9th Annual Conference

OCD Newsletter*

Philadelphia August 9-11, 2002

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From the President

Dear Friends,

As summer approaches, we are thoroughly focused on our plans for the 9th Annual OCF Conference to be held Friday, August 9 through Sunday, August 11, 2002. Our administrative staff can tell you that the planning process seems as complicated as arranging the opening ceremonies at the Olympics! So, in order to pull it off with the minimum of angst and a maximum of success, they have to get into full operational mode at least four months ahead of time. This year the Conference will have more than 60 seminars, workshops and support groups. It will feature many of the best known and most widely respected OCD researchers and clinicians. There will be a variety of "tracks" offered for people dealing with OCD: parents of children with the disease; adults suffering with OCD; kids and teens; and mental health professionals. We urge you to review the program listings so you can decide which sessions you want to attend. Below is a sampling of each day's activities.

We will start on Friday with workshops that include presentations on Cognitive Behavior Therapy (CBT) for hypochondriasis, co-occuring OCD and Panic Disorder and/or Social Anxiety Disorder, an update on research relating to surgery and deep brain stimulation, Self-Directed Exposure & Response Prevention (E&RP), strategies and solutions for parents of kids with OCD, story writing for kids, neuroimaging research, and two seminars on CBT techniques for mental health professionals. Drs. Edna Foa and Marty Franklin of the Center for the Treatment and Study of Anxiety at the University of Pennsylvania will teach these courses. Additionally, there will be a number of support group meetings on Friday evening. And, of course, at 9:15 pm Drs. Jonathan Grayson and Lee Fitzgibbons, assisted by the "campers" from the Philadelphia G.O.A.L. group and the Philly OCF affiliate, will be heading out on the Third Annual OCD Camping Trip!

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Hoarding – A Successful Compulsion

by James Claiborn, Ph.D.

Hoarding is a problem that is asked about frequently in connection with Obsessive Compulsive Disorder (OCD). We can define hoarding as acquiring and keeping objects to such an extent that they begin to impair the normal use of one's living space. Most of the time, non-hoarders do not think the saved objects have little or any intrinsic value. However, it is also possible that a hoarder is a collector as well. There are other disorders sometimes associated with hoarding including Obsessive Compulsive Personality Disorder (OCPD). However, in most cases, it is likely that the individual hoarder has a variation of OCD.

People who hoard typically acquire excessive amounts of certain things and have difficulty or are unwilling to dispose of accumulated material. This leads to incoming material far exceeding outgoing material. The result is that the person's living space becomes filled with material and what would be considered normal use of much of their living space becomes impossible. Furniture may be used as a place to pile objects. Indeed, any flat surface may become a place upon which to pile things.

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From the Foundation

As a person whose OCD was not diagnosed and treated until way into adulthood, I consider making effective treatment available for children and adolescents with OCD one of the most important things that the Foundation does. Up until the nineties, the accepted wisdom was that individuals did not develop OCD until late adolescence, early adulthood or maybe even early middle age. This despite the fact that every adult who was seeking treatment was reporting that he or she had had it since childhood.

The problem with OCD is that, unlike a lot of other serious mental illnesses, it can be masked. Sufferers, as young as 5 and 6, instinctively know that there is something a little "off" about the rituals they feel obligated to perform and the disturbing thoughts that seem to have taken up permanent residence in one section of their brain. So, they camouflage their compulsions and their family, friends and teachers grow use to some "quirkiness" in their behavior (won't go to sleep until mom or dad has answered a catechism of questions in exact order, or their toys are lined up exactly or they've washed their hands a certain number of times). But, the child with OCD isn't acting out. As a matter of fact, she becomes very upset when she does anything wrong or does not perform "perfectly." So, it's natural to accommodate the "quirks" and not ask any questions or be alarmed.

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In This Issue

BULLETIN BOARD

Do you suffer from Obsessive-Compulsive Disorder and live within commuting distance of New York City?

Are you on medication but still have symptoms? You may be eligible to participate in a research study that would provide cognitive-behavioral therapy and medication at no cost to you.
The Anxiety Disorders Clinic at the New York State Psychiatric Institute invites you to participate in a research study of cognitive-behavioral therapy for Obsessive Compulsive Disorder. 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 2X per week for 2 months at the New York State Psychiatric Institute 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.

Brain Imaging Studies in Individuals with OCD

Using pilot data obtained from an Obsessive-Compulsive Foundation Research Award gxrant as the basis for his application, Dr. Philip Szeszko from Hillside Hospital in New York received a five year grant from the National Institute of Mental Health in May, 2001 to conduct brain imaging studies in individuals with OCD. His research will use imaging modalties such as diffusion tensor imaging (DTI) and functional magnetic resonance imaging (fMRI) to better understand which brain regions play a role in the neurobiology of OCD. DTI is a relatively new imaging modality that permits the characterization of white (connecting) matter in the brain and may be considered an index of how brain regions are interconnected and able to communicate with each other. Functional magnetic resonance imaging (fMRI) is a noninvasive technique that can monitor brain activity during the performance of neuropsychological tasks. Study participants will also have comprehensive neuropsychological, clinical and diagnostic assessments. It is hoped that ultimately the information learned from these studies will be able to inform treatment strategies.

Are You Experiencing:

- persistent repetitive thoughts
- repetitive senseless actions
- repeated washing, counting or rituals
- contamination fears
- hoarding

You may be eligible to participate in a research study funded by the National Institute of Mental Health. This study uses magnetic resonance imaging to identify brain circuits that may play a role in causing Obsessive Compulsive Disorder, but does not provide treatment. You will be reimbursed for your time and sessions are scheduled at your convenience.

For a free confidential telephone screening to determine study eligibility, please call (718) or (516) 470-8157.

HILLSIDE HOSPITAL North Shore – Long Island Jewish Health System.

A UCLA Research Study of Obsessive Compulsive Disorder

A 12-week, double-blind study testing different quantities of investigational drug and placebo in patients suffering from Obsessive Compulsive Disorder (OCD).

Do you experience recurrent time-consuming obsessions or compulsions, persistent ideas, thoughts, impulses, or images such as fear of contamination? Do you practice repetitive behaviors such as excessive handwashing, cleaning, and checking? If you are over the age of 18 and are not currently attending behavioral therapy, and experience one or more of these symptoms, you are invited to participate in a research project studying an investigational medication for Obsessive Compulsive Disorder at the UCLA Neuropyschiatric Institute.

Participants in the study will be eligible for an extensive psychiatric evaluation that will be provided at no cost to those who qualify. You must not be in behavioral therapy. There will be monetary compensation for participants' time.

Study conducted by Dr. Alexander Bystritsky, Department of Psychiatry, UCLA.

If you or someone you care about is interested in participating, please call (310) 206-5133 or (310) 794-1038.

Study of St. John's Wort for the Treatment of Obsessive Compulsive Disorder

The Clinical Trials Department at Rogers Memorial Hospital-Milwaukee under the direction of John Greist, MD and James Jefferson, MD and the Dean Foundation, under the medical direction of Leslie Taylor, MD are seeking volunteers to participate in a 12-week outpatient study of St. John's Wort for the treatment of

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The Obsessive-Compulsive Foundation (OCF) is an international not-for-profit advocacy organization with more than 10,000 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 registered treatment providers; and the distribution of books, videos, and other OCD-related materials through the OCF bookstore and other programs.

Hoarding – A Successful Compulsion

(continued from page 1)

The most commonly hoarded items are papers. This can include papers most people would consider important, such as, tax records along with unimportant papers, such as, brochures, advertisements, junk mail, newspapers, magazines and scraps of paper with notes, shopping lists, etc. Some keep food products, broken items to be fixed, clothes, books, craft materials and leaves. In rare and extreme cases, hoarders have been known to save feces or urine. Another extreme form involves hoarding animals and the occasional story of someone living in a home with hundreds of cats or dogs often including carcasses of decaying animals are probably best understood as incidents of hoarding OCD. Much more common, however, is a description of rooms filled with piles of papers, clothes and similar items often criss-crossed by narrow paths between the piles.

The hoarder may label parts of his material as a collection. These collections can include books, toys or other objects that may be considered valuable by many people. The hoarder may, however, believe his collection would be valued by others when this is not realistic. One hoarder had a collection of pictures of staircases. She believed her children might want them some day. Another explained that she kept newspapers because someday her grandchildren (not yet conceived) might be interested in contemporaneous coverage of events.

There is at present not enough information about how common this problem is. But judging from the number of times questions are asked about it in on-line support groups and the occurrence in clinical populations, it is reasonable to speculate that hoarding is actually a common problem. People with OCD are often unwilling to seek treatment at least in part because of embarrassment or shame about their disorder. Most questions about hoarding come from concerned family members rather than the individual with the problem, suggesting that hoarders are even less likely to come into treatment than others with OCD.

This reluctance to seek treatment and the difficulty treating hoarding as a behavior lead to speculation about what is different in this population. One idea is to describe hoarding as a "successful compulsion." In OCD in general, compulsions are seen as a method to reduce anxiety or other forms of distress; and, to some extent, they must work or people would not continue to engage in them. The individual with a contamination fear may wash to reduce anxiety when she believes she has been exposed to contamination. Avoidance of situations which arouse anxiety is also important in OCD. The contamination fear may lead to avoiding touching certain objects, going certain places or lead to other limits on activity. Yet, OCD is described as an anxiety disorder in part because most people who have it have considerable anxiety in spite of their engaging in both avoidance and compulsive rituals. Many individuals with the hoarding form of OCD seem to have significantly less anxiety than the average OCD patient.

If the anxiety in OCD is generated as a result of interpretation of intrusive thoughts as described in a cognitive model, then what is driving a hoarder to hoard? Hoarders seem to have intrusive thoughts about: not having something that might be needed or valuable; not being able to remember something important; or possibly wasting something. When objects are disposed of, a hoarder may want to go to great lengths to make sure their disposal was done properly. The need to remember and the imperative not to waste or to dispose of something improperly are linked to "responsibility," a theme that runs through many OCD symptoms. The anxiety generated by the thoughts may be reduced quickly by knowing that the individual still has possession of the material. And the anxiety associated with intrusive thoughts, such as, "what if I need this and can't get it in the future," that occur when a hoarder is exposed to a new object can be quickly managed by acquisition. The anxiety is assuaged by the rationale: "If I get it now, I will have it if I ever need it." Some hoarders also report gaining some sort of comfort or pleasure from their possessions. They may indulge themselves by just looking at the things they have acquired or surrounding themselves with the piles of things that they've collected.

When the idea of a "successful compulsion" was discussed on an e-mail list of hoarders, a number of the subscribers indicated that they did think this was an apt description. They explained that they did have anxiety and that the model of a "successful compulsion" did not truly describe the experience of hoarding. Remember that in all OCD we understand compulsions to be a method for dealing with anxiety. Yet, ironically, people often report anxiety about having to engage in compulsions. Sometimes people avoid doing things because they know that they will be stuck for long periods engaged in some compulsive ritual. They may consider the ritual absurd but still feel required to do it.

One difference with hoarding is that hoarders often do not acknowledge the absurdity of the ritual. They may argue about it not being good to waste, explain that they will really read all the collected newspaper articles again or someone in the future might be interested in whatever object they are discussing. More commonly, hoarders have anxiety when their hoard is threatened in some way. A pending visit from a landlord can be terrifying. The hoarder may fear how others will react to the situation and experience shame because of how people respond to the hoard.

Some hoarders will report anxiety when they look at their own piles of clutter. This often results from concern about their things not being organized. The disorganization is the aversive part of hoarding not its interference with function. Hoarders see objects as unique so that they cannot be stored together. One hoarder described trying to organize possessions as like trying to organize snow flakes. This metaphor is telling because it illustrates how the differences rather than similarities of objects contribute to the confusion. This is known as having under-inclusive categories. Things that don't belong together cannot be stored together. The anxiety generated by thoughts of needing to organize possessions is most often dealt with by avoidance or procrastination. Sometimes, paradoxically, the desire to organize may lead to more hoarding. The hoarder may buy lots of containers in which to store his things. But due to under-inclusive categories, be unable to make use of them. Thus, the containers become part of the hoard rather than a solution.

There are two well-established treatments for OCD, serotonin reuptake blocking medications and cognitive behavioral therapy (CBT). Hoarding as a specific form of OCD does not seem to respond well to medication. One reason for this poor response may be that the medication works by reducing intensity and frequency of intrusive thoughts. This, in turn, allows the individual with OCD to engage in formal or informal behavior therapy including exposure to anxiety producing situations. Because hoarders already successfully avoid or manage much of their anxiety, the medication doesn't have a noticeable impact. Also, medication does not change the distorted value a hoarder places on his/her possessions. A lessening in valuation is necessary for a hoarder to begin to be able to dispose of his hoard. So, they do not experience any relief from medication. It may be that medication would make CBT more tolerable. But people who are not distressed by a behavior are unlikely to seek help in changing it. Finally, the individuals, who report they don't fit the model described above, are individuals who are highly motivated to change their hoarding. They are involved in a support group and committed to changing. They seem to represent a minority of hoarders for whom hoarding is no longer a "successful compulsion."

How to Use the ADA

*By Sharon Lewis, JD**
Patricia Perkins, JD

A few months back I told you in "From the Foundation" that Sharon Lewis, JD, my best friend from high school, and I wanted to educate people with OCD about how they could use the Americans with Disabilities Act to help them get or keep a job. After tossing our ideas back and forth, we finally decided to do a regular column in the OCD NEWSLETTER about the ADA and OCD. Readers could submit questions or problems and we could answer them. Sort of Ann Landers and Dear Abby for OCD. Sharon, who has always been the thoughtful one, has suggested that we have to insert a caveat here. So, I will. **This column and the musings in it are not meant to be legal advice. If you have questions or concerns about a specific situation, you need to discuss any actions or steps you are considering taking with your own attorney before you act.**

To start things off, I'm going to present a scenario (actually it's my own personal situation from 1986 before the ADA was enacted) and use it to illustrate how and where you might be able to use the ADA.

The Situation: Lawyer works as an associate in a medium size law firm for four and one-half years. Some time after four years, she starts checking and rechecking her work. This is considered a good thing for lawyers to do because if a lawyer makes a mistake, it can be costly for the client and her firm. Legal work involves lots of documents, filings, deadlines and court dates. Everything has to be filed correctly, at the right place, at the right time.

The partners she works for don't think it strange that she calls the court clerk again and again to make sure a pleading has been filed correctly and in a timely fashion. As a matter of fact, the firm won an appeal because she called and checked six different times. Not to mention the fact that checking takes time and time is billable for attorneys. Finally, after a week in which she had driven down to the office at 3 a.m. to make sure that the margins on all the pleadings she had filed met the requirements of the Practice Book and had gone back to the Avon town hall to do a title search twice, just to be sure, she decided that something was wrong and made an appointment with a psychiatrist. He gave her some Ativan samples, told her she was anxious and asked her to help him with a planning and zoning problem. He didn't diagnose OCD. The Ativan didn't help. Her vacation was coming so the partners suggested she start it a couple days early and come back in a couple of weeks all relaxed.

The "anxiety" or whatever got worse over the first few days of the vacation. She called the planning and zoning psychiatrist and asked to be hospitalized. Another doc suggested OCD, but said it was extremely rare and there was no cure. She ran out of vacation time in the hospital. They put her on paid medical leave. After three months, she came back to work for three days and when she got stuck in the bathroom on the fourth day with a totally contaminated wardrobe, she checked herself into another hospital. Finally, in total desperation, after five months of steady deterioration, she signed up for a ten-week drug test as a inpatient at Yale.

Fast forward to 2002, the Americans with Disabilities Act of 1990 (ADA) is in effect and the 9th Circuit Court of Appeals has decided Humphrey v. Memorial Hospitals, the first appellate case applying the ADA to a person diagnosed with OCD. In this case, Humphrey, a medical transcriptionist, could not get to work on time and sometimes not at all because she engaged in obsessive rituals, involving washing and preparing her hair, dressing and getting her papers together. To accommodate her, the hospital allowed Humphrey to work a flexible schedule and to come in any time during a 24-hour period or to call if she could not come at all. When this didn't work and Humphrey continued to be late or absent, the Hospital fired her. Humphrey sued under the ADA. The 9th Circuit Court of Appeals (the federal appellate court for her region) held that the hospital violated the ADA because it refused her request to allow her to work at home or, as an alternative, to taking a leave of absence.

Back to the situation with our associate. Remember we are pretending that this situation is happening now, more than a decade after the passage of the ADA and after the courts have started writing opinions interpreting the ADA. How could this situation play out now with the ADA as the law? Would this situation be covered by the ADA?

Yes, the ADA covers employees with disabilities that substantially limit a major life activity such as seeing, hearing, breathing, speaking, performing manual tasks, caring for oneself and working. A person diagnosed with a mental illness, such as, OCD, when it is interfering with the individual's ability to care for herself and function, would be covered under the ADA. There is a "BUT" here though. There have been two US Supreme Court decisions recently that raise the question of whether the ADA covers an individual whose condition can be controlled by medication and/or the symptoms recur because the individual has stopped taking the meds. There are arguments to rebut this positions, i.e.: that the failure/refusal to take meds is itself a symptom of the mental illness and/or that if and when the meds are not effective to prevent the symptoms from breaking through, then the person is covered. *(However, this is fodder for a whole other column. If someone is interested, write and tell us and we'll develop these points.)*

What protection does the ADA afford a person with a covered disability? The ADA prohibits an employer from discriminating against a person because of his or her disability and specifically requires an employer, once aware of the disability and need for accommodation, to make a reasonable accommodation to enable that person to overcome the barriers caused by the disability and perform the essential functions of the job.

In a hiring situation, the employer may not take into account whether an otherwise qualified person has a disability or whether the disability may require a reasonable accommodation. In the situation like our associate's where the person is already employed, the employer may not terminate or otherwise adversely affect the person if his or her disability requires a reasonable accommodation. While the law does identify a number of possible reasonable accommodations, such as part-time or modified work schedules, reassignment to a vacant position, it does not provide an exhaustive list and contemplates that there may be other similar accommodations. Among these are leaves of absence. Also, the law requires that the employer discuss with the employee what possible accommodations would be effective to enable the employee to perform the essential functions of the job. While the employee's preference must be considered, the employer gets to pick. Moreover, the ADA does not require an employer to retain an employee whose disability is such that there is no reasonable accommodation that would enable the employee to make him or her

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When You Have OCD

able to perform the essential functions of the job. The ADA does not require the employer to lower its standards and can require an employee with a disability to perform the essential functions of the job to the same standards as other similarly situated employees.

Would our hypothetical "me" be protected under the ADA? The first question would be: does her disorder interfere with her performing the essential functions of her job? Let's see. Because of the OCD, she cannot get to work (she could not decontaminate herself enough to leave the house); she cannot complete any projects in a timely fashion (timeliness is an essential part of an attorney's job) because she has to continually recheck everything she produced; and she cannot make any decisions because her OCD doesn't allow her to feel she has researched the law sufficiently.

There is no question that our associate whose OCD was out of control and incapacitating her was an individual with a disability covered under the ADA. At least by the time she was hospitalized, the law firm was aware that her OCD required an accommodation. When the law firm believed that it was anxiety and suggested that she start her vacation early, the partners would not necessarily be on notice the associate had a disability covered by the ADA and the burden would have been on the associate to disclose the disability and to request an accommodation. When, how and to whom to disclose a disability and to identify and request an accommodation will be the subject of a later letter.

So, at the time our associate was exhibiting OCD symptoms and clearly unable to function, was there a reasonable accommodation required under the ADA? The short answer is yes. A leave of absence.

Now the longer explanation. Since the law firm was aware of the associate's disabling OCD, it was required to provide a reasonable accommodation that would enable the associate to overcome the symptoms and perform the essential functions of her job. It was required to discuss with the associate as well as with other relevant professionals (such as the associate's treating doctors) to see if the OCD were treatable such that the associate would be able to perform the essential functions of the job and to determine what would be necessary and effective to enable the associate to do so. In many situations, both the individual with a disability and the employer look for an accommodation that would allow the individual to continue to work and be paid. In the Humphrey case that we discussed in the beginning of this letter, that's what Humphrey wanted when she initially believed that a flexible work schedule would be effective to address her OCD symptoms and the hospital agreed that a flexible work schedule was a reasonable accommodation.

In situations like our associate's (and Humphrey's when the flexible work schedule did not work for her), where the symptoms are so severe that the individual with OCD can't function, a leave of absence may be the reasonable accommodation required.

Whether a leave of absence is a reasonable accommodation depends on a number of factors: The individual with a disability needs to provide some evidence from his or her treatment provider, diagnosing the disability and stating that it is sufficiently treatable to enable the individual to control the symptoms and perform the essential functions of the job. The treatment provider should also suggest in a written report what the expected outcome is and how long treatment is going to take. This is what Humphrey's doctor did. He gave a statement saying that the OCD was treatable and that a leave of absence would afford her the opportunity to begin a course of treatment to get her symptoms under control.

Humphrey had also asked to work at home as an alternative to a leave of absence. One reason the 9th Circuit held that allowing Humphrey to work at home was also a possible reasonable accommodation was her doctor's statement that he thought working at home was worth a try to see if Humphrey could perform her job if she wasn't under the stress of having to leave the house and get to work on time.

What this tells us is that for a leave of absence to be considered reasonable, its purpose should be to provide the individual the opportunity to obtain treatment in order to control the symptoms so the individual can return to work and perform the essential functions of the job. You should be aware that at the time a request for a leave of absence as a reasonable accommodation is made and at the time the individual asks to return to work the employer may require the individual be examined by a doctor of the employer's choosing to satisfy itself that: (1) there is a covered disability; (2) it is the cause of the symptoms interfering with job performance; (3) the leave of absence is for the purpose of obtaining treatment designed to enable the individual to return to work; and (4) upon a request to return to work, the individual will then be able to perform the essential functions of the job.

The employer's policies on medical and personal leaves will be taken into account. An employer must allow an individual with a covered disability to take medical or personal leaves under the same condition as other similarly situated employees. Most policies that allow for extended unpaid leaves of absence (more that 6 months) are usually allowed only at the discretion of the employer. The employer will likely require the type of professional opinion discussed above. The longer the leave, the more likely the employer will argue that it is not reasonable and an undue burden to hold the job open. If the employer can prove that this is its situation, there may be no guarantee that the job will be available when the employee is ready to return to work.

However, there's a back-up position - The Family Medical Leave Act. The FMLA requires an employer of a certain size to allow its employees 12 weeks of unpaid leave for a serious medical condition. The employer must allow an employee on a FMLA leave to return to the same or equivalent job and to continue to pay the employer portion of any employer-sponsored health benefits the employee is enrolled in at the time he or she requests the leave. An individual with a disability covered by the ADA, who needs leave in addition to the 12 weeks of the FMLA, would then request extended leave as a reasonable accommodation and would need to provide the information described above.

So, if your OCD spirals out of control while you are employed and prevents you from performing the essential functions of your job, you don't have to risk being fired or go out on disability. You can request a leave of absence as a reasonable accommodation so that you can get treatment.

If you've got questions about the ADA and whether you're covered or not, write us at the Foundation. We'll try to answer them in subsequent issues of the OCD NEWSLETTER.

** Sharon Lewis is a practicing attorney in Minnesota and a former Minnesota Assistant Attorney General.*

Research Digest

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

It is certain that potent serotonin reuptake inhibitors (selective SRIs) – citalopram (Celexa), fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), sertraline (Zoloft) and clomipramine (Anafranil), a serotonin-norepinephrine reuptake inhibitor (SRI-NRI) – are effective treatments for OCD. However, these usually produce a partial rather than complete recovery. Studies that increase our knowledge of SRI mechanisms and extent of effects will facilitate better use of present medications and development of new medications. Recognizing that a few individuals suffer severe OCD that is unresponsive to SRIs and cognitive behavior therapy, we have also reviewed results of the most current report on individuals with OCD treated with neurosurgery.

The following is a selection of the latest research articles on OCD and related disorders in current scientific journals on these topics (JHG).

Efficacy of sertraline in the long-term treatment of obsessive-compulsive disorder
American Journal of Psychiatry, 159:88-95, 2002, L.M. Koran, E. Hackett, A. Rubin et al.

This study is important because it not only looked at the effectiveness of sertraline (Zoloft) in long term maintenance treatment of OCD, but also because it was a placebo-controlled study. Having responded to sertraline after 1 year of treatment, 223 patients were randomly assigned to a 28-week double-blind trial of sertraline or placebo. The average dose of sertraline was 183 mg/day. The effectiveness of sertraline was maintained for the 28 weeks. Interestingly, only 24% of the patients switched to the placebo relapsed during the 28 weeks of placebo. This low relapse rate may indicate a continued benefit from the previous 52 weeks of therapy with sertraline. Other studies looking at relapse with drug withdrawal have had relapse rates of 40%-89% after variable lengths of medication treatment.

Mirtazapine treatment of obsessive-compulsive disorder
Journal of Clinical Psychopharmacology, 21:537-539, 2001, L.M. Koran, T. Quirk, J.P. Lorberbaum et al.

Approved by the U.S. Food and Drug Administration in 1996 as an antidepressant, mirtazapine (Remeron) promotes serotonergic as well as noradrenergic neurotransmission and researchers hypothesized that it could be an effective treatment of OCD. Ten patients participated in this 10-week open trial of mirtazapine. Dosage was started at 15 mg/day and increased to 45 mg/day at the end of the second week. With only a 20% response rate, mirtazapine seems less effective than selective serotonin reuptake inhibitors (SSRIs) for treatment of OCD. However, two of four patients receiving first-time OCD medication therapy responded. None of the patients who had not responded to previous SSRI treatment responded to mirtazapine. Researchers speculate that as OCD seems to respond better to higher SSRI doses, the dosages of mirtazapine may have been too low. They suggest future studies start at 30 mg/day and go up to 60 mg/day. Also, 10 weeks may be too short a time to see benefit in OCD.

Differential cerebral metabolic changes with paroxetine treatment of obsessive-compulsive disorder vs major depression
Archives of General Psychiatry, 59:250-261, 2002, S. Saxena, A.L. Brody, M.L. Ho et al.

With the aid of new brain imaging techniques, researchers are trying to determine how medications affect the brain and work to control mental disorders. Paroxetine (Paxil), a selective serotonin reuptake inhibitor (SSRI), is an effective treatment for both OCD and major depressive disorder (MDD). This study compared brain scans (positron emission tomography or PET scans) of 25 individuals with OCD, 25 with MDD and 16 with both OCD and MDD before and after 8 to 12 weeks of treatment with paroxetine. Additionally, brain scans were obtained for 16 healthy controls. All patient groups received the same paroxetine dose for the same length of time, but the brain metabolism in specific brain regions differed significantly between patient groups. Brain physiology was found to be disorder-specific (OCD vs. MDD vs. OCD + MDD) and response-specific (response or nonresponse to paroxetine treatment). This indicates that while SSRIs treat both OCD and MDD, they have different effects in the two disorders and their combination. As disorders have different symptoms reflecting dysfunction in different parts of the brain, effective treatments should also work in different brain structures.

The caudate nucleus in obsessive-compulsive disorder. Reduced metabolism following treatment with paroxetine: a PET study
International Journal of Neuropsychopharmacology, 5:1-10, 2002, E.S. Hansen, S. Hasselbalch, I. Law and T.G. Bolwig

To study how paroxetine (Paxil) works in OCD, brain glucose metabolism was compared in 20 OCD patients before and after at least 3 months of treatment with paroxetine. Positron emission tomography (PET) scans were used to measure brain glucose levels that indicate brain activity. Because of conflicting results in earlier PET studies in OCD patients who were also depressed, these researchers excluded patients with comorbid depression. Treatment with paroxetine was started with 20 mg/day with dosage increases to 40-80 mg/day by six weeks of treatment. There was a high response rate, 80% of patients being 'much' or 'very much' improved with Yale-Brown Obsessive Compulsive Scale (YBOCS) scores below 15. In those individuals responding to paroxetine, there was a significant decrease in brain glucose metabolism in the right caudate nucleus. Metabolic changes induced in particular brain regions of OCD patients as a result of successful treatment with paroxetine were similar to findings in a majority of imaging studies with behavior therapy, clomipramine and other selective serotonin reuptake inhibitors. In particular the right caudate nucleus is involved in the pathophysiology of OCD and appears to be an area of the brain affected when either behavior therapy or OCD medications are beneficial.

Quetiapine augmentation of serotonin reuptake inhibitors in obsessive-compulsive disorder
International Clinical Psychopharmacology, 17:37-40, 2002, N. Mohr, B. Vythilingum, R.A. Emsley et al.

Augmenting serotonin reuptake inhibitors (SRIs) with atypical antipsychotics can be effective for some individuals with treatment resistant OCD. Quetiapine (Seroquel) is a newer atypical antipsychotic that is used to augment SRIs, but one with little research supporting this use. Charts of 8 patients with treatment resistant OCD receiving the combination of an SRI and quetiapine were reviewed. Four of these eight patients became responders within 4 weeks of augmentation with quetiapine. Although this is not a prospective controlled study, the data are consistent with other studies suggesting that approximately one-half of OCD patients resistant to treatment with SRIs may respond to augmentation with an atypical antipsychotic. Overall, quetiapine was well tolerated by the patients, with the exception of one patient who developed excessive sedation. As there have been reports of emergence or exacerbation of OCD symptoms by atypical neuroleptics in individuals with schizophrenia, it is of interest that there were no cases of OCD symptoms worsening with quetiapine.

(continued on page 7)

The Keys to Readiness for Treatment

by Aureen Pinto Wagner, Ph.D.

"Alex just isn't motivated. He says he wants to go to therapy, but when its time to do it, he just won't get his act together and he blows a fuse if we say anything. It's just so aggravating." If your child is like Alex, you are in good company. It's easy to become frustrated if you assume that your child's reluctance is intentional. But, when Alex says he won't do his treatment exercises, it's hardly like saying he won't pick up his room or take out the garbage. In reality, it may not be a matter of intent or will; like Alex, your child may not yet be ready for treatment.

Aureen Pinto Wagner, Ph.D.

How many children actually enjoy living with OCD? I have yet to meet one. Although most children have a wish to be rid of OCD, they also need to be ready to participate in treatment. To be ready, they need to be able to channel the desire to get well into the action to get well. Why is readiness so crucial to treatment? It's because Cognitive-Behavioral Therapy (CBT) for OCD involves actively learning and using a set of skills to overcome the urges and injunctions of OCD. Learning CBT is quite similar to learning how to ride a bicycle. You can do a lot to help your child learn how to ride a bicycle, but eventually, your child must learn to ride for himself. Likewise, your child must learn how to overcome OCD for himself. You cannot do it for him. He will only learn when he's ready. Ironically, when your child feels pressured, he is less likely to want to do it for himself. He will hardly be charmed into treatment by the insistence of parents or therapists.

In my work with children and adolescents over the years, I have found that the keys to readiness are effective stabilization, communication, persuasion and collaboration. Your CBT therapist must work closely with you and your child to build readiness for treatment.

Stabilization comes first. A child who is overwhelmed and struggling to get through the basics each day simply does not have the wherewithal or mindset to consider CBT. Just getting through each day with OCD consumes all his energy. Your child needs some respite from the dual challenges of OCD and everyday living. Flexibility in expectations, accommodations at home and at school can ease the initial pressures on your child. In severe situations, some children may need medication to reach a reasonable level of functioning before they can even entertain the thought of CBT. Families need stabilization too. Blame, shame and conflict don't help a child feel safe enough to risk the challenges of CBT. Calm, supportive and understanding families set the stage for treatment readiness.

Effective communication dispels the misconceptions and fears that may be holding your child back from participating. Communication about the primary CBT concepts of exposure, habituation and anticipatory anxiety is essential to preparing a child for treatment. OCD is overcome by confronting fears (exposure), experiencing habituation (getting used to the anxiety, much like you get used to the cold water in the swimming pool) and understanding that confronting fears seems harder before you do it than when you actually do it (anticipatory anxiety). Exposure may appear both counterintuitive and daunting at first glance; a child who is afraid does not exactly want to hear that he must face his fear to overcome it. When children don't understand CBT, they are unnecessarily intimidated by it. Communicating CBT concepts to children can be challenging. I developed the metaphor of the Worry Hill to convey these concepts in child-friendly language. Almost any child or adolescent can relate to the image of riding a bicycle up a big hill. Exposure feels like the ride up the hill. It can be hard to huff and puff up a hill, but if you don't quit, you can get to the top of the hill. Once you get to the top, it's smooth sailing down the other side of the hill. You can only coast down the hill if you first get to the top. Likewise, you can only get past your fears if you face them. When you do, you find out that they are not even half as scary as you imagined.

Third, effective persuasion helps children see the necessity for change, the possibility for change, and the power to change. Your child must be helped to see the benefits of overcoming OCD; this convinces him of the necessity for change. When he learns that OCD can be successfully overcome, and that many others have done it, he sees the possibility for change. Finally, the child must know that he has the power to change. He must understand that he can take charge and take control of OCD instead of letting it control him. OCD is such a coercive force that it leads your child to believe that he has no choices; he is a prisoner of his mind. The recognition that he has the power to change is a liberating experience for the child. I remember Alex's words when he was ready for treatment: "I didn't know it was even possible to get over OCD. I thought I just had to do what it told me. When you told me it was my choice, I knew I could do it."

Finally, collaboration makes your child a vital partner in treatment. After all, he is the star performer. With your therapist's guidance, your child must become a key player in his own treatment. He must be involved in setting goals and deciding the pace of treatment, as is suitable to his age and maturity. When your child is a collaborator in his treatment, he takes ownership of it. He becomes more invested, committed and enthusiastic. The journey to recovery becomes his.

Dr. Wagner is a Clinical Child Psychologist and the author of "Worried No More," "Up and Down the Worry Hill," and its forthcoming companion guide, "What to Do when your Child has OCD: Strategies and Solutions."

Research Digest

(continued from page 6)

Prospective long-term follow-up of 44 patients who received cingulotomy for treatment-refractory obsessive-compulsive disorder
American Journal of Psychiatry, 159:269-275, 2002, D.D. Dougherty, L. Baer, G.R. Cosgrove et al.

Psychosurgery, also called neurosurgery, has been reserved for those individuals whose OCD is severe and has not responded to behavior therapy or to the large array of medication treatments available. Cingulotomy is the most common psychosurgical procedure used and involves creating small lesions in the area of the brain called the cingulate gyrus. Often a second operation (enlarging the initial lesion) is performed if the patient did not respond to the first cingulotomy. This is a follow-up study of 44 patients who received one or more cingulotomies for treatment-resistant OCD at Massachusetts General Hospital. At an average follow-up time of 32 months, 32% of patients previously unresponsive to medication and behavioral treatments for OCD were much improved after cingulotomy and another 14% were partial responders. Few adverse effects were reported and most adverse effects, including effects on memory, resolved shortly after the surgery. One patient developed seizures that responded to anticonvulsant medication and one patient had a worsening of preexisting urinary incontinence.

From the President

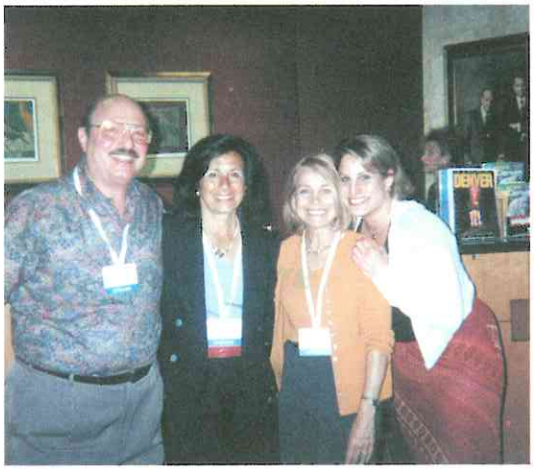
(continued from page 1)

This year's goal for our Program is to have presentations that not only discuss the latest research efforts, but also explore the most effective treatments for OCD and how one can utilize them. That is why we have asked Dr. Pierre Blier of the University of Florida School of Medicine to be our keynote speaker. On Saturday morning his presentation, "A Step Toward More Effective Pharmacotherapies," will explain to us how a better understanding of how serotonin reuptake inhibitors modify serotonin transmission in the brain structures involved in OCD has led to the identification of new targets for treating OCD. Dr. Blier worked with animators at Disney Studios in Orlando to produce an animated film to illustrate how these newly developed pharmacological agents work.

Also on Saturday, there will be two "centerpiece" seminars: "Pure Obsessions" and "Body Dysmorphic Disorder." These seminars will feature panels with professionals and sufferers who have overcome these particular problems.

Hands-on demonstrations of CBT, specifically designed to treat these two OCD variations, will be included. There will also be a two-hour "Question and Answer" program featuring Michael Jenike, M.D. He will answer questions from the audience on medications and treatment modalities. There are more workshops for children and their parents, including one by Dr. Tamar Chansky. She will present "Freeing Your Child from OCD." "Adolescence Sucks...and then there's OCD" will be led by Drs. Fitzgibbons and Landsman and Kathy Parrish. Saturday's program will also include presentations on a variety of subjects including Generalized Anxiety Disorder, hoarding and improving your relationships.

We are planning a relaxed and fun-filled evening on Saturday night. First, there will be a reception and then a light supper. Raffle tickets will be sold until the after-supper drawing. This year, we have included a special raffle for kids under 18. Proceeds from the raffles will go to the OCF Research Fund. This year each registered guest will get one raffle ticket to start off with. But we know that everyone will want to buy more. Last year, with a boost from the Lancer Family and Bob Selig, we were able to raise over $5,500 for the Research Fund. We would love to be able to raise $25,000 at this year's conference. That's the amount needed for one average grant.



Be sure to come to the Second Annual Film Festival to be held Saturday night after the Reception. If you have a film that you would like to submit, call our executive director, Patti Perkins, for more details at (203) 315-2194.

The 2002 OCF Art Contest and Exhibit will offer a $1,000 first prize, a $100 second prize, and a $50 third prize. This year's sponsor is our generous member, Patrick Johnson of Salt Lake City. The Art Contest is open to any

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artist interested in or affected by mental illness. All the pieces entered will be on exhibit Friday and Saturday. Paintings, photographs, sculptures and other visual media are eligible. For more information, call our deputy director, Jeannette Cole, at (203) 315-2190, ext. 18.

Among the many scheduled seminars included in Sunday's program, one will feature Dr. Jenike in collaboration with Gayle Frankel and Anna Mae Yurkanin as they hold a Town Meeting on Recovery. Other presentations will focus on CBT by phone, the history of OCD and coping mechanisms for parents.

After the Conference concludes on Sunday, the Foundation will be hosting the first meeting of the OCD Genetics Consortium. Attending will be researchers from around the world who are working to unravel the genetics of OCD. We anticipate that this will be the beginning of a very fruitful collaboration leading to the discovery of the causes of OCD, more effective treatments and, eventually, a cure.

Before we began to work on the 9th Annual Conference, we carefully reviewed the evaluations that you completed at the Denver Conference and the input that you have been providing over the last year. Now all we need is your presence and participation at the Philadelphia Conference.

For more information or for a Registration Brochure, call the Foundation at (203) 315-2190, or visit our website, www.ocfoundation.org and register there.

I look forward to seeing you in Philadelphia.

Janet Emmerman
President
OCF Board of Directors

Medication Induced Weight Gain: What Can You Do?

Michael A. Jenike, M.D.
Professor of Psychiatry
Harvard Medical School
Director, OCD Institute at McLean Hospital
Director, OCD Clinic at Massachusetts General Hospital
Director, OC Foundation Scientific Advisory Board

Julie A. Jenike, MS, CCC-SLP
Certified Personal Trainer and Fitness Instructor
Certified Nutritional Consultant
Northeast Rehabilitation Network
World Gyms & Gold's Gyms

Probably the most effective treatment for OCD is cognitive behavior therapy (CBT). However, many of you will require medication at least during the initial stages of treatment. Weight gain is one of the most difficult to manage side effects of anti-obsessional medication, but there is much you can do. This article summarizes our knowledge about drug-induced weight gain and more importantly things that you and your doctor can do to prevent or minimize it. Many doctors are not sensitive to this issue, so you should go to the doctor armed with information.

How common is weight gain with the various anti-obsessional drugs?

The SSRI medications used to treat OCD are more likely to cause weight gain than other classes of antidepressants. Also, some of the SSRIs are more likely to cause weight gain than others. One research group assessed weight changes in patients randomly assigned to long-term treatment with fluoxetine (Prozac), sertraline (Zoloft), or paroxetine (Paxil). They found that the number of patients with >7% weight gain from baseline was significantly greater for Paxil-treated compared with either Prozac-treated or Zoloft-treated patients. Others found similar findings with Paxil being much more likely to cause weight gain (up to 25% of subjects) than either Prozac (6.8%) or citalopram (Celexa) (3.9%). Other studies have shown minimal or no weight gains with Celexa.

Some patients do not improve much with SSRI medication alone, and doctors sometimes add a second drug in an effort to augment the response. Drugs that are sometimes added are the so-called atypical neuroleptics such as olanzapine (Zyprexa), risperidone (Risperdal), quietiapine (Seroquel) and ziprasidone (Geodon). These drugs can also cause weight gain. Researchers have looked specifically at adolescent patients who were treated with Zyprexa, Risperdal, and Haldol (an older neuroleptic). They found that the Zyprexa and Risperdal groups experienced significant weight gain between baseline and after treatment, whereas the average weight of the Haldol group did not change. Average weight gain was significantly higher for the Zyprexa group than for the Risperdal group. Extreme weight gain (defined as >7% gain) was recorded in 90% of Zyprexa -treated patients compared to 43% of those on Risperdal and 12% (1 patient) on Haldol. Other data suggest that Geodon does not cause weight gain in most individuals. The authors noted that adolescents are more likely to gain weight on medications than adults.

Why do people gain weight on medications?

On medications, one may feel sedated and require more sleep. This can result in less activity with fewer calories expended throughout the day.

There is some evidence that OCD patients preferentially choose to snack on carbohydrates, and this alone may predispose OCD patients to gain weight. Also, the SSRIs are associated with even more carbohydrate craving. Some patients treated with SSRIs have a significant increase in carbohydrate craving together with weight gain shortly after the beginning of treatment.

Since patients gaining weight often say that they are not eating more, it is tempting to speculate that there may also be a drug-induced lowering of metabolism. We could only find one paper demonstrating such a change in metabolism. The authors note that weight fluctuations reflect a balance between caloric intake and caloric expenditure. Thus, weight gain is due to positive energy balance, which may be explained by an increase in total calories consumed and/or a reduction in calories used by the body. Resting metabolic rate (RMR), which reflects the number of calories utilized by an individual in a resting state, represents at least 70% of the total daily calories burned by an individual. If a reduction in metabolic rate occurs, an individual would gain weight without increasing caloric intake. To determine whether or not alterations in resting metabolic rate might occur in drug-treated depressed patients, they carefully studied three female inpatients hospitalized for depression. Three separate measurements were taken during the drug-free period and again during the second and fourth weeks of antidepressant treatment. All three subjects treated with antidepressants showed a decrease in RMR, ranging between 17% and 24%. The authors noted that these kinds of changes reflect a reduction in daily caloric requirements of about 300-400 kcal. Thus an individual might be expected to gain a pound every 9-12 days independent of any change in caloric intake. These results support the idea that weight increases occurring during medication treatment may be due, at least in part, to changes in metabolic rate.

The SSRI medications affect a brain chemical called serotonin. The effects of serotonin on appetite and food intake can be mediated by activation of specific serotonergic receptors (5-HT2C receptors in the hypothalamus). Receptors are specific sites where drugs act in the brain. For example, mutant mice that lack these receptors become obese as a result of increased food intake. Drugs that block these receptors cause weight gain in both humans and animals, while administration of drugs that stimulate these receptors result in decreased food intake, decreased subjective hunger, and weight loss.

Celexa, Prozac, and Prozac's metabolite, norfluoxetine, may influence 5-HT2C receptor regulation by binding directly to those receptors. Zoloft was not found to have significant binding to this receptor. Chronic SSRI treatment also has been reported to attenuate the function of 5-HT2C receptors.

Thus there may be a number of factors that are contributing to drug-induced weight gain including less physical activity, changes in metabolism, and direct effects on serotonergic receptors. Since each of these factors will vary from person to person, there can be a wide variability of response. Some patients can gain 100 pounds while others gain nothing.

How can a person prevent or minimize weight gain with diet and exercise?

There are ways to help offset weight gain by following some simple, but tried and true methods. First, keep in mind that you may need fewer calories after you start medication if your metabolism is slowed. If you do not lower food intake, you may gain weight. Adopting a healthy diet, with a focus on lean proteins, fresh fruits and vegetables, whole grains, and heart healthy monounsaturated fats like olive and canola oils, is one way to start. Be careful not to eat huge amounts of food at a sitting. Most restaurants give you 3-4 times a suggested serving size. Learn to order sensibly when eating out, ask for dressings and sauces on the side, avoid fried and fatty foods, and order grilled, baked or poached entrees such as chicken, pork tenderloin, and fish.

Exercise is another important factor in preventing weight gain. Cardiorespiratory exercise (i.e.. aerobics, walking, biking, jogging) and resistance training (i.e.. lifting weights, using resistance bands and tubes) are both equally important. Cardio exercise increases the heart rate and helps to promote improved cardiac fitness, in addition to burning calories and raising metabolism. Resistance training helps to build lean muscle, which in turn can cause increased metabolism and decrease in the body's

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BULLETIN BOARD

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Obsessive Compulsive Disorder (OCD). You may qualify to participate if:

* You are between the ages of 18 and 65
* You have experienced symptoms of OCD for at least the last year
* Your general health is good
* You have written and oral fluency in English

Eligible participants will receive a comprehensive psychiatric diagnosis, frequent assessments by a physician and research medication at no cost. Participants will be reimbursed for travel.

For additional information please call:

Beverly Duty, study coordinator or Gemma Warner, study coordinator.
Rogers Memorial Hospital-Milwaukee
11101 West Lincoln Avenue
West Allis, WI 53227
(toll free) 1-877-676-6600

Dean Foundation
2711 Allen Boulevard
Middleton, WI 53562
(toll free)1-800-844-6015 ext.2338

Study on Skin Picking

The Bio-Behavioral Institute of Great Neck, New York, is currently conducting a study investigating skin picking behavior as a symptom of various disorders including the obsessive compulsive spectrum. We are interested in gathering information about demographic variables, situational and emotional triggers, co-morbidity, and family variables. As a study participant, you will receive a screening and evaluation at no cost to you.

If you are over the age of 18, please call us at (516) 487-7116 to learn more about this study.

Family Involvement in the Group Treatment of Hoarding/Savings Behavior

The Bio-Behavioral Institute of Great Neck, New York, is currently recruiting individuals who engage in compulsive hoarding and their respective family members to participate in a treatment study investigating the effects of family involvement in treatment outcome. Qualified participants and their family members will engage in a 16-week treatment group consisting of psychoeduction and cognitive and behavioral treatment.

If you are interested, please call us at (516) 487-7116 to learn more about this study.

Cognitive Therapy for Obsessive-Compulsive Disorder

Massachusetts General Hospital/Harvard Medical School is seeking participants with Obsessive-Compulsive Disorder (OCD) to take part in a research study. The purpose of the research study is to examine the effectiveness of cognitive therapy for OCD. Participants will receive:

- a clinical evaluation, at no cost
- 22 sessions of cognitive therapy, at no cost

If you are between the ages of 18 to 65 years and suffer from OCD, you might be eligible for this study. You must be able to attend weekly sessions in Boston. You may not receive any benefits from participating. It is possible that your OCD symptoms may improve from the cognitive therapy examined in this study. So far, there is some evidence that cognitive therapy may help individuals suffering from OCD, however, clinical testing is still investigational at this time.

This study is being conducted by Sabine Wilhelm, Ph.D., and Gail Steketee, Ph.D. If you are interested in further information about this research, please contact Ulrike at the OCD Clinic/Harvard Medical School at (617) 724-4354, or email at: buhlmann@wjh.harvard.edu

University of California, Los Angeles Obsessive Compulsive Disorder Research Program: PET Scan Study

This is a 12-week study that is researching the effects of the medication Paxil (Paroxetine) on brain glucose metabolism in people with Obsessive Compulsive Disorder.

All study participants receive 12 weeks of treatment with Paxil, a medication that has been shown to be effective for OCD. Participants who do not show significant improvement in OCD symptoms at the end of 12 weeks, will be offered a second medication – Risperidone to augment the effects of the Paxil. Risperidone will take approximately another 4 weeks to show effect. A PET (Positron Emission Tomography) scan of the brain is done prior to commencing the medication regimen, and at the end of 12 weeks. A third scan may be done for those participants who go on to take Risperidone. Participants will also receive an MRI (Magnetic Resonance Image) scan of the brain.

The purpose of this research is to observe changes in brain metabolism before and after treatment in an attempt to help us to identify the specific brain regions responsible for OCD.

For more information on this study, please feel free to call Karron Maidment RN, M.A. (310) 794-7305.

Brown University School of Medicine Seeks Participants for a Follow-Up Study of Obsessive Compulsive Disorder

Participants are needed for an NIMH-sponsored study that is designed to prospectively follow the long-term course of OCD in individuals with a primary diagnosis of OCD. This study is the first one of its kind, and will ultimately provide important new information about many aspects of treatment and the assessment of OCD. This is an interview study with annual follow-ups. Participants will be paid $25 for the first interview and $40 for annual follow-up interviews. Participation is strictly confidential.

Individuals (ages 6 and older) who have been diagnosed with OCD and have sought treatment for their OCD symptoms within the past 18 months are eligible to participate. Screening for this study takes approximately 10 minutes on the telephone.

Please contact:
Maria Mancebo, M.A.
Butler Hospital
345 Blackstone Boulevard
Providence, RI 02906
(401) 455-6216
mmancebo@butler.org

See You in Philadelphia for the OCF 9th Annual Conference Aug. 9-11, 2002

Butler Hospital Has Special Programs for Treatment Refractory OCD

The following is an interview with Steven Rasmussen, MD, who is the medical director at Brown University's Butler Hospital in Providence, R.I. The Butler Hospital Program for Treatment Refractory OCD. While the OCD group at Brown/Butler offers psychopharmacological treatments and cognitive behavior therapy, including Exposure & Response Prevention Therapy, to people with OCD on an outpatient basis, it also has a special program for individuals suffering with OCD for whom all other treatments have previously failed. This very restricted program includes surgery and an experimental process, Deep Brain Stimulation.

NEWSLETTER: What programs do you have at Butler Hospital for individuals with OCD?

RASMUSSEN: We offer a full range of pharmacologic and behavioral therapy treatments for outpatients. We also offer a treatment program for patients who have failed all other treatments.

NEWSLETTER: Do you have inpatient facilities for people in your Treatment Refractory OCD program? What are they?

RASMUSSEN: We occasionally hospitalize patients who are in our neurosurgical program who are too ill to stay in a nearby hotel. We try to deliver as much of the behavioral treatment as possible in the patients' home setting. We do not have specialized inpatient resources, though our inpatient nurses are very highly experienced in treating severely ill patients with OCD. We do not have a program like the OCD Institute at McLean that offers 'round the clock CBT.

NEWSLETTER: Can an individual participate in this Treatment Refractory OCD Program without being an inpatient?

RASMUSSEN: As long as the patient is not a danger to him or herself or require total care, we prefer to treat them as outpatients.

NEWSLETTER: What is the typical length of your Treatment Refractory Program?

RASMUSSEN: We have no typical length for our program. We design a program that fits each patient's individual needs. We have a cooperative arrangement with the OCDI at McLean, which allows us to take advantage of the group and individual treatment there.

NEWSLETTER: What treatment modalities do you use in this Treatment Refractory Program?

RASMUSSEN: Our Treatment Refractory OCD Program only accepts patients who have failed behavioral treatment elsewhere. We prefer to take patients who have already failed other intensive behavioral programs like the OCDI. We offer surgical options using the gamma knife and a newer approach that has recently been FDA approved for Parkinson's disease called Deep Brain Stimulation.

NEWSLETTER: Is it necessary for someone in your program to be on medication?

RASMUSSEN: All patients applying to our program must have failed trials of available medication. We often see patients who are on many medications but have had no response to them. These patients can often benefit from some of the new surgical approaches.

NEWSLETTER: Can you describe your program for our readers?

RASMUSSEN: Our program is centered on our research on neurosurgical treatment for OCD. We have completed gamma capsulotomies on 40 patients who have failed to respond to all available treatments over the past 8 years. At two-year follow-up, 55% are very much improved and have shown a 35% or more drop in their YBOCS scores. One of the forty patients has had a significant increase in apathy and a-motivation but there are no other adverse effects of the surgery on neuropsychologic function or personality. We are currently testing the effects of deep brain stimulation, a reversible procedure, in severely ill intractable OCD patients. Our intensive behavioral program is designed to make certain our patients get good behavioral treatment both prior to and after surgery.

NEWSLETTER: Butler Hospital has long been in the forefront of OCD treatment, would you describe the family centered treatment that was developed at Brown?

RASMUSSEN: We have been very fortunate to have Barbara Van Noppen, a gifted therapist, who has been responsible for most of the family centered treatments developed at our site. We have always held that significant others are inextricably and unavoidably involved in most patients rituals. We do not evaluate patients without involving their significant other. One of our most useful services is the multifamily support group that has been running since 1984 on a monthly basis. We also run family groups. The basis of our family centered treatment is described in *Learning to Live with OCD*, a booklet that was developed by Barbara in the 1980's and that is available from the OCF.

NEWSLETTER: Who would be a candidate for treatment in your Treatment Refractory OCD Program? Someone with very severe OCD, moderate OCD?

RASMUSSEN: We accept patients who are 18 and above, who have been severely ill for more than 5 years and have failed all available pharmacologic and behavioral treatments.

NEWSLETTER: What would be a typical first day in your Treatment Refractory OCD Program?

RASMUSSEN: A typical first day in our program would be evaluations by a multidisciplinary staff including two psychiatrists, a neurologist, a neuropsychiatrist and our behavioral therapist. Part of the evaluation is to develop a behavioral contract about the plan for exposure and responsive prevention.

NEWSLETTER: How many patients are in the Treatment Refractory OCD Program at any one time?

RASMUSSEN: We only accept ten to fifteen severely ill patients per year.

NEWSLETTER: Would you explain how you integrate group therapy and family therapy into your program?

RASMUSSEN: Most of our group and family treatments are for patients from the surrounding New England area. From time to time, patients in our Treatment Refractory OCD Program participate in our group or family treatments with local patients. We try to individualize treatments. Group is extremely effective for some patients and not for others. Family is essential for some and counterproductive for others.

NEWSLETTER: How many people are on the staff that deal with treatment resistant patients? Who are they? Can you give us a snapshot of their clinical and research backgrounds?

RASMUSSEN: Our treatment team is made up of three full-time psychiatrists, a neurologist, a neuropsychologist and a highly experienced behavioral therapist. We also work closely with 4 highly experienced OCD cognitive behavioral therapists in the community, including Barbara Van Noppen, who also works in family centered treatment.

Dr. Jane Eisen and I have been associated with the OCD clinic since 1985. Dr. Ben Greenberg, who was the former chief of the OCD Clinic at the National Institute of Mental Health and who has been working in OCD research for 10 years, recently joined us and is leading our research in deep brain stimulation for OCD. Dr. Henrietta Leonard,

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Butler Hospital Has Special Programs for Treatment Refractory OCD

an outstanding child researcher and clinician from the National Institute of Mental Health, has also been here for 8 years and has an OCD clinic for children and adolescents at Rhode Island Hospital.

Richard Marsland is the behavioral therapist who works with our toughest cases including all of those in the surgical program. He has been associated with the clinic since 1985. In the beginning he had several of our sickest patients live in his home for months at a time. Though that service is not currently available, Rich is another gifted clinician that we have been fortunate to have on our staff.

NEWSLETTER: Do you also treat OC Spectrum Disorders in your program?

RASMUSSEN: Dr. Katharine Phillips has an outstanding research program in Body Dysmorphic Disorder (BDD) and is right down the hall from us. We have accepted an occasional BDD patient into our surgical program. We treat no other spectrum disorders.

Newsletter: How do you handle relapse prevention in your program?

RASMUSSEN: We find that for many patients the greatest risk is when they return to their home environment. We try to maintain close contact with therapists in the patient's home area to ensure continuity of the treatment plan. Close attention to daily structure and routine is necessary as well as keeping up with behavioral homework, even after surgery.

NEWSLETTER: Do you treat children and adolescents in this special program?

RASMUSSEN: We cannot offer treatment to those under the age of 18.

NEWSLETTER: Brown/Butler has always done a great deal of research on OCD and its spectrum disorders. What kinds of research are you and your colleagues involved in now?

RASMUSSEN: We currently are involved in several major research projects. Those include: 1) developing neurosurgical treatments for patients who have failed to respond to all other treatments; 2) a large prospective follow-up study with 400 patients with OCD whose primary aim is to determine the course of OCD and the impacts that available treatments are having on relapse and remission rates; 3) a sib pair genetic study that is being coordinated by Dr. Gerry Nestadt at Johns Hopkins; and 4) improvements in behavioral and family treatments for OCD.

NEWSLETTER: Can someone who is in the Treatment Resistant Program participate in any of your research protocols?

RASMUSSEN: All patients who enter this program have agreed to take part in the neurosurgical research study. They may also participate in the other studies if they meet entry criteria.

NEWSLETTER: How do you handle situations where a patient's OCD revolves around his/her home? Does someone from the staff visit the person's home?

RASMUSSEN: If possible, we try to do home visits. There are many patients in our experience whose OCD is at its worst in the home environment. Unfortunately, reimbursement for home visits is limited. We feel that for those who fail office-based treatment, home intervention is a must.

NEWSLETTER: Are your treatment programs covered by private insurances? Medicare? Medicaid?

RASMUSSEN: The deep brain stimulation is a research procedure for which the costs are covered. The gamma knife is not currently reimbursed as part of our research programs.

NEWSLETTER: Does Butler have any subsidies or scholarships for individuals who cannot afford to pay for treatment?

RASMUSSEN: We don't have subsidies or scholarships but we offer free psychiatric treatment as part of our research programs.

NEWSLETTER: How does an individual get admitted to this program? Does he have to have a referral from his own treatment provider or can he self-refer?

RASMUSSEN: Patients can self-refer but we must also have contact with their treatment provider(s) for them to be accepted into the program.

NEWSLETTER: Do you treat individuals who have co-morbid conditions, alcohol or substance abuse?

RASMUSSEN: Most patients we see have comorbid depression and anxiety. They must be substance free for 6 months to be accepted into our program.

NEWSLETTER: If someone is interested in one of the Brown/Butler OCD programs, whom should they contact? What is the phone number or e-mail address to get further information on or to apply to be in your program?

RASMUSSEN: They can call my office at 401-455-6209 or e-mail Dr. Greenberg or me at either Steven_Rasmussen@brown.edu or bdg@butler.org.

Preparing For the Conference: How the Presenters Do It

*by Fred Penzel, Ph.D.**

It always seems that the OCF's national conference sneaks up on me without my even realizing it, and I find myself faced once again with preparing my presentation and making travel plans. My particular topic is titled "Very Superstitious: OCD and the Nature of Magic," a new and interesting topic for me, and one I am looking forward to presenting to conference attendees.

Fred Penzel, Ph.D.

No matter how many of these meetings I have attended (and they add up to quite a few), I always feel a sense of excitement at being part of an event of this type. I come away feeling revitalized and rededicated to my work in helping those with OCD.

Apart from my own work, this year's location presents a bit of magic for those of us on who live on Long Island – a location that we can actually drive to this year. As a result, quite a number of my patients have expressed an interest in going, and I have done my best to encourage others as well.

They have been asking me about what particular advantages there would be in their attending, given the fact that they are already in therapy and can attend meetings at our facility. My answer usually includes the following points:

* Attending the national meeting gives you the opportunity to meet and hear what some of the nation's leading experts have to say – a chance to get an overview of the field as it currently stands.

* There is the opportunity for you to meet literally hundreds of others with OCD, to make friends, to share experiences, and to see that you are not alone (I always meet many really great people there, myself).

* There is also the opportunity to break the stigma – to join in and have a good time with everyone, and see that all those others are simply ordinary folks from many walks of life who also just happen to have OCD, like you.

* To learn more about their disorder from the professionals, the top self-help people, other consumers, and their families.

I suppose there might be more reasons to attend, but how many more do you need anyway? I look forward to seeing all of you there, especially those who have contacted me by phone or e-mail during the last year. Hope you can make it!

Dr. Penzel has been presenting at the Annual OCF Conference for almost as many years as there has been a conference. He is a licensed clinical psychologist and author of **"Obsessive-Compulsive Disorders: A Complete Guide to Getting Well and Staying Well."*

From the Foundation

(continued from page 1)

Then comes the day (it could be at 9 or 12 or 15 or 17) when the compulsions and obsessions take center stage. To everyone's amazement, the child who yesterday couldn't even stand the possibility of being late for school, won't come out of the bathroom. Can't come out of the bathroom because she can't get the germs off her hands. Germs, she is sure, are going to contaminate everyone she encounters and cause them to become deathly sick.

Now, we know that OCD begins really early. We just don't know it's there until the sufferer reaches a point where it can't be hidden anymore. That can happen at 3 or 65. However, no matter how devastating it is for a child to have OCD, the earlier it emerges the better. Because the earlier the child learns to distinguish what are OCD thoughts, the earlier he can free himself from them. The most pernicious thing about OCD is how it "contaminates" a life. But now, for the first time in history (and that ain't no exaggeration), we have the means to diagnose and effectively treat OCD. Early diagnosis and treatment gives us a chance to change a child's life for the better. Not only because we are freeing these children from painful obsessions and compulsions, but also because we are giving them a chance at a life where OCD hidden or overt is not going to dominate every choice and decision.

One of the worst things about OCD is that even when the sufferer isn't going through an acute phase, OCD controls her. Every choice and decision from what courses you are going to take, to what schools to apply to and which person to date and ultimately marry is shaded by the OCD. It's in the background, asserting its claim. Ultimately, every one of these choices is made to accommodate the OCD.

Now, because we can diagnose and treat children and adolescents with OCD, we have a chance to give them the ability to make their choices and decisions without having to accommodate their OCD. But, to be able to exercise the right of OCD – free choice, a sufferer needs to know all about OCD – what it is, what it isn't, how to detect it, how to manage it, how to get free of it.

Working with three people from the Menninger Clinic, Constantina Boudouvas, Susan Nelson and Nancy Trowbridge, we've developed a way to help educate our teens to control their OCD. It's a webzine just for teens with OCD, called "Organized Chaos." Some of our kids at the Menninger OCD Clinic came up with the name.

A webzine is a magazine published on a web site. "Organized Chaos," whose first edition is scheduled for early summer 2002, will be appended to the Foundation's website, www.ocfoundation.org. "Organized Chaos" will be accessible only to teens with the password. They can get the password by calling the Foundation at 203.315.2190 after June 15, 2002.

The editorial philosophy behind "Organized Chaos" is to get kids with OCD the information they need to control their OCD their way. It is definitely a magazine for teens, not younger children. We want it to be edgy and to really address the questions and problems that they are facing in a format and manner that appeals to them and that they can identify with. There will be articles and columns written by treatment providers, college kids and young professionals with OCD and stories, essays and poems by teenagers with OCD. In the first issue, there's a column by Dr. Michael Jenike and Julie Jenike about how to control medication-induced weight gain, an essay by a twenty-something with OCD recounting his experiences trying to self-medicate, a column by Dr. Joyce Davidson on medication, an essay on being hospitalized for OCD and the first installments of a feature called, "What We Do When We're Not Obsessing."

The plan is to publish three issues of "Organized Chaos" a year. This year, the first edition will go up in early summer. The second edition which is slated to be on-line at the end of September will be written and put together at the 9th Annual OCF Conference in Philadelphia. Writing advisors are going to be in the Kids Hospitality Suite along with an art therapist on Friday and Saturday, helping any teen who is interested to write an article, column, feature, story or interview for the second issue. They'll be doing some photography for the webzine too.

We are hoping that "Organized Chaos" gives our kids another tool to use to free their lives from OCD. Please support it by encouraging your teen to call for the password or just give him this article to read.

Ciao,

Patricia Perkins

Medication Induced Weight Gain

(continued from page 10)

ratio of fat to lean muscle mass.

Combining proper nutrition with cardiorespiratory exercise and resistance training can not only help prevent weight gain and other health-related ailments, but also increase energy levels which can offset some of the sedative effects of medications. The effects of exercise can also generate improvements in self-esteem and positive well-being.

What drug options are available to manage weight gain?

If all else fails, we sometimes try adding a second drug for a few weeks to try and assist with weight loss. Cytomel is a thyroid hormone preparation that can be used to speed metabolic rate and is sometimes used for a few weeks to help weight loss. Sometimes a few weeks of a stimulant drug like Ritalin (methylphenidate) will help curb appetite. One drug that often helps a lot with weight loss associated with anti-obsessional medication and is safe in low dose (ie, 50mg) is Topamax (topiramide). There is a recent of report of the ulcer drug, nizatidine, reducing the weight gain associated with Zyprexa by as much as 50% without affecting the effectiveness of the Zyprexa. Chromium piccolinate is recommended by some people (can be gotten in health food stores), but we have limited and unimpressive experience to date.

SUMMARY: What can you do to manage weight gain?

1. Avoid drugs that have a high likelihood of causing weight gain. The worst offender of the SSRIs medications is Paxil and of the atypical neuroleptics is Zyprexa. Since there are good alternatives to these medications, they should be used first.

2. As soon as you are about to begin anti-obsessional medication, pay particular attention to diet and an exercise program.

3. If you are gaining weight on one of these medications, immediately talk to your physician about switching to another comparable drug. You may not gain weight on a similar drug. Each person has a genetically-defined different set of brain receptors, and one drug may cause weight gain in one person and weight loss in another.

4. If the above are not working for you, talk to your doctor about adding another medication that may help with the weight gains. Cytomel, Ritalin, nizatidine and Topamax are agents that may be useful.

5. Probably the most effective tactic is to lower the dose of SSRI medication or even stop it. Many OCD patients can taper and some even stop medication if they pay particular attention to CBT techniques. CBT causes no weight gain unless your therapist

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At the 9th Annual OCF Conference
August 9 – 11, 2002
Wyndham Franklin Plaza Hotel
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FIRST PRIZE: $1,000.00

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* sponsored by Patrick Johnson

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