

## From the President

Dear Friends,

On Sunday afternoon, August 11, 30 scientists came together at the Wyndham Franklin Plaza Hotel in Philadelphia for the first meeting of the OCD Genetics Consortium. Several of us from the Obsessive Compulsive Foundation Board of Directors and staff had the unique privilege of sitting in on the meeting. Since so many of you have contributed to this group, I wanted to share with you my observations of what was a

truly amazing experience. As we listened to researchers present information about their work directed at solving the OCD puzzle, I realized with great satisfaction the amount of research being directed at this disorder. We were, indeed, watching the group that had the tools and the drive to find a cure for OCD.

Dr. David Pauls of Harvard Medical School, as acting co-chair of the group, moderated the meeting. He emphasized that the purpose of this initial meeting was specifically to get to know one another and learn about each other's work. He told the group in his opening remarks that he wanted to devote time to exploring the various types of models for research collaboration, looking at every possibility from a consortium to a confederation. He also pointed out that any collaborative group that was formed would be set up "to facilitate rather than to impede the progress of any of the participating individual groups."

According to Dr. Pauls, "the purpose of establishing a consortium is to assure uniform assessments so that researchers can benefit from each others' sample collections. The ultimate goal is to find effective treatment for OCD. We want to set up a group that helps us achieve that goal, not that hampers us in our work."

While we have used the term, "consortium" in setting up this venture, it might not be the most effective structure for success. Consequently, Dr. Pauls encouraged the group to explore other models as we move forward. For instance, Dr. Pauls introduced a "confederation" model and defined it as a group that consists of individual sites and researchers who are independently funded and free to publish the results of their work without reference to the group as a whole. Based on his own experience, Dr. Pauls recommended this type of collaboration.

While he appreciated being named as co-chair of the Consortium, Dr. Pauls emphasized that he wanted the group to ultimately choose its own leadership. It is his belief that the only way that the group could work together successfully is if it chooses its own leadership.

He also suggested that the group select an advisory board from among genetics researchers who are not involved with OCD. He felt that the investigators forming this board should be very experienced and from all over the world. The advisory board should be beneficial from both a research and funding prospective.

The next item on the agenda was a short presentation by a representative from each one of the research sites.

Each representative spoke about his/her group's research and clinical activities. The projects ranged from interviewing sibling pairs to searching for the gene candidates that might be responsible for transmitting the OCD.

Dr. Pauls then reviewed the history and structure of the Tourette's Syndrome Association's Genetics Consortium, whose members have

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Consortium member  
Dr. Michele Pato



Dr. Don Black,  
OCD researcher  
from the  
University of  
Iowa



Barbara Wagner and Dr. David Pauls, co-chair of the Consortium, chat about research.



Drs. Miguel Euripedes and Maria Rosario-Campos, representing Brazil and the Yale Child Center on the OCD.

## How Do I Know If My Therapist Can Treat OCD?

By Lisa Jo Bertman, Ph.D.  
Tulane University School of Medicine

The goal of this article is to help persons with OCD, their families, and friends to find appropriate treatment for OCD. Finding a qualified therapist can be a discouraging and draining procedure if not educated about what to look for in a therapist.

Consequently, this may leave little or no energy for actually doing the treatment. In this article, I'll be reviewing the important questions to ask and the answers one should get if the therapist has experience with treating OCD.

I will also be outlining what to expect in the treatment and when to consider other types of treatment.

### What should I ask a potential therapist?

It is probably not necessary to visit in session with several therapists prior to choosing one. Below are some specific questions to ask a therapist over the phone prior to making an appointment.

**1. Question:** What is your orientation?

**Answer:** Behavioral or Cognitive Behavioral.

**2. Question:** Do you do exposure and response prevention treatment?

**Answer:** YES. This is the most essential aspect of treatment for OCD. Exposure and response prevention (E&RP) is a type of behavioral treatment and is the most efficacious treatment for OCD when combined with medication. It is not enough to

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## Bulletin Board

### Brain Imaging Studies in Individuals with OCD

Participants need to be within commuting distance of Long Island, New York.

Using pilot data obtained from an Obsessive-Compulsive Foundation Research Award grant 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 modalities, 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. If you have OCD, you may be eligible to take part in this study. Study participants, who will need to be able to commute to Hillside Hospital, will also have comprehensive neuropsychological, clinical and diagnostic assessments. There is no treatment provided in this study. 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.

### Intravenous Anafranil Study for Treatment Refractory OCD

This study is investigating whether pulse loading of Anafranil, 150mg on day one and 200mg on day two, results in a marked decrease in the severity of OCD symptoms in treatment refractory cases, and whether this decrease exceeds that produced by double-blind oral pulse loading of identical doses. We plan to enroll 38 patients at Stanford University and 38 at the University of Cincinnati and the University of Florida. Patients are randomly assigned to pulse load intravenous Anafranil or oral Anafranil. Five days after finishing the pulse loading of Anafranil all patients start 12 weeks of treatment with open-label Anafranil. Patients must be at Stanford, Florida or Cincinnati for one week at the beginning of the study and one day at the end of the study. The 12 weeks of open-label oral Anafranil treatment can be completed in the patient's home city with the assistance of the patient's usual treating psychiatrist.

To be eligible, patients must be 18 to 55 years of age, have moderately severe or severe OCD of at least one year's duration, and have failed to benefit substantially from two or more adequate trials (in terms of dose, > 8 weeks in duration) of anti-OCD medications. Patients who have failed to benefit from previous trials of oral Anafranil are eligible for the study. Additional eligibility requirements will be reviewed with each patient during a detailed phone screen. For more information contact:

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### Do you suffer from Obsessive-Compulsive Disorder? Are you on medication but still have symptoms? Do you live within commuting distance of New York City?

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.

### Hoarding Study at UCLA

This is a 12-week study for people with the hoarding type of OCD. The study involves having a PET (Positron Emission Tomography) scan of the brain before and after 12 weeks of treatment. Treatment involves taking the medication paroxetine (Paxil) for 12 weeks, with the option to take a second "augmenting" medication at the end of the 12 weeks if response to Paxil is minimal. The study also involves having an MRI (Magnetic Resonance Image) of the brain. This helps to accurately "map" the PET scan.

The purpose of the study is to look at changes in brain metabolism before and after treatment. This aim is to identify the brain systems that mediate response to treatment with medication in the type of OCD.

This research is being conducted on campus at the University of California, Los Angeles. For more information, call Karron Maidment, RN, MA, at (310) 794-7305.

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## OCD NEWSLETTER

The OCD Newsletter is published six times a year.

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

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

## How Do I Know If My Therapist Can Treat OCD?

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ask the question since some therapists use other behavioral techniques but do not do E&RP.

There are three follow-up questions recommended if the response to question #2 is YES.

**1. Question:** Would you participate in the E&RP sessions?

**Answer:** An affirmative response would be important for someone who is confident they will be unable to do self-directed E&RP and will need the assistance of a therapist. Please note that it is not clinically beneficial to do therapist-assisted E&RP for a prolonged number of sessions. Therapist-assisted E&RP should be combined with self-directed E&RP and eventually the therapist should be faded out of doing exposure work with the patient.

**2. Question:** Do you practice home-based treatment?

**Answer:** Some individuals have OCD symptoms that are confined to their home or are significantly worse in the home. For these individuals, a therapist who comes to the home would be ideal. Please note that it is difficult to find a therapist who will come to the home.

**3. Question:** How many patients have you treated with OCD?

**Answer:** This response could vary. A safe recommendation would be a therapist who has had significant experience treating OCD and anxiety disorders. Some red flag responses are, "Oh, you would be my first" or "It has been a long time since I have treated anyone with OCD."

### What should I expect to happen during the assessment and initial treatment?

**Assessment:** The assessment phase is usually completed within two or three sessions. During this time, the therapist will ask many questions related to OCD symptoms and will likely administer a Yale Brown Obsessive Compulsive Scale, a questionnaire that measures symptom severity. Potential questions include:

- Which specific situations, thoughts, images, objects trigger anxiety or discomfort?
- When and where does compulsive behavior occur?
- Describe the frequency, intensity, and

duration of compulsive behavior.

- What situations, objects, and/or persons are completely avoided?
- What is feared if rituals are prevented?
- What is the role of family members in OCD symptoms?



Dr. Bertman has presented on E&RP at Annual OCF Conferences.

**Treatment:** Once the therapist has completed a thorough assessment of obsessions, compulsions, avoidance behavior, and triggers, treatment should proceed by organizing and negotiating with the patient how the fears will be addressed. As previously mentioned, the treatment of choice for OCD is E&RP. Exposure involves confronting fears, situations, and thoughts that produce discomfort. Response prevention involves not engaging in the response(s) that make the person feel more comfortable. The goal of E&RP is habituation. Habituation refers to getting used to or ignoring things that have produced a strong emotional reaction. Therapist and patient will generate a hierarchy of fears that goes from least anxiety-producing to most anxiety-producing. With the fear hierarchy, the person is gradually introduced to fears; once there is mastery of one fear, the person addresses the next item on the hierarchy.

**Important note:** Although the appropriate treatment for OCD is straightforward and not mysterious, it is not an easy treatment to do. The treatment involves considerable collaboration between therapist and patient, so it is important to trust your therapist and feel comfortable discussing your concerns openly.

### When is it appropriate to consider other types of treatment?

Many times individuals with OCD will have other difficulties or diagnoses as well. Depression is the most common condition that is associated with OCD. Family and/or marital discord are also

typical among OCD patients. After an adequate trial of OCD treatment, other therapies may be indicated to help regain functioning in life (e.g., managing daily life stressors and interpersonal relationships). However, it is usually recommended that a general psychotherapy, family, and/or marital therapy begin once OCD symptoms are more manageable, and the person regains control of daily living skills.

### What do I do if there is no one in my area who is qualified to treat OCD?

Unfortunately, this question is frequently asked since there are so few qualified OCD therapists in many areas. If this is your situation, here are two options to consider:

1. Purchase an OCD self-help book and try treatment independently or with a therapist functioning as a coach. There is a very good treatment manual called *The OCD Workbook* by Bruce Hyman, Ph.D. and Cherry Pedrick, R.N. The book provides step-by-step instruction on self-directed cognitive behavioral treatment.

2. The Obsessive Compulsive Foundation conducts Behavior Therapy Institute (BTI) training in various locations throughout the country. The BTI is a three-day intensive training for mental health professionals who are providing care for persons with OCD. The BTI will help therapists design and implement cognitive behavioral treatment plans for their clients. The BTI is taught by experts in the area of treatment of OCD and related spectrum disorders. If you want more information about having your local therapist attend the BTI session, contact Jeannette Cole at the Obsessive Compulsive Foundation.

Good luck!

### 2003 OC Foundation Research Awards Applications Now Available

Please call Jeannette Cole, deputy director, at (203) 315-2190, Ext. 18, to request applications for the 2003 OC Foundation Research Awards.

## Affiliates and Support Group Activities

### OCFMC HOSTS EDUCATIONAL CONFERENCE

by Anne Coulter

"Treatment Changes Lives" was the theme of the OCD Professional and Consumer Conference, jointly sponsored by the Obsessive Compulsive Foundation of Metropolitan Chicago (OCFMC) and the University of Illinois at Chicago (UIC) College of Medicine. This educational conference provided attendees with a wide range of information about the disorder, with a special emphasis on treatment.

More than 300 participants – mental health professionals, people with OCD, family and friends, and conference faculty – gathered at the Holiday Inn Chicago Mart Plaza on May 4, for:

- 24 concurrent sessions for professionals and consumers
- Four discussion groups for adults and two for children and teens
- A full-day, hands-on behavior therapy workshop for professionals
- Two special day-long sessions for children (7 to 11) and teens (12 to 17)

Session topics included: pharmacology; genetics and neurobiology; comorbid disorders; other anxiety disorders; behavior therapy; treatment of specific populations (women, small children, and the elderly); family responses to OCD; parenting a child with OCD; and working with the schools. In addition, a "Real Life Stories" panel included discussion by several people who are successfully managing their disorder.

A full-day behavior therapy workshop for professionals provided intensive training on how to design and implement a behavioral therapy treatment plan for OCD patients. The OCFMC's goal was to help more mental health specialists in the Chicago area become familiar with effective approaches for treating OCD. Workshop attendees also had the opportunity to take advantage of a post-conference consultation with a faculty advisor.

Kids and teens were a critical – and uplifting! – part of the day. In the kids' session, participants were encouraged to express themselves through storytelling, music and sculpting. At one point, the kids paraded through the conference hallways, singing a song they'd written about OCD. Teens watched an award-winning play about OCD and created their own short documentary video about living with the disorder.

"For many of the children, it was the first time they met other kids with OCD. We watched them get more comfortable with each other and really open up throughout the day. It was one of the most rewarding parts of the conference," said Susan Richman, OCFMC president.

The conference was made possible, in part, by grants from Melissa Sage Fadim and the Sage

Foundation, Wyeth Pharmaceuticals, and Pfizer Pharmaceuticals. The OCFMC is also deeply grateful to the terrific conference faculty and volunteers who made the day a huge success.

### THE NEW JERSEY AFFILIATE OF THE OBSESSIVE COMPULSIVE FOUNDATION

Presents its **Third Annual Conference** featuring "**Freeing Your Child From OCD: Finding Your Way on the Road to Recovery**".

by Tamar Chansky, Ph.D.

Plus, Parents of OCD Kids Panel

Sunday, October 20, 2002

10:00 am – 2:00 pm

Somerset Marriott, Somerset, NJ

Advanced registration fee (before 10/6/02) \$40

After 10/6/02 and on site \$45

CEH CREDITS AVAILABLE

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

### OBSESSIVE COMPULSIVE & RELATED DISORDERS LES GRODBERG MEMORIAL LECTURE SERIES 2002 - 2003

Sponsored by the Greater Boston Affiliate of the Obsessive Compulsive Foundation  
McLean Hospital, De Marneffe Building  
(Room 132)  
Belmont, MA 02478

The OCF of Greater Boston, in conjunction with McLean Hospital, presents a series of pre-eminent speakers in the field of OCD and related disorders. An informal social is held from 6:30 pm - 7:00 pm. Each presentation begins at 7:00 pm.

November 5, 2002

**The Genetics of OCD**

David Pauls, MD

December 3, 2002

**Cognitive Behavior Therapy for Pediatric OCD**

Dr. Kathleen Trainor

January 7, 2003

**Kids Rights Within the School System**

Ken McElhane

February 4, 2003

**Body Dysmorphic Disorder**

Robert Oliverdio, Ph.D.

March 4, 2003

**Cognitive Therapy for OCD**

Jennifer Cullen, Ph.D.

April 1, 2003

**Violent and Sexual Intrusive Thoughts**

Deb Osgood-Hynes, Psy.D.

May 6, 2003

**New Research and Treatment in the Field of OCD**

Dr. Thilo Deckersbach

June 3, 2003

**OCD in the Workplace**

Alan Siegel, LICSW

Following each speaker presentation, there are several free self-help groups open to the public. For more information please contact Denise Egan-Stack at (617) 855-2252.

### THIRD TIME LUCKY!

by Fred Penzel, Ph.D.

Well, we did it again – held our Third Annual Long Islanders Against OCD Picnic this last June the 30th. Our purposes, as always, were to help give OCD sufferers in our region a sense of community, to help break down some of the stigma of the disorder, to give some people a



Rob Lancer and Dr. Fred Penzel with Joey Penzel, welcome folk to the picnic.

nice day out of the house with others they might not have had otherwise, and, last but not least, to raise money for the Genetics Consortium. We succeeded on all counts.

Long Islanders tend to be an independent bunch. Some of us like to refer to ourselves as the OCF's unaffiliated affiliate. What we lack in organization, we make up for with enthusiasm. Much of the organizing was done by members of the generous Lancer family and me.



Happy picnickers smile for the camera

We had a beautiful day and 65 attendees. Among those in attendance were Roy C. (founder of OC Anonymous), a number of OCA members, and those belonging to our local G.O.A.L. group. Between our admission fee, a raffle, and some extra contributions, we managed to raise a record \$960 as a result of our event. Not bad at all!

The moral of the story is that it doesn't take much to make a difference. All you need is a sunny day, a shady spot, and a bunch of people willing to have lunch together for one afternoon. Think about trying it yourself in the

## How to Use the ADA When You Have OCD

by Sharon Lewis, JD\*  
Patricia Perkins, JD

In the past two issues of the OCD NEWSLETTER, we've been writing about how people with OCD can use the Americans with Disabilities Act to get and keep a job. Now we have to deal with a curve the US Supreme Court threw citizens with disabilities in several cases it decided recently.

According to the lawmakers who passed the ADA, its purpose is to protect individuals with disabilities from being barred from doing jobs they have the talent, training and ability to do. This, according to the language of the Act, was their intention anyhow. A person is described as "disabled" under the ADA and therefore able to claim its protections if s/he has a physical or mental condition that substantially impairs a major life activity. According to the regulations and case law that have been developed to implement the ADA, major life activities include: caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, working, concentrating, making decisions, and interacting with others.

Moderate to severe OCD (when you spend more than a couple of hours a day on rituals and compulsions) certainly substantially impairs a sufferer's life activities, including, for instance, the ability to work an uninterrupted day, to take care of oneself, to travel, to concentrate without distractions. Based on the plain language of the Act and the regulations that were developed to implement it, one would think that people with OCD would be within the group the Act was meant to protect. That's what one would think; but, unfortunately, one would be wrong. The justices have decided that whether a person is "disabled," which is defined as being "substantially impaired," has to be determined with regard to any mitigating or corrective measures. I know, you're asking in everyday English, what does this mean.

Well, the justices are saying that if you have a serious illness, such as, OCD, but you have it under control through medication or therapy, to the extent that your symptoms no longer "substantially impair" your major life activities, then you are no longer "disabled" and cannot avail yourself of the protections and accommodations of the ADA. Whoa! You have to ask what is being encouraged and rewarded here? Obviously, not the courage and steadfastness that makes a person strive to work and accomplish things despite obstacles and limitations! The question one has to ask here is: Why try to get better when that is only going to make you worse off? What good is the ADA to someone who has employed medication and/or therapy to recover sufficiently to perform all the essential elements of a job, if she can't be hired for the job or can't get the accommodations she needs because she isn't protected by the ADA from discrimination? Thanks to the justices do we have a law that we cannot use when we need to?

The unsatisfying answer is: "No, but it's a lot more difficult!" The Supreme Court decision does not mean that a person is no longer disabled under the ADA simply because she takes medication to control

her illness. However, now the question is a person must then show that with or without medication she is substantially limited in a major life activity.

Although working is considered a major life activity, this is the most difficult substantial limitation to prove and is one that puts the disabled individual in a Catch-22. To prove a substantial limitation on the major life activity of working, a person must show that she is disabled from performing a broad class of jobs for which she is otherwise qualified and not just the job in question. The Catch-22 is that the more effectively the disabled individual demonstrates a substantial limitation in working, the more likely she will be considered unqualified to perform the essential functions of the job.

To see how this plays out, let's create a hypothetical person with OCD and put her in a situation where she needs the protection of the Act. We'll say she's a college-graduate in her mid-30's. She worked for a major manufacturing company as an accountant for 10 years before her subclinical OCD became acute and totally disabling. The OCD caused her to be late for work or to miss work completely. On the brink of losing her job, she was diagnosed with OCD and went to her employer and asked for a leave of absence as an accommodation under the ADA. Since she was "substantially impaired" at the time, and she fit the definition of a "disabled person" under the ADA, she was granted the leave for treatment as an accommodation.

Our hypothetical person uses the leave of absence to try different medications until she finds one that works and then starts working with a therapist on Exposure and Response Prevention. She works really hard and gets her OCD under control enough so that she can return to work and perform effectively all the essential elements of her job as an accountant. However, she is still "insubstantially" impaired. She can't get to work on time consistently (although she's willing to stay late to make up the time) and she needs to take time off during the week to go to behavior therapy. So, she's going to need some accommodations.

But, now that the Supreme Court has decided, because her condition has to be evaluated in its "mitigated" state, she will have to prove that either her OCD or her medication substantially limits her in a major life activity other than working. Now that she needs the accommodations promised her under the Act, will she be entitled to them? It's hard to believe that laws that were meant to help individuals can do so much unintended harm.

What can she do now that the Justices have foreclosed her from the protections of the Act? In an attempt to answer this question, we visited the web page of the Bazelon Center for Mental Health Law. The people at the Bazelon Center have been involved in most of the major litigation in the past several decades that has secured civil rights for individuals with mental illness. They have been pondering the Catch 22 the Supreme Court has created with these rulings and have come up with some suggestions that we felt we should pass on to you.

Their first idea was that anyone who found herself in a situation similar to our hypothetical account-

ant should insist that her situation be evaluated from another point of view, i.e., whether or not she has substantial limitations on other major life activities besides the activity of working. It may be that the medication can have made it possible for a person to perform all the essential functions of her job but still not have helped/cured all the substantial limitations caused by the disability. For instance, in our hypothetical, our recovering accountant may be limited by the OCD in eating (she still is not free from the obsession that her food is contaminated) or she may not be able to get to work in a timely fashion because of some still prominent cleaning rituals, even though the medication has cancelled out the obsessions and checking that were making it impossible for her to do her job as an accountant.

Eating is obviously a major life activity as is being able to get to where you're supposed to be in a timely fashion. Our accountant will need to document these limitations for her employer. Her treatment provider could write a report detailing the limitation and how it affects her eating and ability to leave the house and get to work on time consistently but does not prevent her from performing all the essential elements of her job. The court hasn't mandated that the accommodations be linked to the substantial limitations. This approach will be helpful for anyone with OCD who is recovering, but not recovered, (except, perhaps, for those with scrupulosity who won't be able to utilize this substitute because of their disability, scrupulosity). But that's a topic we can address in a later column.

An alternative to demonstrating that the OCD, despite the medication and treatment, continues to cause a substantial limitation on a major life activity, the Bazelon lawyers came up with is to have our accountant or anyone in this situation be judged by whether the mitigating factor itself, i.e., the medication, imposes any substantial limitations of a major life activity. In our accountant's situation, this could be the fact that the medication she takes to control her obsessions and compulsions, causes her to be extremely tired. The need to have more than 8 hours of sleep a night or naps during the day may be a substantial limitation. It could also be that someone on antiobsessional medication is experiencing gastrointestinal distress. It's irrational. But, because of the wording of these recent opinions, the side effects of the mitigating medication, rather than the actual disabling condition itself, are what make our hypothetical accountant eligible for the accommodations she needs for her OCD.

Another suggestion from the Bazelon group is that anyone seeking accommodations under the act when they have a "controlled" disability should demonstrate that the measures they are using to mitigate their disability do not fully control the effects of their impairment. In other words, they should explain that while the medication or therapy control the obsessions and compulsions most of the time, they still have incidents where they are not. Intermittent but substantially limiting episodes may support a determination of a current disability.

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# Research Digest

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

In this issue we review articles about medications used to treat OCD and one article where cognitive behavior therapy (CBT) was provided to patients, some of whom were receiving SRIs. We use the abbreviation SRI to refer to both the SSRIs (selective serotonin reuptake inhibitors: citalopram [Celexa]; fluoxetine [Prozac]; fluvoxamine [Luvox]; paroxetine [Paxil] and sertraline [Zoloft]) and to clomipramine (Anafranil) which is a non-selective but potent serotonin reuptake inhibitor (SRI) effective in treating OCD.

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

## The adequacy of pharmacotherapy in outpatients with obsessive-compulsive disorder

**International Clinical Psychopharmacology**, 17:109-114, 2002, D. Denys, H. van Megan and H. Westenberg

This paper reports on the treatment history of 313 patients with OCD referred to an anxiety clinic in the Netherlands from 1997 to 2001. This was not a first-time OCD diagnosis for these patients and the average patient had received three treatment trials in the past. Prior to admission, 24% of OCD patients had never received serotonin reuptake inhibitor (SRI) drug therapy or behavior therapy and 89.5% had never received behavior therapy. For those prescribed SRIs, approximately 50% had never taken the maximum effective doses. Overall, a large proportion of patients with OCD failed to receive adequate treatment and many patients were prescribed SRIs at doses below those recommended in treatment guidelines. Researchers speculate on reasons for this lack of adequate treatment, including side effects of the drugs, physicians being unfamiliar with the guidelines, and patient reluctance to accept treatment.

## Cognitive-behavioral therapy with and without medication in the treatment of obsessive-compulsive disorder

**Professional Psychology: Research and Practice**, 33:162-168, 2002, M.E. Franklin, J.S. Abramowitz, D.A. Bux et al.

Is it beneficial to combine cognitive-behavioral therapy (CBT) and selective

serotonin reuptake inhibitors (SRIs) medication treatment? This uncontrolled study cannot definitively answer this question, but the study and clinical implications discussed suggest benefit of CBT alone and when added to effective medication. A main finding is that CBT appeared to be helpful whether or not patients were also receiving drug therapy. The authors conclude that patients who are not already taking medication for OCD prior to starting CBT do not necessarily need to begin medications to benefit substantially. They also suggest that CBT response is quite good for patients who continue medication and patients do not need to discontinue or change their medications.

## Neuropsychological performance in medicated vs. unmedicated patients with obsessive-compulsive disorder

**Psychiatry Research**, 109:255-264, 2002, D. Mataix-Cols, P. Alonso, J. Pifarre et al.

This study compared the neuropsychological performance (mental functioning) in medicated versus unmedicated patients with OCD. Medications were serotonin reuptake inhibitors (SRIs) – clomipramine (Anafranil), fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil) or sertraline (Zoloft) – or clomipramine plus SSRI – or SRI plus benzodiazepine. Assessments were made of intelligence, attention, memory, ability to learn, visual-motor skills and overall cognitive functioning. SRI-medicated patients with OCD were able to perform on mental functioning tests at a level comparable to that of SRI-free patients. These results suggest that OCD medications do not have significant effects on the intellectual functions of patients with OCD. Patients with OCD often fear medications will affect their ability to think clearly and these results are reassuring for those individuals responding to OCD medications.

## Prospective identification and treatment of children with pediatric autoimmune neuropsychiatric disorder associated with group A streptococcal infection (PANDAS)

**Archives of Pediatrics & Adolescent Medicine**, 156:356-361, 2002, M.L. Murphy and M.E. Pichichero

den onset of OCD and/or tic disorders associated with streptococcal infections. This paper reports on 12 school-aged children with new-onset PANDAS who were treated with 10 days of an antibiotic (penicillin, amoxicillin or cephalosporin). In each case it was their first episode of PANDAS and there was a positive throat culture for streptococcal infection. Each child had abrupt appearance of severe OCD behaviors, accompanied by mild symptoms and signs of tonsillitis. The number of prior episodes of streptococcal infection was the only factor that appeared to predict a more severe, relapsing course of PANDAS. There was a dramatic, rapid response to the antibiotic treatment with OCD, anxiety and tic symptoms disappearing an average of 14 days after treatment began. Half of the children did have recurrence of OCD symptoms associated with streptococcal infections that again responded to antibiotic treatment.

*Once children are identified as having OCD symptoms associated with streptococcal infections and treated with antibiotics, the question is how to prevent future occurrences. An earlier study of penicillin prophylaxis (A pilot study of penicillin prophylaxis for neuropsychiatric exacerbations triggered by streptococcal infections, M.A. Garvey et al., Biological Psychiatry, 45:1564-1571, 1999) found no benefit in using penicillin to prevent episodes of OCD. The children with PANDAS received penicillin for 4 months but the penicillin did not prevent recurrences of OCD. Researchers suggested that the doses were not high enough and this should be furthered studied. (JHG)*

## Selective serotonin reuptake inhibitor discontinuation syndrome: a review

**Advances in Therapy**, 19:17-26, 2002, L. Tamam and N. Ozpoyraz

In recent years there has been an increased recognition of adverse effects accompanying discontinuation of selective serotonin reuptake inhibitors (SRIs). This article is an excellent review of the topic. Typically symptoms occur within 1 to 3 days after discontinuation or reduction in dose and include having two or more of the following symptoms: dizziness or lightheadedness, nausea or vomiting, headache, fatigue, anxiety, paresthesia,

## Research Digest

(continued from page 6)

sias (sensations such as tingling, numbness or electric shock-like feelings), tremor, sweating, insomnia, irritability, vertigo or diarrhea. In most cases these adverse effects are mild and short-lived. The syndrome occurs more commonly with SSRIs with shorter half-lives (the time it takes for one-half of the medication to be eliminated from the body). It rarely occurs with fluoxetine (Prozac) that has a long half-life of 2-6 days. Half-lives of other SSRIs are 33 hours for citalopram (Celexa), 15-22 hours for fluvoxamine (Luvox), 10-21 hours for paroxetine (Paxil), and 26 hours for sertraline (Zoloft). Adverse effects with drug discontinuation have been reported most frequently for paroxetine, the SSRI with the shortest half-life, and the syndrome has occurred with dose reductions and missed doses for paroxetine. If this syndrome occurs, going back on the SSRI usually resolves the symptoms within 24 to 48 hours. The best way to avoid adverse effects when discontinuing SSRI treatment is to slowly taper off the medication over several weeks.

*The following studies provide further support for the use of atypical antipsychotics – olanzapine (Zyprexa), quetiapine (Seroquel), risperidone (Risperdal), and ziprasidone (Zeldox) – to augment SRIs in OCD patients with insufficient response to an SRI alone. (JHG)*

**Quetiapine addition to serotonin reuptake inhibitor treatment in patients with treatment-refractory obsessive-compulsive disorder: an open-label study**

**Journal of Clinical Psychiatry, 63:700-703, 2002, D. Denys, H. van Meegen and H. Westenberg**

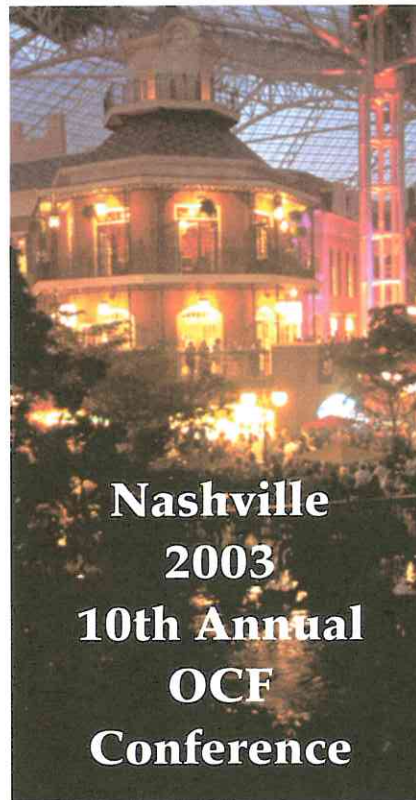
It is estimated that 40% to 60% of patients with OCD do not respond to treatment with serotonin reuptake inhibitors (SRIs). Ten patients with OCD who had not responded to at least 3 previous treatments with an SRI at maximum dose and duration received quetiapine (Seroquel) in addition to an SRI for 8 weeks. The SRI used in this study was paroxetine (Paxil) and venlafaxine (Effexor), a serotonin and norepinephrine reuptake inhibitor, was also studied. Seven of the 10 patients responded to quetiapine addition. This is the first study to show that treatment-refractory OCD patients may benefit from addition of quetiapine to ongoing SRI therapy.

**Risperidone as adjunctive treatment for SSRI-refractory obsessive-compulsive disorder**

**Biological Psychiatry, 51:51S, 2002, L. Xiaohua, W.T. Jackson, R.S. May et al.**

This double-blind study compared risperidone (Risperdal), haloperidol (Haldol) and placebo addition to ongoing SSRI treatment in 14 OCD patients with continuing severe OCD symptoms. Both risperidone and haloperidol addition markedly improved the OCD symptoms, particularly residual obsessions, but haloperidol had more side effects. Researchers suggest risperidone is a promising medication to combine with an SSRI for OCD patients with severe obsessions of violence or sexual misconduct not responding to the SSRI alone.

*This study replicates the positive results obtained with risperidone augmentation of SRIs reported in an earlier controlled trial (A double-blind, placebo-controlled study of risperidone addition in serotonin reuptake inhibitor-refractory obsessive-compulsive disorder, C.J. McDougle et al., Archives of General Psychiatry, 57:794-801, 2000). (JHG)*



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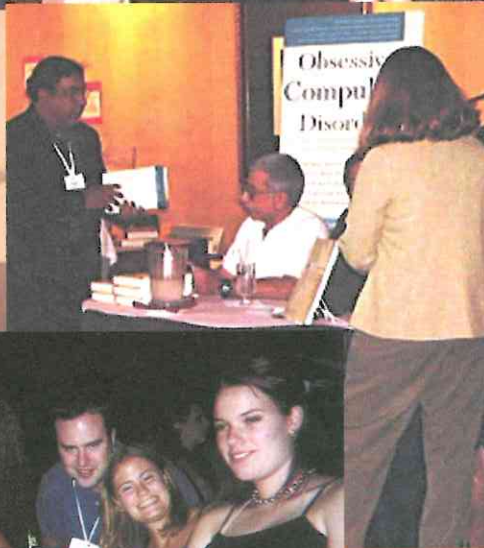
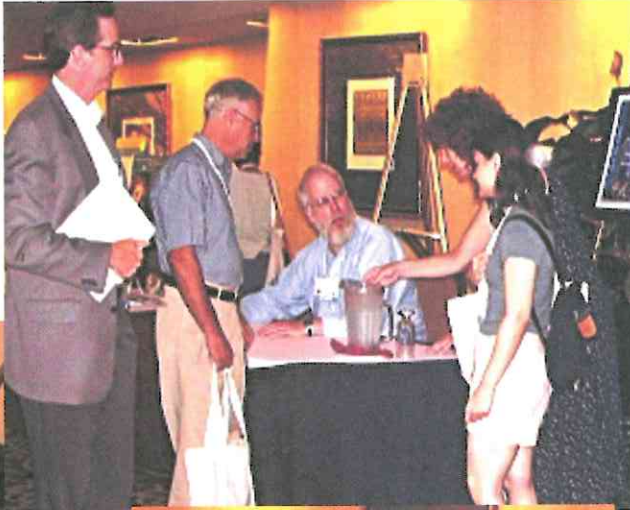
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# Scenes From The 9th





# Annual OCF Conference



# 3RD ANNUAL VIRTUAL CAMPING TRIP



# 3RD ANNUAL OCF ART CONTEST AND EXHIBIT



First Prize



Second Prize



## From the President

(continued from page 1)

been working together for 15 years. Dr. Pauls is a member of this group. It is his belief that the OCD group could learn from both the triumphs and mistakes of the TSA Consortium.



Consortium member  
Dr. Sanjaya Saxena  
from UCLA

One of the things, he had learned from participating in the Tourette's group was the necessity for forming subcommittees.

He suggested that the group consider setting up, to begin with, a steering

committee to study various formal structures for collaboration. At the next meeting, this committee could report on its considerations and conclusions.

It was agreed that the role of the OCFoundation would be to assist in recruiting participants for the multigenerational and sibling pairs studies at the different research sites and, of course, to raise funding to underwrite the group's work.

After discussing organizational and structural issues, the group focused on its purpose. It would be: "Moving ahead the study of the genetics of OCD."



Taking part in the exchange of ideas at the consortium meeting

I left the meeting with a renewed sense of purpose and hope that I want to communicate to you. Listening to these dedicated investigators plan a future of working cooperatively, I realized that their work is giving us a means of realizing the Foundation's ultimate goal: securing effective treatment for everyone with OCD. Please join me and the Foundation in supporting them by participating in their studies and raising funds for their collaborative venture.

Janet Emmerman  
President  
OCF Board of Directors

## Bulletin Board

(continued from page 2)

### Investigational Drug Treatment Study for Obsessive Compulsive Disorder

If you are between the ages of 18 and 65, you may qualify for a no-cost research study to evaluate the efficacy of an investigational drug in the treatment of OCD. This study is being conducted at Massachusetts General Hospital in Boston, MA. This study will be 12 weeks in duration and requires blood draws and ECG's at one or two week intervals over the 12-week span. All participants must be free of medications two weeks prior to starting in the study. For a free confidential telephone screening to determine eligibility, please call Lisa Jenike at (617) 645-3989. Principal investigator: Michael Jenike, M.D.

### 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 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. Participants have to live within driving distance because interviews are in person.

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

### 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 par-

ticipants who go on to take Risperidone. Participants will also receive an MRI (Magnetic Resonance Image) scan of the brain.

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

### A UCLA Research Study of Obsessive Compulsive Disorder

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 Neuropsychiatric 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.

This study will be 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.

### Research Participants Wanted for a Brain Function Study

Dr. Scott Rauch and colleagues at the Psychiatry Department at Massachusetts General Hospital are conducting a research study to examine brains function in people who suffer from Obsessive Compulsive Disorder.

The entire study will take 3 to 4 hours and will involve a brief interview, filling out questionnaires and completing cognitive tasks while "pictures" of your brain are taken using functional Magnetic Resonance Imaging (MRI).

Only individuals without pacemakers, aneurysm clips or other metallic objects in the head and upper body are eligible for MRI. Participants will be paid up to \$100 for their time.

Who is Eligible? Individuals who are:

- Right-handed
- Between the ages of 18-45
- Currently suffering or have previously suffered from OCD
- Not pregnant

For more information, contact Katherine McMullin at (617) 726-5594.

(continued on page 14)

# Chicago School of Medicine Has Developed I.

*An interview with Cheryl Carmin, Ph.D., Brian Martis, M.D., and Pamela Wiegartz, Ph.D., of the OCD Clinic at Chicago School of Medicine about their OCD treatment programs and research studies.*

**NEWSLETTER:** Can you describe the OCD treatment programs that are available at the Stress & Anxiety Disorders Clinic at the University of Illinois at Chicago School of Medicine?

**DR. CHERYL CARMIN:** (Director, Stress & Anxiety Disorders Clinic) We have recently developed a separate OCD Clinic that is a part of our Stress & Anxiety Disorders Clinic. Dr. Pamela Wiegartz is directing the clinical portion of the program and Dr. Brian Martis will be overseeing the research component. We are able to offer various levels of care for our OCD patients. With an emphasis on providing exposure and response prevention as well as pharmacological treatment, we have clinicians skilled in outpatient treatment, intensive outpatient treatment, and inpatient treatment services. Since our staff members are not just specialists in OCD, they also have the skills to provide evidenced-based treatment for many of the other conditions that often co-exist with OCD.

**DRS. PAMELA WIEGARTZ AND BRIAN MARTIS** (Co-Directors, OCD Clinic and Research Program): Our vision is to develop a program of excellence providing integrated treatment and research for patients and families with OCD. We strive to provide expert diagnostic assessment and treatments (ERP and pharmacological) as well as skilled clinical resources for patients with refractory OCD or complicated OCD. The research program will be closely linked and involve studies into both clinical and brain-related aspects of OCD.

**NEWSLETTER:** What is the design of your intensive treatment program? How many hours a day? How many days a week?

**WIEGARTZ:** Treatment is designed collaboratively with the patient and tailored to individual needs based on symptom profile, symptom severity, and comorbid conditions. However, most patients who participate in the intensive program receive one-on-one exposure and response prevention (ERP) for about 2 hours per day, each weekday. When appropriate, patients may also attend group therapy sessions focused on areas, such as, stress management or social skills or may be referred for adjunctive services like marital or family counseling.

**NEWSLETTER:** What treatment modalities do you employ in your intensive treatment program? Do you employ both psychopharmacology and cognitive behavior therapy? Any other treatment techniques?

**MARTIS:** Our strategy in an intensive treatment situation involves not only the use of empirically supported interventions like ERP and pharmacological treatments, but also assessment and intervention into other significant areas of the person's

alternative strategies with an open mind, providing patients with information from both the research literature and our clinical experience to help them make informed decisions about their treatment.

**NEWSLETTER:** What is the guiding philosophy behind your intensive treatment program?

**WIEGARTZ AND MARTIS:** For a program to be effective, we believe that treatment must be individualized and based on awareness of the person and their situation as a whole. Treatment focusing solely on a person's OC symptoms in the absence of the broader context of their lives is destined to fail. To this end, the goal of our multidisciplinary program is to effectively integrate a variety of services that involve not only the patient, but also the people significant in their lives.

**NEWSLETTER:** What is the duration of your program? Is it tailored to individual patient needs or is it a set period of time?

**WIEGARTZ:** Since interventions are planned on an individual basis and can be impacted by a number of patient-specific factors, duration of treatment varies quite a bit.

**NEWSLETTER:** What level of severity does your program serve? Severe? Moderate? Treatment refractory?

**WIEGARTZ AND MARTIS:** We provide services to people with the whole range of symptom severity. However, because of our reputation as OCD specialists, we tend to see a lot of patients who have more severe symptoms as well as those patients for whom many treatments have not worked.

**NEWSLETTER:** Can only adults enroll in your program or do you treat adolescents and children also?

**CARMIN:** The Stress & Anxiety Disorders Clinic as well as the OCD Clinic provide services primarily for older adolescents and adults. Within the Department of Psychiatry, we have a Pediatric Stress & Anxiety Disorders Clinic that provides treatment for our younger patients. We have a strong collaborative relationship with the staff in that clinic and they provide outpatient treatment for children and adolescents. The pediatric clinic staff treats OCD as well as OCD spectrum disorders.

**NEWSLETTER:** Can you describe a typical course of treatment in your program? Where does a patient start with Cognitive Behavior Therapy and where do you expect him or her to be at the end of the program?

**WIEGARTZ:** Individual outcomes vary and patients come into the program with a wide range of resources and/or limitations. While OCD is not a "curable" disorder at this point in time, our goal is to minimize the impact of OCD and improve quality of life. Goals are set with each patient at treatment outset and their program is structured to facilitate the achievement of these personal goals.

**NEWSLETTER:** Can you explain how you introduce a patient to exposure and response prevention therapy and how you help him/her to acclimate to it?

**WIEGARTZ:** Exposure and response prevention can be an intimidating endeavor for anyone. We try to alleviate some of the inevitable anxiety associated with beginning ERP by carefully educating the patient about the rationale for and the process of exposure therapy before treatment commences. We emphasize a collaborative patient-therapist relationship and approach exposures in a gradual fashion. Our therapists are supportive, yet encourage patients to challenge themselves with exposures. After treatment, patients often report to us that, while difficult, ERP was not as unpleasant as they had anticipated.

**NEWSLETTER:** What part do medications play in your treatment protocol? Does every participant in your program have to be on medication? Who determines what medications a patient will try and how or if a medication will be changed or augmented?

**MARTIS:** Our treatment protocol is flexible and individualized. For example, some patients do not want to take medications. Others are reluctant to start ERP before experiencing some relief. Still others may have other conditions (like pregnancy). We assess a patient, explain our recommendations to them, outline alternatives and really help the person decide the strategy they want to take (within reasonable limits of course!).

**NEWSLETTER:** Can a patient participate in your intensive program if s/he does not want to take a medication?

**WIEGARTZ AND MARTIS:** Absolutely.

**NEWSLETTER:** How many treatment providers are involved in the OCD treatment program at the Stress & Anxiety Disorders Clinic? What are their academic and professional backgrounds?

**WIEGARTZ AND MARTIS:** Currently the OCD clinic has a psychologist, a psychiatrist and the services of an advanced clinical nurse practitioner and a social worker (all of whom have a special interest and expertise in OCD). As an academic medical center, we also include a training component in our program, which enables interns, externs, and residents to participate in the OCD program.

**NEWSLETTER:** What is your patient-to-staff ratio?

**CARMIN:** This is a surprisingly difficult question to answer. Given the demands on a clinician's time when providing ERP – especially intensive outpatient or inpatient ERP – we use a team approach. All of our more senior psychiatry residents and our psychology fellows, interns, and externs have the opportunity to learn and become involved in providing ERP for our OCD patients. Thus, we have "hidden" resources beyond our full-time faculty and staff.

**NEWSLETTER:** Do patients in your pro

# Outpatient and Intensive Treatment Programs

other over the course of the program?

**WIEGARTZ:** As it stands, our treatment program provides mainly individual therapy. We do encourage patients to attend existing OCD support groups in the community and are working to develop OCD-specific group therapy options here at UIC.

**NEWSLETTER:** OCD is a chronic illness, what kind of relapse prevention program do you provide?

**WIEGARTZ AND MARTIS:** This is an excellent question. We believe that this is an important aspect of treatment that, unfortunately, is often overlooked. Relapse prevention is part of our program right from the first meeting. Educating patients and their families, providing information about external resources such as the OCF and local support groups, and involving the patient and family in planning treatment directions are all part of this effort. Further, when the intensive component of treatment has ended, we take special care to plan appropriate follow-up sessions, identify potential roadblocks to successful maintenance of gains, and determine what adjunctive services may be required to resolve situations that may impede continued progress.

**NEWSLETTER:** Do you involve family members and significant others in your treatment program?

**CARMIN:** Involvement of family can be critical to treatment success. We do our utmost to integrate family into treatment. At times, this means educating family members about OCD and how their good intentions to respond to the OCD sufferer's needs may, in actuality, be a form of extending a ritual. If treatment is going to work, it is important that all family members understand just how complicated the disorder is and how crucial their role in a family member's recovery can be. We will often ask interested family or friends to accompany us on exposure and response prevention excursions so they can learn how to be an effective coach.

**NEWSLETTER:** What kind of follow-up care do you provide for program participants?

**MARTIS:** Broadly, we see two kinds of patients. One group is evaluated and followed up by a therapist and/or psychiatrist here at our center. The other group consists of people who come solely for a brief course of treatment or a consultation and who have their own therapist/psychiatrist closer to where they live. We then function as a resource to their provider.

**NEWSLETTER:** Besides your intensive treatment program, do you offer other treatment programs, such as, individual weekly therapy or group therapy?

**WIEGARTZ:** We offer a range of treatment services, depending on the needs of the patient. When daily treatment is not required or is impractical, we do offer less intensive options such as weekly therapy.

**NEWSLETTER:** Do you have residential

facilities or in-patient facilities for patients with severe OCD?

**WIEGARTZ:** We do not have residential facilities at present, but are able to accept inpatients on a limited basis and provide them with intensive ERP and medication consults under the auspices of our general psychiatric inpatient unit.

**NEWSLETTER:** Can you admit patients on an emergency basis into your program?

**MARTIS:** Many of our patients do make appointments in response to a crisis. Depending on the nature of the emergency and availability of therapist time we try to accommodate them.

**NEWSLETTER:** Is there a waiting list or waiting period for people who want to enter your intensive program?

**WIEGARTZ:** There is generally a short waiting period for initial evaluations, about 2-4 weeks. After the initial evaluation and treatment planning sessions, treatment can commence relatively quickly.

**NEWSLETTER:** Can individuals with comorbid conditions or substance abuse problems be admitted to any of your OCD programs? Will they receive treatment for these co-occurring problems simultaneously?

**WIEGARTZ AND MARTIS:** Given the nature of OCD, it is not uncommon to see patients with comorbidities. We deal with these on an individual basis according to the needs of the patient and whether we have the resources to help him. Depending on the problem and severity it is sometimes essential that a person get treatment for the comorbid condition in order to make meaningful progress with ERP. If serious substance abuse/dependence is an impediment to recovery, then we refer them to our addiction services and work together with those clinicians to ensure optimal treatment outcome.

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

**WIEGARTZ AND MARTIS:** We do accept patients with OCD-related conditions, such as, Body Dysmorphic Disorder and Trichotillomania, and are fortunate to have clinicians in our program who have both experience and extensive training with these populations. Currently, we do not offer services for primary diagnoses of Tourette's and ADD although we may expand to include these disorders in the future.

**NEWSLETTER:** If a person lives outside of daily commuting distance to the program, are their residential facilities available for him or her through the program?

**CARMIN:** One of the limitations of being located very close to downtown Chicago is that housing costs can be prohibitive. While UIC does have arrangements with local hotels for reduced cost rooms, it may still be approximately \$100.00 per day to stay at a hotel. We are investigating a variety of alternatives; but, at present, we do not have any low cost housing arrangements available.

**NEWSLETTER:** How do you handle a situation where a person with OCD's rituals are

centered at his/her home or place of work?

**WIEGARTZ:** Since this is frequently the case, we have gotten quite creative at addressing this situation. Often our therapists are able to conduct periodic home or work visits to assist the patient with exposures specific to that setting. When this is impossible or impractical, we are sometimes able to simulate these exposures within the therapy session and then create a plan for the patient to practice at home. In those cases, it is often helpful to have a trusted family member or friend "coach" the patient on these exposure tasks.

**NEWSLETTER:** Are there any research programs at your Center that patients can participate in?

**CARMIN:** Very shortly, we will be starting a clinical trial examining whether escitalopram (Lexapro) will assist in the reduction of intrusive thoughts in our OCD patients. The treatment associated with the study is free to those who meet the criteria for participation.

**MARTIS:** We are also in the process of conducting neuroimaging studies in OCD using neuropsychological tests and functional MRI

**NEWSLETTER:** Are your programs covered by private insurance? Medicare? Medicaid?

**CARMIN:** We are an equal opportunity provider! We accept a broad range of insurance plans, including Medicare and Medicaid, as well as commercial insurance. We also verify every patient's benefits prior to accepting him or her into treatment so we can inform our patients of just what their benefits cover. I would also remind readers that, in many cases, Medicare may only cover about half of the costs of treatment and that Medicaid, since it is administered by one's home state, may not provide coverage outside of the state where you live.

**NEWSLETTER:** Does your Clinic have any programs to provide assistance to individuals who don't have the necessary financial resources to afford treatment at the Center?

**CARMIN:** At present, we do not. We have relied on both OCF and our local affiliate, the Obsessive Compulsive Foundation of Metropolitan Chicago (OCFMC), to provide information to individuals whose financial resources are stretched thin.

**NEWSLETTER:** If someone is interested in enrolling in your programs or wants more information, who should s/he contact and how?

**WIEGARTZ AND MARTIS:** If someone is interested in inquiring about diagnostic evaluation, treatment (ERP and/or medications), psychopharmacological consultation, or options for treatment resistant OCD they can call the following numbers:

OCD Clinic: (312) 355-3000, option #2.

Dr. Pamela Wiegartz: (312) 413-9589 (Diagnostic evaluation, cognitive behavioral treatments).

Dr. Brian Martis: (312) 355-3795 (Diagnostic evaluation, psychopharmacological treatments, refractory OCD).

## Bulletin Board

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### Obsessive-Compulsive Disorder Study

The Mood and Anxiety Disorders Program of Emory University is conducting a research study for people diagnosed with Obsessive-Compulsive Disorder (OCD) and on medication. This study will test the effectiveness of an additional medication to obtain further benefit in OCD.

Participants must be at least 18 years old and in stable medical condition. A psychiatric evaluation, study medication, a physical exam, and laboratory tests are provided at no cost. Participation will last up to 8 weeks. The clinic visits will take place at Wesley Woods Health Center, 1841 Clifton Road. All involvement is confidential.

For more information, please call: (404) 712-MOOD, or visit [www.emoryclinicaltrials.com](http://www.emoryclinicaltrials.com)

Eligible participants include those who are:

- Currently experiencing symptoms of Obsessive-Compulsive Disorder:
  - Repetitive, persistent unwanted thoughts
  - Repetitive behaviors (such as checking or handwashing)
  - Rigid routines and rituals
  - Fear of germs or contamination
- In stable medical condition
- 18+ years old
- Currently on a serotonin-reuptake inhibitor; those who are not on an SRI may still contact the Mood and Anxiety Disorders Program for more information.

### Inpatient\* Medication Study

The Yale Clinical Neuroscience Research Unit in New Haven has received approval for a six-week inpatient medication study. The study is for patients with Obsessive Compulsive Disorder who are currently taking a serotonin-reuptake inhibitor and are still experiencing distressing symptoms. Patients will remain on the SSRI and the medication riluzole will be added. Riluzole is a benzothiazole medication that is FDA approved for use in ALS. Riluzole's mechanism of action in ALS is unknown but thought to be due to its blockade of glutamatergic transmission. Preclinical and neuroimaging studies have implicated glutamatergic hyperactivity in the pathogenesis of OCD.

All treatment on the Clinical Neuroscience Research Unit is free of charge. We do not go through insurance. Patients should plan to remain on the Research Unit for approximately seven weeks for this protocol. An increased length of stay can be negotiated for treatment purposes. Patients sign in voluntarily to a 13-bed unit and are expected to participate in groups

For more information, contact Suzanne Wayslink, RNC, at (203) 974-7523 at the Connecticut Mental Health Center. HIC#15638.

\* at time of printing there is now an outpatient program available.

### OCD and Depression

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

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

Further information is available by contacting Dr. Abramowitz at (507) 284-4431, or via e-mail: [abramowitz.jonathan@mayo.edu](mailto:abramowitz.jonathan@mayo.edu).

### 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 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

### Genetics and OCD

The Mayo Clinic OCD/Anxiety Disorders Program is seeing adults who have received successful or unsuccessful medication treatments for OCD.

The purpose of this research is to examine the genetics of treatment response to serotonin medication in patients with OCD. Participants will undergo a clinical evaluation, blood draw, and urine screen and be reimbursed for their participation.

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

For further information, contact Dr. Schwartz at (507) 284-4431, or via email: [schwartz.stephanie@mayo.edu](mailto:schwartz.stephanie@mayo.edu).

### The New York State Psychiatric Institute Seeks Participants for Magnetic Resonance Imaging Study

This study seeks to learn more about the causes of various neuropsychiatric disorders including OCD. The study involves taking an MRI image of the brain. MRI is a safe, painless, radiation-free way to "take a picture" of the brain. It also involves responding to questions about medical and psychological histories and completing various neuropsychological assessments.

Who is Eligible? Individuals with OCD, Tourette's and/or ADHD as well as healthy controls between the ages of 6 and 65 are eligible. Participants will be compensated \$80 for their time.

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

**Note: The study will be conducted at the Yale Child Study Center in New Haven, CT, not at NYSPI.**

### Family Involvement in the Group Treatment of Hoarding/Saving 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 psychoeducation and cognitive and behavioral treatment. If you are interested, please call us at (516) 487-7116 to learn more about this study.

### 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.

### Geodon Augmentation in Serotonin Reuptake Inhibitor-Resistant OCD

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

To be eligible, patients must be 18 to 65 years of age, have a primary diagnosis of OCD, and have had between one and three adequate trials (adequate dose, > 12 weeks in duration) of an SRI with unsatisfactory response.

Subjects will receive the benefit of an evaluation of symptoms, general health discussion with the doctor and research staff, health information derived from laboratory tests, and help in referrals for additional treatment, if needed. They will also be paid for travel and time. (Please note that the reimbursement policy may vary with sites).

Contact info:  
Stanford University Medical Center,  
Department of Psychiatry/OCD,  
401 Quarry Road, Stanford, CA 94305-5721.  
Coordinator: Helen Chuong, M.S.  
(650) 498-5644, helenc@stanford.edu

Emory University  
Mood & Anxiety Disorders  
1841 Clifton Road, 4th Floor  
Atlanta, GA 30329  
Coordinator: Bettina Knight, R.N.  
(404) 727-3700, bknight@emory.edu

Mt. Sinai Hospital  
1 Gustave Levy Place  
New York, NY 10029  
Coordinator: Jennifer Greenberg, B.A.  
(212) 659-8732,  
jennifer.greenberg@mssm.edu

UCLA Anxiety Disorders Program  
300 UCLA Medical Plaza, Suite 2200  
Los Angeles, CA 90095  
Coordinator: Tanya Vapnik, Ph.D.  
(310) 206-5133, Tvapnik@mednet.ucla.edu

UF Behavioral Health Clinic  
2970 Hartly Road, Suite 202  
Jacksonville, FL 32257  
Coordinator: Margaret Dean, RNC, MN  
(904) 292-2773, mdean@psych.med.ufl.edu

### Cognitive Therapy for OCD

Massachusetts General Hospital/Harvard Medical School is seeking participants with Obsessive Compulsive Disorder 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 free clinical evaluation
- 22 sessions of cognitive therapy at no cost

If you are over 18 years of age 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. However, it is possible that your OCD symptoms may improve because of the cognitive therapy being evaluated 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.

The study is being conducted by Sabine Wilhelm, Ph.D. and Gail Steketee, Ph.D. If you would like more information, please contact Jeanne at the OCD Clinic/Harvard Medical School at (617) 734-4354 or by email at jean- nie@wjh.harvard.edu

### Remeron in the Treatment of OCD in Adults

In this study, we are investigating the safety and effectiveness of Remeron (Mirtazapine) in patients with OCD. Remeron has been approved by the Food and Drug Administration for the treatment of depression. The study lasts approximately 20 weeks, with a minimum expectation of 8 visits to the clinic during the first 12 week phase of the study during which all patients will receive active medication. Patients who respond positively to the medication and decide to continue will have an additional 4 visits in the remaining 8 week phase of the study. This extension phase of the study will be double-blind, and will randomly assign 50% of patients to receive placebo (inactive substance) and the other 50% to continue Remeron.

To be eligible for the study, patients must be at least 18 years of age, have OCD as their primary diagnosis, and have not previously participated in more than one adequate trial of an SRI and did not get an adequate response from that trial.

Subjects who participate in this study will receive the benefit of an evaluation of symptoms, general health discussions with the doctor and research staff, health information derived from laboratory tests, and help in referrals for additional treatment, if needed. They will also be paid for travel and time.

Please contact Helen Chuong, M.S.  
Stanford University Medical Center  
Department of Psychiatry/OCD  
401 Quarry Road  
Stanford, CA 94305-5721  
(650) 498-5644  
helenc@stanford.edu

## ADA & OCD

(continued from page 5)

Also, even if the OCD or meds do not cause substantial limitations in a major life activity, the accountant might nevertheless be disabled within the meaning of the ADA if the employer regards her as disabled. This would require evidence that the employer held the mistaken belief that the person with OCD can't work based on myths or stereotypes about how the OCD affects a person's behavior.

To finish our hypothetical, if our accountant is successful in demonstrating that she continues to experience substantial limitations on one or more major life activities other than working (and that she is, therefore, entitled to the protections of the ADA), there must be reasonable accommodations for her inability to consistently get to work on time and to take time off each week for therapy. Courts seem to accept an employer's argument that the ability to get to work consistently at a predictable time is an essential job function. In the case of our accountant, she should probably request a flexible work schedule allowing her to come to work at a later but specified time and then to work later to put in an 8-hour day. Unless the job is one that requires her presence during normal business hours, a flexible work schedule may very well be a reasonable accommodation. It would be reasonable if the employer had written policies allowing for flexible work schedules generally and/or if the employer allowed non-disabled individuals to work flexible hours. As to our accountant's need to take time off for therapy, the ADA and its regulations contemplate that additional unpaid time off may be a reasonable accommodation. The employer would have the difficult burden of proving that allowing predictable time off for therapy imposes an undue burden. Our accountant could also look to the Family Leave Act which generally gives an employee the right to take intermittent time off (for up to 12 weeks each year) to care for a serious medical condition (which may or may not also be an ADA disability).

It's incredibly demoralizing to realize that the justices of the US Supreme Court have made it very difficult for citizens for whom Congress has tried to give much needed protections to utilize them. However, while we wait for someone to present an argument to them that will persuade them to change their ruling, we suggest you get your accommodations by employing the arguments the Bazelon group has suggested. Also, we all can watch how the lower federal courts apply the Supreme's Court narrower interpretation of how mitigating measures affect the determination of who is disabled under the ADA. The Bazelon Center cites a recent 7th Circuit decision in *Gile v. United Airlines, Inc.* as a very positive decision upholding a jury verdict against United Airlines for failing to make reasonable accommodations for an individual whose medications and other mitigating measures have been ineffective in removing substantial limitation in major life activities but, with accommodations, did not prevent her from performing the essential functions of her job.

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

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