, to residential treatment. The content of these treatments tends to be multimodal, often using a disease or twelve step orientation supplemented with cognitive and behavioral strategies. Naltrexone and acamprosate are medications approved by the FDA for treating alcohol-dependent patients. A large multicenter trial found that naltrexone and behavioral interventions both reduced alcohol intake, but that acamprosate had no effect on alcohol intake (Anton et al., 2006). Ondansetron has been shown to be effective in treating early-onset (predominantly male) alcoholism (Johnson et al. 2000). Methadone, naltrexone, LAAM (levoalpha-acetylmethadol), and buprenorphine

are pharmacological options for maintenance treatment of opioid dependence. A variety of medications have been evaluated for cocaine dependence, and disulfiram and baclofen have demonstrated early promise in randomized controlled trials (Carroll et al., 2004; Shoptaw et al., 2003). These medications can generally be used safely with SRIs when treating SUDs in OCD patients (except possibly fluvoxamine when used in methadone patients by possibly causing increased levels of methadone and potential toxicity). There are limited data supporting the efficacy of medications for the treatment of anxiolytic and sedative, cannabis, hallucinogens and other stimulant dependence.

The third phase of recovery is the maintenance phase. For some individuals, highly structured environments, such as halfway houses, are helpful in promoting longterm success. For others, some type of ongoing focus on recovery is important in the maintenance phase. Although exposure and response prevention forms of cognitive-behavioral therapy have shown clear benefit for OCD, when a SUD cooccurs with OCD, the therapy may also need to focus on relapse prevention forms of cognitive behavioral therapy. Attendance at twelve step programs such as Alcoholics Anonymous, Narcotic Anonymous, and Cocaine Anonymous is associated with better outcomes in numerous correlational studies. Alternative mutual support groups with less focus on the spiritual aspect of recovery, such as Women for Sobriety, SMART Recovery and Rational Recovery, are increasingly available across North America. These interventions can be used simultaneously with exposure and response prevention therapy for OCD.

Co-occurring SUDs in individuals with OCD are common and require treatment. Although the timing of the treatments has not been studied, it is our clinical experience that a person can safely and effectively receive treatment, both pharmacological and psychosocial, for both disorders simultaneously. In fact, because treatment of either OCD or an SUD could be complicated or even compromised by the presence of the other untreated condition, we believe simultaneous treatment may prove most effective in addressing both disorders. Research on effective treatments for individuals with OCD and an SUD are greatly needed.

For references, contact Dr. Grant at 612-273-9737 or e-mail him at grant @umn.edu.

FEELING IMPERMANENCE - OR "No

By Patricia M. Perrin, Ph.D. OCD and Anxiety Treatment Center, Houston, TX

I have observed in many primarily obsessional patients whom I have met and treated that sometimes they are consumed only with whether they actually feel, have felt, or will ever again feel a particular feeling. Their compulsive behaviors include checking, reassurance seeking or reviewing events to see how they once felt. These behaviors are not motivated by the need to prevent harm to themselves or loved ones, and not simply to get the obscure "just right" feeling that one gets from checking an already checked lock, but apparently to get a "just right" feeling about the constancy or permanence of a particular emotion. Rather than throw this manifestation of OCD in either of the large "just right OCD" or "obsessional" pots, I consider it an instance of an overlap of the two. Because the obsession is about the certainty of what one felt and the "ongoing" nature of the feeling, I have dubbed this phenomenon "feeling impermanence." The name seemed to fit, as the problem of feelings perhaps not being permanent resembled the issue of "object permanence," a concept taken from cognitive developmental theory - more on this

The concept seems to resonate with some of my obsessional patients, and with audience members who heard this concept presented at the 12th and 13th OC Foundation Conference. So I wish to invite a larger audience to consider this concept and to add examples which may fit, or to tweak or challenge the concept in ways that might make it more useful.

Perhaps the most easily recognized example of feeling impermanence would be someone who has what we call "relationship OCD." Someone with relationship OCD really loves his/her spouse or relationship partner, and wants to remain with him/her. Unfortunately, he or she constantly experiences doubt as to whether he or she really loves that person, whether he or she is with the wrong person, and whether the events that trigger doubt are actually evidence that he or she does not love their partner or, worse yet, never did! Here, the feeling that seems to be fleeting or nonexistent is love.

Another emotion that people struggle to feel sure about is found in scrupulosity, i.e., religious or moral obsessions. Here the feeling that is in doubt is one of being faithful or good enough. The third type I

have seen, especially in children, is a fear that if things don't go the way they want them to go that they not only will be disappointed, but that they will never be happy again. So the feeling in need of being permanent in this case, is happiness. The child's fear of never being happy again can be triggered by uncertainty about whether things will go his or her way, by true disappointment, or when an afternoon is unplanned and they cannot feel certain that the next thing they do will be fun.

And, of course, there are unique feelings that do not fall neatly in the above three categories, of love, faithfulness, or happiness, which fit the model as well. They all seem to have some characteristics in common which remind me of the notion of "object permanence (or object constancy)" coined by French developmental psychologist, Jean Piaget, who studied cognitive development in infants and children.

"Object permanence" is the ability to remember that something, or someone, continues to exist even though he, she, or it is not present. At five to seven months of age, if a baby is about to seize an object and it is covered with a cloth, or moved behind a screen, the baby withdraws its hand and cries or screams, apparently in fear. The baby reacts as if the object has been reabsorbed.

At eight or nine months of age, the baby searches looking under a screen or behind a barrier, for example, when an adult is playing peek-a-boo with the baby. The fear appears to be gone, because the baby is aware that, though out of sight, the object or person continues to exist. The baby somehow can hang onto the memory of the object, without visual evidence, whether the object is present but hidden or not actually present at that moment. Clearly memory capabilities are advancing.

Separation anxiety coincides with the emergence of object permanence. The baby is able to call up mental pictures of people. Babies learn about people leaving before they learn about returning. It seems that games involving separation and return, like peek-a-boo, are helpful in reducing anxiety in babies.

Like babies lacking object permanence, an OCD sufferer with feeling impermanence needs evidence that emotions continue to exist in order to feel certain and secure. So although feeling impermanence is a case of "just right" OCD in that one seeks to

get rid of a sense of unease, it is a special case in that it is more about hanging onto an emotional feeling, like love, versus comfort.

Feeling impermanence is also characterized by a belief that a feeling, once felt, should continue to be felt at the same intensity. If it is absent or diminished, doubt sets in as to whether the feeling ever was there or will return. The person tries to relieve anxiety and the "not right" feeling by compulsively reviewing how one felt in the past compared to now, and by seeking reassurance by telling the significant other that he is doubting his feelings. The hope is that the other person will reassure the doubter that his or her feelings are real and that they have a wonderful relationship. This reassurance neutralizes the anxiety briefly, but as in all cases of OCD, relief gained through neutralization is short-lived, and is, therefore, not a solution. In fact, compulsive checking and telling aimed at getting reassurance only worsen the anxiety and "not right" feelings.

The child who has attained object permanence, and who therefore can anticipate the return of the person, finds playing peek-a-boo fun and exhilarating; however, the OCD sufferer finds the apparent disappearance of a feeling intolerably painful. There is no excitement in anticipating the return of the elusive feeling, and it is replaced by unbearable uncertainty.

I do not believe there is any evidence that OCD sufferers actually have impaired memory. Rather it seems that they lack confidence in their memory and therefore act as if they do not remember things like locking doors, or in this case, having had an intense feeling. Also, individuals with OCD tend to pay too much attention to non-essential details and to ignore more important ones. So perhaps someone who focuses on the disappointment dealt to him/her by some minor infraction on the part of his/her partner (e.g., an oversight or a minor disagreement), is committing the common cognitive error of giving excessive importance to a relatively minor event. The more essential enduring feelings and connections between the partners are minimized.

Another interesting characteristic of individuals with feeling impermanence is that if efforts to reclaim a feeling fail or are inconsistent, hopelessness and depression instantly occur. I have seen children learn of a disappointment or learn of even an

W YOU FEEL IT, NOW YOU DON'T"

uncertainty about something working out the way they wanted it to be followed by them becoming very depressed. They say things like they don't know if they'll ever be able to be happy again, and sometimes they have thoughts of suicide. As soon as a plan is made so that they have the possibility of being happy again, or as soon as they are able to do what they think will bring happiness or fun again, they feel better. However, that feeling is again fleeting; and depression, hopelessness, and anxiety easily return. The urgency with which they implore parents to take them to do something fun, or to take them to buy something which will reinstate happiness, or to allow them to redecorate their room, or to reassure them that life will be good again is not a manipulation. These compulsive demands, which can be draining on parents (or spouses), make the OCD symptoms worse.

The feelings that may be targeted by feeling impermanence include love, faith, happiness, exhilaration, connectedness, fulfillment, being present, satisfaction, and feeling something is perfect. The obsession is that it is important to maintain a constant, intense level of feeling. If not, the fear is that 1) the feeling was never there; 2) I was pretending to love, be a faithful Christian, Jew, Muslim, etc., but I was a fake; 3) life is meaningless without this feeling; 4) I cannot tolerate the loss of the feeling, the uncertainty, or the sense of incompleteness; or 5) if I cannot reclaim the feeling, something bad might happen, such as, I may have to divorce my spouse, God may disapprove of me and send me to hell, or I may never be happy again.

So what would be the kind of evidence that would trigger someone with relationship OCD to think they do not really love their partner? They might see the partner coming out of the shower one morning, not looking his/her best, or the partner might forget the sufferer's birthday or plan something that does not fit the picture one had of how a day would go, leading to disappointment, or they might have an argument. They might see someone else in passing whom they find attractive. The intrusive thought might be "If I don't find her attractive at this moment, perhaps I never did or never will again," or "if I feel anger toward him or her, it must mean I don't feel love, so maybe I never did or never will again, and will have to end the marriage." They may take attraction to someone else as evidence that they are no longer committed to their

spouse, although to prevent this would require overriding centuries of genetic programming necessary for the species to survive. These thoughts occur in good marriages, where the sufferer honestly proclaims that s/he loves his/her spouse and would never want to end the relationship.

I always think of OCD as an opportunist, which finds an opening and rushes in with a disturbing, intrusive thought involving doubt. So the argument, or seeing the wife without make-up, or being disappointed, or seeing an attractive woman leads to doubt. One might think, in a culture in which the divorce rate is so high, "perhaps here is evidence that my marriage will be yet one more casualty."

Similarly, someone seeking to have the perfect faith may shop churches, checking to see which will give him/her the permanent feeling that s/he has the right faith, or that this is definitively what s/he should do and believe. Or perhaps someone may seek the perfect book that will give him/her the answer to the desire s/he has to know just what s/he must do to be a faithful person. Each book gives the feeling of offering "the way," until doubt sets in or until the next one is encountered, leaving the reader hopeless of ever knowing the "right" way to be a good person of faith. This sort of scrupulosity is more than just trying to say the perfect confession in order to hang onto the "just right" feeling. It's about feeling that the core feeling of believing in God is elusive. One moment a person enjoys peace about their faith, and the next, s/he compulsively compares him/herself to his/her friends and think s/he is a poor excuse for someone claiming to believe.

Compulsions involve checking for reassurance (with spouse, minister, therapist), as well as checking one's memory to see what that feeling felt like, if it was ever really there. Or someone might check the library or bookstore one more time for the book which has the answer about how to live a life of faith. The child who wants to hang onto a feeling of happiness may wear friends down by asking to be included in things or by pouting around friends if they do not want to do what the sufferer wants to do, thereby alienating the friends. Or the child may check to see if s/he are on a friend's My Space list of favorites; and if not, they may feel hopeless and depressed.

Compulsions may also include avoidance of triggers, e.g., avoiding seeing happy couples or not going to church.

They may self-reassure that their feelings are real, but they often torment spouses asking for reassurance. They may seek the good or happy feeling by buying something new only to return it when it does not continue to provide the necessary intensity of the good feeling. One may engage in the wishing ritual written about in a previous newsletter article by Dr. Jonathan Grayson. One may wish for an idealized picture of life to be true or for a particular feeling to stay or to stay at a certain intensity, or s/he may wish uncertainty, emotional or physical pain, or feelings of failure would go away.

In terms of treatment, exposure and response prevention is still the treatment of choice. Once the triggers for the obsessions about a feeling not being permanent are identified, exposures can be designed. One of my favorites is exposure to uncertainty, which is fairly easy to design. Imaginal exposure tapes can be made containing triggering scenarios, which the sufferer listens to repeatedly until the anxiety habituates. Habituation is reached when compulsions are abandoned or blocked; and when others are involved in providing reassurance, they agree to not give reassurance.

In one case, a married woman had impermanent feelings about 1) being a strong enough Christian, 2) being a good mother, and 3) being sure she married the right man. Her obsession was, if I can't get these feelings to stick, life will be meaningless. Compulsions were checking with her spouse (who was very supportive), comparing her faith with that of others at church, and constantly trying to make her children happy, even going to excessive efforts to please them. At times she felt depressed. However, the depression subsided temporarily if she did her compulsive behaviors. Antidepressants had alleviated any ongoing depression.

Treatment consisted of coaching the husband not to reassure; teaching her exposure to uncertainty; using imaginal exposure tapes; blocking the wishing ritual; and blocking efforts to do things perfectly. The exposure to uncertainty involved plugging a fearful intrusive thought into a formula that allows one to feel uncertain, keeping the anxiety present long enough for it to habituate.

So when an intrusive thought came about not being a good mother all the

 $(continued\ on\ page\ 7)$

Research Digest

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

These reports reinforce the importance of cognitive-behavior therapy as the most effective treatment for OCD. They also confirm that response to serotonin reuptake inhibitors (SRIs) may be delayed, even beyond three months, so long trials with SRIs are appropriate and wise. When long trials of SRIs produce insufficient improvement, adding antipsychotics or topiramate may be helpful, but this also adds complexity and, possibly, the burden of side effects. Three of the reports lend support to involvement of glutamate abnormalities in OCD. In addition to the beneficial effects of these glutamate modulating medications, identification of another factor in the psychopathology of OCD will spur further research on this neurotransmitter.

Self-help with minimal therapist contact for obsessive-compulsive disorder: a review

European Psychiatry, 21:75-80, 2006, D. Mataix-Cols and I.M. Marks

Although cognitive-behavioral therapy (CBT) is an effective treatment for OCD, there is a shortage of trained behavior therapists and treatment is expensive. Selfhelp options of bibliotherapy (reading materials), self-help groups, telephonedelivered CBT and computer-aided selfhelp for OCD were reviewed. No controlled studies of bibliotherapy or self-help groups for OCD were found. Three studies reported effectiveness of exposure and ritual prevention (ERP) instructions delivered by a therapist by phone. BT STEPS,* a fully interactive, computer-aided, selfhelp by ERP program, was effective in two open studies, a large multicenter study and a study enhancing the computer program with brief support from a clinician. Self-help approaches have the potential to help many more patients and to reduce treatment costs. With an average of 80 minutes of clinical support over a 10-week treatment, BT STEPS computer-aided self-help was cost-effective for OCD. Drs. Mataix-Cols and Marks propose a stepped care model for the treatment of OCD. Less complex cases should be offered immediate access to self-help with little support from a clinician. This frees time for experienced therapists to take on more complex cases. These more complex cases would be offered face-to-face sessions with a therapist. Severe or treatment-resistant cases would be offered intensive face-to-face treatment in a specialized hospital setting.

*BT STEPS is not currently available. If it becomes available, we will place an article in this newsletter.

Cognitive behaviour therapy and medication in the treatment of obsessive-compulsive disorder

Acta Psychiatrica Scandinavica, 113:408-419, 2006, K.P. O'Connor, F. Aardema, S. Robillard et al.

This OCD treatment study (43 patients) compared medication, cognitive-behavioral therapy (CBT), CBT plus medication, and placebo. All active treatments, but not placebo, improved OCD symptoms. CBT, with and without medication, was more effective than medication alone. The benefits of CBT were especially evident in cognitive measures. Only the groups receiving CBT showed significant decreases in obsessional doubt, anticipated consequences, ability to resist rituals, and beliefs in the need to perform rituals. CBT had a greater antiobsessional effect than medication, but CBT with medication had the greatest overall clinical improvement in depressive mood.

High-dose sertraline strategy for nonresponders to acute treatment for obsessive-compulsive disorder: a multicenter double-blind trial

Journal of Clinical Psychiatry, 67:15-22, 2006, P.T. Ninan, L.M. Koran, A. Kiev et al.

Researchers evaluated the effectiveness and safety of high-dose sertraline (Zoloft) for patients with OCD who had not responded to standard sertraline treatment. After participating in a 16-week sertraline treatment study, 66 nonresponder patients participated

in this double-blind continuation study. These patients were randomly assigned to an additional 12 weeks of treatment, either continuing on 200 mg/day of sertraline or increasing their dose to between 250 and 400 mg/day. A significant number of patients who had not responded during the initial 16-week treatment achieved a clinical response during continuation treatment with sertraline at daily doses of 200 mg (33% responder rate) or 250-400 mg (40% responder rate). Greater OCD symptom improvement was reported in the highdose sertraline group. Higher daily dosage of sertraline was well tolerated; there was a similar occurrence of side effects in both dosage groups. These OCD experts suggest that if higher than approved doses of sertraline are used, there should be periodic attempts to reduce the dose to standard levels (50-200 mg/day) to determine whether high doses are still necessary.

A systematic review: antipsychotic augmentation with treatment refractory obsessive-compulsive disorder

Molecular Psychiatry, 11:622-632, 2006. M.H. Bloch, A. Landeros-Weisenberger, B. Kelmendi et al.

The effectiveness of antipsychotic augmentation of serotonin reuptake inhibitors (SRIs) for patients with OCD not responding to SRI monotherapy was evaluated. Nine double-blind controlled studies were identified. Nearly one-third of the OCD patients in these studies responded to the addition of an antipsychotic medication. A subgroup of OCD patients with comorbid tic disorders had a particularly beneficial response to antipsychotic augmentation. Comparing antipsychotic drugs used, there was strong evidence for haloperidol (Haldol) and risperidone (Risperdal) augmentation compared to placebo augmentation. The effectiveness of adding quetiapine (Seroquel) or olanzapine (Zyprexa) was inconclusive. Evidence suggested OCD patients should be treated with at least 3 months of maximum dose tolerated SRI monotherapy before adding an antipsychotic medication because there was a high rate of response (25.6%) to

continued SRI monotherapy past 12 weeks. Results also suggested that antipsychotic augmentation works relatively quickly; patients were unlikely to improve if they had not responded after 4 weeks of treatment. This meta-analysis, a process of combining and comparing research results, supports antipsychotic augmentation, especially with haloperidol and risperidone, as an effective treatment strategy for OCD patients who fail to respond to SRI monotherapy.

Topiramate augmentation in treatmentresistant obsessive-compulsive disorder: a retrospective, open-label case series

Depression and Anxiety, 23:1-5, 2006, M. Van Ameringen, C. Mancini, B. Patterson et al.

There is recent evidence of glutamatergic hyperactivity in OCD, including case reports of glutamate modulating drugs (memantine [Namenda] and riluzole [Rilutek]) improving OCD symptoms. Additionally, there is evidence of a decrease of brain glutamate levels with SRI treatment. Many patients with OCD do not respond or only partially respond to treatment with SRIs. Topiramate (Topamax) is an anticonvulsant drug with glutamatergic properties. In this study, 16 patients who were SRI partial responders or nonresponders had topiramate added to their ongoing SRI monotherapy or SRI combination therapy (other medications such as antipsychotics or benzodiazepines). All patients were treated for at least 14 weeks with topiramate augmentation, the average dose being 253 mg/day. Eleven of the 16 (69%) were considered responders. The average time to response was 9 weeks. A majority of patients experienced side effects, including weight loss, fatigue, word-finding difficulties and paresthesias (body sensations such as numbness). This case series suggests topiramate augmentation may be useful in treatment-resistant OCD.

The effects of topiramate adjunctive treatment added to antidepressants in patients with resistant obsessive-compulsive disorder

Journal of Clinical Psychopharmacology, 26:341-344, 2006, G. Rubio, M.A. Jimenez-Arriero, I. Martinez-Gras et al. In this open trial, topiramate was added to ongoing SRI medication for 12 patients who had not responded to 2 or more adequate SRI trials. Ten patients (83%) responded to the topiramate augmentation, with the average response time being 9.5 weeks. Topiramate was started at 25 mg/day and increased slowly up to an average dose of 200-300 mg/day. Most commonly reported side effects were weight loss, sedation, memory problems and paresthesias. This case series provides further support for topiramate augmentation as a useful strategy for treatment-resistant OCD.

N-acetylcysteine augmentation in serotonin reuptake inhibitor refractory obsessive-compulsive disorder

Psychopharmacology, 184:254-256, 2006, D.L. Lafleur, C. Pittenger, B. Kelmendi et al.

N-acetylcysteine (NAC) is an amino acid compound that is believed to affect glutamate transmission in the brain. Although this article only reports on one individual responding to NAC, it is of interest because NAC can be obtained without a prescription. This patient had a partial response to fluvoxamine (Luvox), which she had been taking for 12 years at a daily dosage of 300 mg. NAC was added to the fluvoxamine, starting with 600 milligrams daily and increasing the dosage to 3 grams daily over 6 weeks. The NAC was continued at 3 grams per day for another 7 weeks. There was significant improvement in her OCD symptoms and this improvement was maintained at a 2-month follow-up visit. This is a single case report; it is not advised to use NAC at this time. Instead, this case report suggests further study of NAC and other glutamate modulating agents for OCD is warranted.

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Fund

Feeling Impermanence

(continued from page 5)

time, she did exposure to thoughts of uncertainty "Maybe I'll never feel like a good mother again, maybe I will. There's no way to be sure." She not only improved dramatically, but she is able to use the tools she learned independently, without the therapist's help.

A 12 year old girl who does very well in school fears that she will be unhappy or bored. If there isn't a plan to do something fun or to have a friend over, she is triggered to have the intrusive thought that life isn't ever going to be good, and she immediately feels hopeless. She too was successfully treated for depression with antidepressants, and only reported fleeting depressive feelings in response to identified triggers. She utilized exposure to uncertainty, thinking "if I don't have a plan for the rest of the day, maybe I'll never be happy again, maybe I will. I just don't know for sure." Her mother helped her with response prevention by blocking her attempts to get reassurance (she did not reassure her). Her anxiety habituated successfully. When she occasionally has the intrusive thought, she recognizes it as OCD and uses the exposure to uncertainty.

So, although, we have known for some time that we must help individuals with OCD to live with uncertainty, we also must help them to live with impermanence. The Buddhists and other writers (e.g., Eckart Tolle, author of The Power of Now) have long known that impermanence is a principle which we all must accept, i.e., an awareness that all there ever is is the present moment, the now, and to operate as if there is anything more is an illusion. It seems that anxiety across the board keeps one's focus on the past or the future and prevents staying present. When I offer the idea of staying present as a goal to individuals with OCD, the idea appears to resonate as desirable. First, good exposure techniques must free them from enough anxiety and ritualizing to be able to be present.

Perhaps identifying the feeling impermanence form of obsessional OCD or "just right" OCD will help some sufferers who previously had not been entirely understood. Then they will be free to navigate life with its predictably unpredictable fluctuations in emotions, such as, love, feeling connected with God, or happiness, that give life meaning without fearing that these feelings have abandoned them.

OCD, RECOVERY AND REAL ESTATE: A STOI

For parents of children with OCD, the quest to discover effective treatment options for their children requires relentless determination. Mary is no different. As the mother of a daughter with OCD, Mary (who asked that we not reveal her last name to protect her daughter's privacy) waded through misdiagnoses, dismissive doctors, and her family's private pain in her pursuit of the best treatment options for her daughter.

Along the way, Mary became an OCF member and was determined to raise money for OCD research in a unique way. She earned her real estate license and decided to use the commissions from her real estate sales to support OCF-sponsored research. Her special area of interest is the genetic transmission of OCD.

Although Mary learned a lot about OCD, she says that OCD taught her important life lessons, too. "When I took a personality test, the clinician said that I had one attribute that was way over the normal range. I wondered what that could be," Mary said. "She told me that some people would call it obstinacy but it was really persistence. I gained awareness that this is a great attribute when used against a formidable opponent like OCD, but not worth the energy for many of life's ordinary inconveniences. OCD taught me perspective on problems, persistence through them, and to cherish the peaceful times."

The following is an interview with Mary about her resolve to support her daughter and the work of the OCF.

NEWSLETTER: How has OCD affected your family?

MARY: Hugely! I grew up with a sibling with OCD which was not a recognized or named disorder back in those days. It greatly affected my childhood and young adulthood until my sibling got some control over it. Many times, our vacations were disrupted, although I have to credit my parents with trying to plug along as normally as possible. Having police show up periodically at home, because a concerned neighbor called, got to be embarrassing. I didn't have friends over because it was hard to explain the strange behavior, which would have frightened them off anyway. My parents searched the country for answers and found few. They didn't allow inaccurate labels to be put on my sibling which was wise.

When I married, I was a bit concerned about having children after experiencing the challenge my parents had faced. When I did have my daughter, I was at home full-time with her and noticed her anxiety at a very early age – maybe 6 years old. It looked all too familiar! A child psychologist at our local

children's hospital gave me the diagnosis of OCD. I then took my daughter to D.C. to see Judy Rapoport, one of the original OCD researchers and the author of *The Boy Who Couldn't Stop Washing*. It still wasn't clear how to get help even though I now had a name for it. Even with our family background, I found that everyone thought I was creating "the problem" and refused to help me, even though I really needed a break at times.

I must say, however, that my relationship with my daughter is the closest one in my life and it is because I was uniquely qualified to understand that she was not difficult on purpose and so I was able to hang in there with her knowing it was not her fault and she is a fighter...it was very hard to watch her

struggle. I feel uniquely blessed to understand this disorder so well, but to be unaffected by it so that I can hopefully champion the cause in some way.

NEWSLETTER: How did you find a good treatment provider to help your child?

MARY: Trial and error unfortunately; it took 7 years and some serious missteps with St. John's Wort that put us in a pretty desperate situation before our

pediatrician recommended the double-boarded neurologist/psychiatrist who empowered us with hope and respect. My daughter liked the fact that he was a neurologist, because then we knew her problems were of a neuro-biochemical nature, and not caused by family dynamics or a difficult personality – although everyone around us implied otherwise. It takes a very perceptive professional to see OCD for what it is and not blame someone for causing it.

This experience has also taught us not to put too much stock in others' opinions, especially the negative ones – the therapist was wrong about it always running your life and many people along the way were wrong about what "caused" it. Thinking independently saved our self-respect and enabled us to move on in search of relief. I would run from anyone who strips you of hope and blames the family.

Likewise, protect your overwhelmed child from unkindness as much as possible. I always had my daughter's playdates at my home and made a big effort to encourage social interaction. Your child often cannot make social things work without you helping her over some hurdles. It does make a difference in the long run, even though it may seem like there is no end in sight and you are doing much more than parents of "normal" kids. I used to use self-talk to encourage myself to keep going. I would acknowledge that I had a special needs child of a different sort - one that few could understand - and that I would protect with privacy. The family needs to bond together to fight this formidable disorder. Naturally a family under this kind of stress is going to accommodate things in "dysfunctional" ways, but I think OCD is the "horse" in front of the "cart"!



NEWSLETTER: What advice would you give parents about what to do when a child has OCD?

MARY: Tell your loved one that you will always be there for her no matter how hard it gets and that you will do anything within your power to help her in her struggle. I know it sounds obvious, but it is powerful to have someone express unconditional love to you directly in your hour of greatest need.

I think it is important to point out to your loved one that you recognize that OCD traits are not her personality and that you would like to help her uncover her true personality that is being masked by the OCD. I think people don't distinguish between the two. My daughter's "unearthed" personality is decidedly upbeat, adventurous and fun-loving. I could see glimpses of those traits, but they were definitely overshadowed by OCD traits like apprehension and inflexibility. In our case, animals - really an assortment of household pets - were very therapeutic and offered the kind of love that can reach someone in a lot of pain.

RY ABOUT GETTING WELL AND GIVING BACK

Offering hope is the single most important thing you can do to give a struggling person the energy and drive to keep trying. We were told by our doctor that OCD was one of the easier things to deal with that he sees on a daily basis. That sure took the dread factor out of the situation and gave us hope and renewed energy to try something from the "menu" of options he presented us with. This was a studied contrast to the therapist we visited the week before, who told my daughter to get used to struggling with OCD because she would have to live with it the rest of her

The other helpful doctor further empowered my daughter by asking her what she would like to try and what amount of medication she was comfortable with starting on, explaining the customary range of each. Instead of mandating a regimen that she would "have to stick with for 8 to 10 weeks" even if it was not working out so well – he partnered with her to help her make some choices, which he assured her could be altered according to her input and comfort level. Having some degree of control and a knowledgeable person to give her choices and information allowed her to try some medication to which she had previously been adamantly opposed. When she found a medication that broke the strong hold of the OCD, she was able to implement some other coping measures and practice derailing thoughts before they could get a grip on her.

NEWSLETTER: Which of the Foundation's initiatives are you most interested in?



MARY: The genetic research means a lot to me because I believe that OCD has been in four generations of my family – traveling through the females.

NEWSLETTER: Why do you think the Foundation's commitment to funding research is so important?



MARY: Since my childhood in the sixties, the disorder has been named and understood biochemically, and demystified, to some degree. These are huge strides in a couple of decades. I would like to fund more research to figure out the genetic transmission of this disorder as well as determine why some medications work well for some patients and not for others.

NEWSLETTER: You gave the Foundation a large contribution for its research program last winter. How did you raise that money?

MARY: I looked at my resources in terms of my business aptitude, my social network and

time and energy constraints and decided that it was too late in life for me to become a medical researcher (my minor was actually in biology!). But perhaps I could support a researcher if I could earn some money! So I decided to go into real

estate and see how well I could do. The idea (to use commissions from real estate sales was) the best way I could think of to make money at this stage of life. Luckily, my idealism has helped me through what is actually quite a challenging field to break into successfully. But, I made a promise to God and

myself that if my daughter was ever set free, I would do something to make a difference for those who suffer. After all, my life has been uniquely fashioned for this challenge from the very beginning. I would like to have grandkids, too, and we must move forward to find some answers for the next generation.

NEWSLETTER: Would you encourage other OCF members to contribute to the OCF

research program?

MARY: Of course! Many small amounts make a large difference. Remember at some point we reach critical mass, or the tipping point, as it is also referred to. I never want to look back and wonder what would have happened if I had tried to make a difference. I learned from OCD to savor every peaceful moment and make the most of the good stretches.

NEWSLETTER: Does your daughter have her OCD under control?

MARY: Yes. She is able to travel on her own to third world countries, where she has been on mission trips in some pretty "earthy" venues. She loves foreign cultures and has a heart for the people. Presently, she is in Morocco learning Arabic and living with a Muslim family. She ate what she thought was a date out of a bowl and discovered that it was a brown piece of soap! Now that's a clean obsession!

My daughter got her OCD under control because her doctor gave her the tools she needed and, I must say, more than a few people prayed for her recovery.

She now knows her limits pretty well and will tell me directly when I am asking too much of her especially when she is feeling vulnerable due to lack of sleep, stress or other things. I know you'll believe me when I tell you that I DO back off and let her handle it because she has gained a hard-won ability to manage her OCD and I respect that – but I will always be there if she needs me.

Pictured are the houses whose commissions went to the OCF Research Fund.

FROM THE PRESIDENT

(continued from page 1)

Disorders, Depression, and Anxiety Disorders, such as OCD. She became interested in behavioral therapy at that time, and has stuck with this treatment modality throughout her career.



Diane Baney Davey

In 1992, Diane received her Masters in Business Administration from Boston University with a Concentration in Health Care Administration. Still at McLean, Davey became involved with the development of

enhanced residential and partial hospital programs, as well as a business that provided home-based behavioral therapy to psychiatric patients. The majority of these patients had Obsessive Compulsive Disorder and this is where she had her first exposure to OCD patients. Through this project, she was introduced to Michael Jenike, who was working on the opening of the OCDI. It was at this time that she was asked to join the Institute as Program Director. The OCDI opened in 1997 and according to Diane, was an immediate success, largely due to the support and the encouragement the Institute received from our foundation. Diane was invited to join the OCF in 1999, served as the Treasurer of the Board, and is currently Chair of the Affiliates Committee and a member of both the Public Relations Committee and the Nominating Committee.

Dr. Jenike's affiliation with the Obsessive Compulsive Foundation began in 1987 when he first saw Patti Perkins, one of the original founders of the OCF, on the Oprah Winfrey Show. After seeing her discuss her struggle with OCD, Michael wrote her a note telling her how well she had done on the show. Years later, Michael joined the OCF Scientific Advisory Board (SAB) and for the last ten years, he has been the Chair of the SAB, and a member of the OCF Board of Directors. He received his medical degree from the University of Oklahoma in 1978 and a post doctorate degree

from the Harvard School of Public Health. Dr. Jenike is presently a professor of Psychiatry at the Harvard Medical School and a Psychiatrist at Massachusetts General Hospital in Boston, Massachusetts.

Dr. Jenike's advice and guidance in the area of research and patient care has been invaluable, particularly for awarding OCF sponsored research grants. From the early eighties, Michael has been involved in the drug trials of Anafranil, Prozac and Luvox. Michael has written several articles for the OCD Newsletter on medication, brain structural abnormalities in OCD and how to select a behavioral therapist. Additionally, he developed the pamphlet, "Drug Treatment of OCD in Adults: A Guide," which is available for new members of the Foundation. In addition to other works, Michael wrote the book, Obsessive Compulsive Disorders: Practical Management, in 1986. There are three editions of this book, the last published in 1998. While the first two editions were primarily written for clinicians, the third edition attracts a broader audience by including up-to-date (i.e., Internet-driven) resources for those struggling with OCD and their family members.

Michael also participates in the on-line discussion forum OCD-List that Chris



Dr. Michael Jenike

Vertullo, another OCF Board member, started. He responds to questions that pertain to medicine, CBT, and exposure and response prevention (ERP). I would be remiss if I failed to men-

tion his superb clinical skills, as I have seen firsthand Michael's ability to connect with the patient who is often paralyzed with fear.

Both Diane and Michael are known for the genuine care and support they offer to OCD sufferers and their families. Being parents themselves, they understand the desire a parent has to find the best medical care possible. We are grateful for all of the time they donate to the OCF, because they always go above and beyond what is asked of them. I would like to conclude this piece with a beautiful statement from Diane about her work with the OCF.

"I can't imagine donating my time to a more worthwhile organization than the OC Foundation. Working with OCD patients and their families on a daily basis gives me a constant appreciation of what a difficult and debilitating disease this is, and how alone and helpless it can make people feel. The OCF has provided information, education and hope to countless patients and their families, and I am proud to be a part of it."

Thank you, Diane and Michael, for making all of us proud to be a part of the Foundation.

Best Regards,

Joy Kant

President of the Obsessive Compulsive Foundation Board of Directors

Dear OCF Conference Attendees:

I wanted to let you know how much I missed you all at the Annual Conference in Atlanta. lust before the Conference I became very ill and was unable to attend. I spoke with so many people before the Conference and also corresponded with you via email that I was so looking forward to meeting first time attendees and seeing old friends. I would love to hear from attendees about your Conference experience or if you have any suggestions for next year. Please write me at: cole@ocfoundation.org or, leannette Cole **Deputy Director** OC Foundation, Inc. 676 State Street New Haven, CT 06511 I am really looking forward to Houston in 2007. See You there!



Overcoming Compulsive Washing

By Paul R. Munford, Ph.D.

Reviewed by Gerald Tarlow, Ph.D. Los Angeles, CA

Dr. Paul Munford has written another self-help book for patients with obsessive compulsive disorder. Do we really



need another self help book for OCD? The answer is "yes." The first popular self-help book for OCD was *The Boy Who Couldn't Stop Washing*, which was published in 1989. This

book mainly consisted of different descriptions of patients with OCD. The publication of the book allowed millions of people suffering with OCD to realize they were not alone and to seek treatment. Self-help OCD books progressed over the years to incorporate many of the highly successful behavioral therapy techniques. Books such as Getting Control by Lee Baer enabled many highly motivated patients to utilize the behavior therapy treatment on their own. Most of the next generation of OCD self-help books were very similar in their attempt to offer treatment suggestions for a wide variety of OCD symptoms. In the past few years, we have seen the development of a new generation of OCD books that focus on specific OCD symptoms. Dr. Munford has previously authored a self-help book on OCD checking. Other recent self-help books have covered OCD hoarding and obsessive thoughts. Dr. Munford's current book continues this trend by focusing on obsessive compulsive washing.

Dr. Munford is an extremely experienced clinician who has treated hundreds of OCD patients in his private practice and in intensive outpatient programs. His experience enables him to get across succinctly the most important information regarding the

treatment of OCD washing. The book is very easy to read and full of relevant case examples.

The first chapter, "What You Need to Know to Help Yourself," provides a good introduction to the diagnosis and different theories of the development of OCD. There is also a brief discussion of both anxiety and depressive disorders that occur concurrently with OCD. Although, it might also have been a useful addition to mention OCD spectrum disorders in this chapter.

Chapter two, "Contamination Fears and other Triggers," contains an excellent discussion of why people develop certain OCD symptoms. There is also a very comprehensive discussion of the different contamination triggers, numerous examples of washing and cleaning compulsions and examples of avoidance behaviors.

In the next chapter, Dr. Munford introduces two new self-rating scales for OCD: the Survey of Obsessions and Compulsions for OCD (SOC-OCD) and the Distress and Interference from OCD (DI-OCD). These self-rating scales appear to be very patient-friendly, but need to be validated on more patient samples.

Chapter four, "Face, Embrace and Erase the Fear," introduces the behavior therapy technique of exposure, ritual prevention and awareness therapy (ERPA).

This therapy is Dr. Munford's modification of traditional ERP therapy for OCD. He has added the "awareness" component that emphasizes the patient's ability to pay attention to uncomfortable thoughts and anxiety feelings following traditional exposure. In some ways this component resembles mindfulness training. It is an interesting addition to traditional behavior therapy.

The book presents specific exposure exercises to address the fears of illness, urine, feces and blood. Each of these chapters contains specific instructions that will allow patients to

carry out exposure assignments without a therapist. Dr. Munford shares some very creative assignments with the reader. For example, there are directions for making fake urine and blood that can be used for the exposures. There is an emphasis on gradual exposure for all fears. Included are guidelines for appropriate washing and methods to increase awareness.

The final chapter "Hindrances, Helpers, and Holding on to Success" presents a good discussion of the problems patients may have in implementing the therapeutic techniques. Dr. Munford offers practical solutions for each problem. There is also an important section on how family and friends can help the OCD patient and the book concludes with a short section on maintaining treatment gains.

Perhaps the only thing lacking in this book is a more thorough discussion of the role of medications in the treatment of OCD washing. Overall, this book is a welcome addition to the list of self-help books available for OCD.

Please Designate
the Obsessive
Compulsive
Foundation
as Your
At-Work
Charity of
Choice

Is Your Child With OCD Eligible for Social Security Benefits?

Regardless of the age of your child, the answer might be "Yes."

Although we are all familiar with Social Security's retirement benefits, there is much more. Children with physical and mental disabilities, still dependent on their parents, are also eligible for monthly payments. Suffering from Obsessive Compulsive Disorder may qualify your child to receive this support. It is important that you contact the Social Security Administration for complete information to determine whether your child is eligible, but here is an overview that may help you decide whether or not you should pursue this support.

There are two Social Security programs that can benefit your child. The first is Supplemental Security Income, available to children under the age of 18. The second is Social Security Disability Insurance available to adults who became disabled before the age of 22 and have parents who receive Social Security benefits or qualified for death benefits.

SUPPLEMENTAL SECURITY INCOME

Eligibility

A child under 18 with physical or mental disabilities can qualify for monthly payments from Supplemental Security Income (SSI). There is no set federal SSI payment, amounts differ between states. But, SSI payments are limited to \$30 per month, regardless of where you live, when a child is a resident of a medical facility covered by insurance.

Each child must meet certain criteria to qualify for SSI benefits:

- the child's condition must meet Social Security's definition of a disability and result in marked and severe functional limitations that have lasted, or are expected to last, for at least 12 months,
- the child's income and resources fall within the eligibility limits,
- the child must not be working at a job that pays more than a monthly limit determined each year by the program.

In the SSI program, age 18 is considered an adult and some different criteria may apply.

Applying for SSI

A great deal of information is required to determine your child's eligibility for SSI. You will need to provide detailed information about your child's condition and how it impairs the child's ability to function.

This includes any medical or school records that you have and permission for the doctors, teachers, therapists and other professionals who treat your child to release relevant infor-

mation. In some cases, a medical examination may be required. If so, the agency will absorb the cost. You will also need to provide records showing your child's income and other financial resources, as well as your own.

All information submitted to Social Security is given to the Disability Determination Services in your home state where doctors and trained staff will process the request and decide if all criteria are met. Keep in mind that it can take three to five months for the agency to make a final determination, although exceptions can be made to provide immediate benefits under certain circumstances.

Disability Reviews

Once your child begins receiving SSI, the law requires that his or her medical condition is reviewed at least every three years until the child is 18 years old. During these reviews, you will be asked to provide evidence that your child has been receiving medical treatment for the disability.

SOCIAL SECURITY DISABILITY INSURANCE

Eligibility

Even though Social Security Disability Insurance (SSDI) pays benefits to adults who became disabled before age 22, it is considered a child's benefit because it is paid on a parent's Social Security earnings record. To be eligible the "child" must:

- have at least one parent receiving Social Security benefits, or
- have a parent who, although dead, worked long enough to qualify for benefits under Social Security, or
- have received dependents' benefits on a parent's Social Security prior to age 18 due to disability.

SSDI benefits continue as long as the individual remains disabled regardless of whether the child has ever worked.

Applying for SSDI

The disability rules for receiving SSDI benefits are based on adult disability criteria. As with SSI, the child's disability application is reviewed by the Disability Determination Services in each state. Be prepared to provide as much detailed information as possible about the child's medical condition, including medical records and permission to speak with doctors and therapists. Social Security will contact your child's doctors and therapists directly for reports

OTHER IMPORTANT INFORMATION FOR YOUR CHILD'S HEALTH AND WELL-BEING

In addition to SSI and SSDI, there are other programs and services that can help your child.

Medicaid

Medicaid is a health care program for people with low incomes and limited resources. In most states, children who receive SSI payments qualify for Medicaid; although, in some states you need to apply directly for benefits. Some children can qualify for Medicaid benefits even if the do not receive SSI.

Children with Special Heath Care Needs

When your child receives SSI, Social Security's Children with Special Heath Care Needs program will refer you to health care services managed by each state. These include clinics, private offices, hospital out-patient and inpatient treatment centers, and community agencies.

Even if your child does not qualify for SSI or SSDI, Children with Special Heath Care Needs programs in your local area may be able to help you. Contact your local health department, social services agency or hospital for programs near you.

State Children's Health Insurance Program

The State Children's Health Insurance Program is available in every state and provides health insurance to children from working families without insurance but with incomes too high to qualify for Medicaid. The program includes coverage for prescription drugs and mental health services. Your state Medicaid agency can provide full information about the program. To learn more call 1-877-543-7669 or go to www.cms.gov/schip.

Employment Support Programs

Social Security has many ways to encourage young people with disabilities to work and gain independence that do not negatively impact their SSI or SSDI benefits. A child under 15 years old may qualify for training programs. There is also a program called Plan to Achieve Self-Support (PASS) which allows a child 15 or older to save income and resources for education without impacting his or her income for SSI purposes.

CONTACT INFORMATION

For additional information on all these programs and forms to begin the process of requesting assistance, visit www.social security.gov, call 1-800-772-1213 twenty-four hours a day, or visit your local Social Security office. Please be sure that you have your child's Social Security number and birth certificate, as well as your own Social Security number when beginning the application process.

Bulletin Board

(continued from page 2)

BODY IMAGE TREATMENT RESEARCH STUDY

Do you dislike the way any part(s) of your body (for example, your skin, hair, nose, eyes, and genitals) look? Do you think about your appearance for more than one hour per day? Do you engage in any behaviors intended to check on, hide, or fix your appearance (for example, mirror checking, comparing yourself to others, excessive grooming behaviors)? Or do you avoid any places, people or activities because of your appearance concerns (for example, do you avoid bright lights, mirrors, dating, or parties)? Do your appearance-related thoughts or behaviors cause you a lot of anxiety, sadness, or shame? Do you have problems with your work, school, family, or friends because of your appearance concerns?

If you answered any of these questions with "yes" and if your primary problem is not related to unusual eating habits or weight concerns, you might be eligible to participate in a study at the Massachusetts General Hospital (MGH). If you qualify, you will receive the following: Diagnostic evaluation at no cost and medication treatment at no cost. You will also be asked to fill out some questionnaires assessing body image symptoms, anxiety and mood. If you are interested in participating or would like to get further information, please call Stephanie Renaud at (617) 643-3079 at the Massachusetts General Hospital Body Dysmorphic Disorder Clinic, or email her at bdd@partners.org.

DO YOU SUFFER FROM OBSESSIVE-COMPULSIVE DISORDER?

Do you have unwanted thoughts that are hard to control? Do you have any behaviors that you have to do again and again and cannot resist doing? Have you been diagnosed with obsessive-compulsive disorder (OCD)? Do you have problems with your work or social life because of this?

Dr. Sabine Wilhelm of the Massachusetts General Hospital OCD Clinic and Research Unit is seeking participants for a research study on the use of a medication in combination with behavior therapy to reduce the symptoms associated with obsessive-compulsive disorder. To be eligible, you must: have OCD, be between 18 and 65 years old, be able to commute to the Boston area, be able to participate for 10 weeks, not be pregnant or breastfeeding. If you are interested in this study and believe you are eligible, please contact Dr. Ulrike Buhlmann at (617) 726-5374 or e-mail her at ubuhlmann@partners.org.

Do You Have Obsessive-Compulsive Disorder?

Do you still have symptoms? We are conduct-

ing a research study of an investigational supplemental agent for individuals age 18-65, who have been treated for obsessive-compulsive disorder but still have symptoms.

All study-related procedures and evaluations are provided at no expense. Reimbursement for participation is available. For more information and to find out if you are eligible for this study, please call Joanna at (845) 398-2183.

The Nathan Kline Institute Outpatient Research Program Orangeburg, NY www.rfmh.org/nki

University of Florida Research Study

Do you repeatedly check or arrange things, have to wash your hands repeatedly, or maintain a particular order? Do unpleasant thoughts repeatedly enter your mind, such as, concerns with germs or dirt or needing to arrange things "just so"?

If this sounds familiar, you may have a treatable problem called obsessive-compulsive disorder (OCD). Past research has found that a form of therapy, namely, cognitive-behavior therapy, is helpful in as many as 85% of people with OCD. Researchers at the University of Florida are interested in determining if adding a medication called D-Cycloserine improves the effectiveness of cognitive-behavior therapy in adults with OCD.

To be eligible, you must be at least 18 years old. If you participate in this study, you will be randomly assigned, that is, by chance, as in the "flip of a coin," to receive either the study medication (D-Cycloserine) or a sugar pill in addition to being seen in therapy. The therapy will be held weekly (90 minutes each session) for 12 weeks (12 total sessions). There will also be nine psychiatric evaluations that take place. Three of these evaluations will be comprehensive and take about 2 1/2 hours each (immediately before and after treatment and three months later). Six will be short and take place once a week during therapy (25 minutes each). You are responsible for the cost of therapy. Study medication and the evaluations will be provided at no charge. Participants will also receive financial compensation for their time.

If interested, please contact Dr. Eric Storch at (352) 392-3611 or estorch@psychiatry.ufl.edu.

A FAMILY RESEARCH PROJECT

Who? We are a research team from The Johns Hopkins Hospital who are interested in studying family functioning in different groups of children between the ages of 6-17 years.

What? To study family functioning of children and adolescents with Obsessive Compulsive symptoms and those without symptoms.

Where? In your own home. No hospital or

school visits are necessary.

How? (Parent) A phone interview regarding your child's behavior and daily functioning as well as your relationship with your child. Paper and pencil questionnaires regarding aspects of family functioning.

(Child and adolescent) A phone interview regarding his/her behavior and daily functioning. Questionnaires regarding his/her relationship with you and his/her personality.

Compensation? Your child will be given a \$15 gift certificiate to a book store in exchange for participation. This will be given after all questionnaires and interviews are completed.

How to Join this Research? Call us at 443-287-2292 or e-mail Marco Grados, M.D., M.P.H., at MJGrados@jhmi.edu and let us know if you are interested in participating and when we can reach you.

Your participation will help us understand family functioning in children and adolescents with OCD. Principal Investigator: Marco Grados.

HAVE YOU BEEN DIAGNOSED WITH OCD?

If you are between the ages of 18 and 55, and are diagnosed with OCD but currently not on medication for OCD treatment, you may be eligible for an fMRI research study at Mount Sinai School of Medicine. The study will involve answering questionnaires and undergoing one functional MRI (a non-invasive brain scan). You will be reimbursed for participation in the brain scan. For more information, contact Suah at (212) 241-3116.

Celebrate the
OCF's 20th
Anniversary
by Donating
to the
OCF Research
Fund

Sign Up For The Obsessive Compulsive Foundation's Behavior Therapy Institute on October 13-15, 2006 at the Saint Louis Behavioral Medicine Institute, St. Louis, MO

The BTI is a three-day intensive training course in Cognitive Behavior Therapy for mental health professionals who are treating individuals with Obsessive Compulsive Disorder and the OC Spectrum Disorders.

BTI FACULTY

Throstur Bjorgvinsson, Ph.D.

Program Director, Obsessive-Compulsive Disorder Program,
The Menninger Clinic
Associate Professor of Psychiatry & Behavioral Science,
Baylor College of Medicine

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Bradley Riemann, Ph.D.

Clinical Director, OCD Center at Rogers Memorial Hospital

Reed Simpson, M.D.

Medical Director, Anxiety Disorders Center, Saint Louis Behavioral Medicine Institute Professor of Clinical Psychiatry, Washington University School of Medicine

For more information, contact deputy director Jeannette Cole at 203.401.2069 or email her at: cole@ocfoundation.org

Cost \$795 OCF Professional Members \$995 Non-OCF Members

"The BTI without a doubt was the best professional development event that I have ever attended. All faculty were extremely knowledgeable, accessible, and agreeable interpersonally. I learned a great deal and feel that both my OCD patients and I have benefited quite a bit." BTI Attendee

OCD NEWSLETTER 15

Compliance with Solicitation Regulations

The Obsessive Compulsive Foundation, Inc. ("OCF") is a Connecticut not-for-profit corporation. Its mission is to educate the public and professional communities about Obsessive Compulsive Disorder ("OCD") and related disorders; to educate and train mental health professionals in the latest treatments for OCD and related disorders; to provide assistance to individuals with OCD and related disorders and their family and friends; and to support research into the causes and effective treatment of OCD and related disorders. The OCF's principal place of business is 676 State Street, New Haven, Connecticut 06511-6508. The information enclosed herein describes one or more of the OCF's activities. Your gift is tax deductible as a charitable contribution. Contributions received by OCF do not inure to the benefit of its officers, directors or any specific individual.

A copy of OCF's most recent financial report is available upon request and may be obtained at no cost by writing to OCF at P.O. Box 9573, New Haven, Connecticut 06535-0573 or by contacting its Executive Director at (203) 401-2074. If you are a resident of one of the following states, you may obtain information directly as follows: Florida: A COPY OF THE OFFICIAL REGISTRATION AND FINAN-CIAL INFORMATION MAY BE OBTAINED FROM THE FLORI-DA DIVISION OF CONSUMER SERVICES BY CALLING TOLL FREE WITHIN THE STATE (800) 435-7352, OR (850) 488-2221 IF

CALLING FROM OUTSIDE FLORIDA. OCF'S REGISTRA-TION NUMBER IN FLORIDA IS CH8507. **Maryland**: A copy of the documents and information submitted by the OCF pursuant to the Maryland Charitable Solicitations Act are available for the cost of copies and postage from the Secretary of State, State House, Annapolis, MD 21401, Telephone (401) 974-5534. OCF's registration number in Maryland is 5015. **Mississippi**: The official registration and financial information of OCF may be obtained from the Mississippi Secretary of State's office by calling (888) 236-6167. OCF's registration number in Mississippi is C1143. New **Jersev**: INFORMATION FILED WITH THE ATTORNEY GEN-ERAL CONCERNING THIS CHARITABLE SOLICITATION MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING (973) 504-6215. OCF'S REGISTRATION NUM-BER IN NEW JERSEY IS CH1461800. New York: A copy of the most recent annual report filed by OCF with the New York Secretary of State may be obtained by writing to Charities Bureau, 120 Broadway, New York, NY 10271, Telephone (518) 486-9797. OCF's registration number in New York is 66211. North Carolina: A COPY OF THE LICENSE TO SOLICIT CHARITABLE CONTRIBU-TIONS AS A CHARITABLE ORGANIZATION OR SPON-SOR AND FINANCIAL **INFORMATION MAY BE OBTAINED FROM THE** DEPARTMENT OF HUMAN

RESOURCES, SOLICITATION LICENSING BRANCH, BY CALLING (919) 733-4510. **OCF'S REGISTRATION NUM-BER IN NORTH CAROLINA** IS SL002059. Pennsylvania: A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, (800) 732-0999. OCF's registration number in Pennsylvania is 15687. Virginia: A copy of the OCF's most recent financial statement is available upon request from the State Division of Consumer Affairs in the Department of Agriculture and Consumer Services. Washington: Additional financial disclosure information may be obtained by contacting the Secretary of State toll free, within Washington, at (800) 332-GIVE. OCF's registration number in Washington is 6363. West Virginia: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, West Virginia 25305. **REGISTRATION WITH A** STATE AGENCY DOES NOT **CONSITUTE OR IMPLY ENDORSEMENT, APPROVAL** OR RECOMMENDATION BY THAT STATE. THE OCF DOES NOT HAVE A PROFESSIONAL SOLICITOR. ONE HUNDRED PERCENT 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.

16 SUMMER 2006

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