

OCD Newsletter

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Funding Research: One of Our Most Important Missions

Dear Friends,

Here I go again asking for contributions to the OCF Research Fund. (I have a few kids in college, but I am going to resist the compulsion to beg for myself.) The OC Foundation and all those it represents need your help to raise money for the OCF Research Fund, which supports research into the causes and treatment of OCD. While the OCF has been able to raise money to support many of its



programs (the newsletter, its websites, the Annual Conference, and the Behavior Therapy Institutes) from various sources, it depends entirely on you – people with OCD and the OC spectrum disorders, family members, treatment providers and friends – to fund its Research Awards Program.

Last year, the OCF received 31 research proposals from investigators looking for funding for promising research protocols. The total amount requested was \$1,206,078. Unfortunately, we were only able to fund six of these proposals, totaling \$220,696. This is despite the fact that 2% to 3% of the world's population suffers from OCD and, according to the World Health Organization, it is one of the ten most disabling

conditions in the world. We have to fund much more research to end the suffering and lost productivity caused by OCD.

Luckily, now there is greater public awareness about OCD. But only people with OCD and their families truly understand the cruel and unrelenting pain and suffering it causes. I do not know of any other disorder that causes such excruciating mental pain. I occasionally see patients with both OCD and terminal cancer; and, almost invariably, they tell me they would rather have cancer than OCD. I first heard this from a 25-year old man with terminal kidney cancer when I was a psychiatric resident. His statement shocked me then; but it no longer does after years of treating people suffering from OCD.

The only way we can alleviate this suffering is to find new and more effective treatments. And, this can only be done through creative research. We need to recruit young researchers with talent to do the creative research we need. The only way we can do this is to fund their pilot research now. There are many young researchers working on neuropsychiatric disorders who are interested in studying OCD. Unfortunately, interest is not enough. Young researchers gravitate to areas where funding is available now and will be available in the future.

At this time, there is not as much funding available for OCD as there is for other neuropsychiatric disorders. This lack of funding has a dou-

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Treatment of Pediatric OCD: Recently Completed and Ongoing Research

By Phoebe Moore, Ph.D., and John March, M.D., M.P.H., Duke University

Abbe Garcia, Ph.D., Jennifer Freeman, Ph.D., Henrietta Leonard, M.D., Brown University

Martin Franklin, Ph.D., Moira Rynn, M.D., Edna Foa, Ph.D., University of Pennsylvania

The World Health Organization has identified OCD as one of the world's leading causes of illness-related disability. OCD often begins during childhood or adolescence, and the importance of identifying and getting efficacious treatment for youngsters suffering from the disorder is readily apparent. Early

treatment may very well reduce subsequent illness burden, decrease functional impairment and "derailing" in achievement of important developmental milestones, and reduce the likelihood of developing even more psychiatric comorbidity and substantial functional impairment down the road, which is unfortunately often characteristic of adults with OCD.

Although great strides have been made in research on treatment for OCD in adults, research on the treatment of children with OCD has lagged behind. Our research

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SSRIs For OCD In Children

By Marco Grados, M.D., M.P.H. and Connie Hoe, B.A.
Johns Hopkins University
School of Medicine
Baltimore, MD

Obsessive-compulsive disorder (OCD) in children and adolescents can be treated with cognitive-behavioral therapy (CBT) and psychotropic medications. Recent data point to the increased effectiveness of CBT in eligible children through the use of an exposure-response prevention paradigm. Medication use can be a crucial factor in the improvement of OCD, mood and anxiety symptoms in children; additionally, it can facilitate response to CBT.

Several serotonin-reuptake inhibitors (SSRIs) have been approved by the FDA for treatment of OCD in children given their proven efficacy and safety in controlled clinical trials. These SSRIs include fluvoxamine (Luvox; 8-17 years), sertraline (Zoloft; 6-17 years) and fluoxetine (Prozac; 7-17 years). However, recently released data on the use of antidepressants in children with depression, including SSRIs, merits a review of the use of SSRIs in OCD in children.

The FDA press release of October 15, 2004 has directed drug manufacturers to add a "black box" warning to the health professional labeling of all antidepressant medications in children and adolescents. The antidepressants include the medications approved for OCD in children, fluoxetine (Prozac), fluvoxamine (Luvox), and

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Please Support the OCF Research Fund!

OCF 2005 Research Awards "Call for Proposals"

The Obsessive Compulsive Foundation announces its official "Call for Proposals" for the 2005 OCF Research Awards. The OCF is committed to finding and promoting "Effective Treatment for Everyone" through its Research Awards Program. To further this mission the Foundation is interested in funding research into the brain, its chemistry, structure and functioning; basic neurobiology; the genetics of OCD; the epidemiology and economics of OCD, as well as all aspects of OCD and the OC spectrum disorders that will lead to prevention and treatment advances.

Since 1994 the Obsessive Compulsive Foundation has funded 48 projects totaling \$1,143,089. This money has been donated by OCF members and friends. In 2004 the OC Foundation awarded \$220,696 in research funding. These projects are:

- **Genetic Studies of the Glutamate System in Childhood OCD Including Gene Interaction**, Paul Arnold, M.D., Centre for Addiction and Mental Health at the University of Toronto, Toronto, Ontario, Canada;
- **Family Genetics Studies of Obsessive-Compulsive Disorder**, Carol Mathews, M.D., University of California at San Diego, La Jolla, California;
- **Adjunctive Glycine for OCD**, William Greenberg, M.D., Nathan S. Kline Institute for Psychiatric Research, Orangeburg, New York;
- **Measuring the Effects of Cognitive Behavioral Treatment on Neurochemical Compounds in Pediatric OCD Utilizing Proton Magnetic Resonance Spectroscopy**, Stephen Whiteside, Ph.D., and John Port, M.D., Mayo Clinic, Rochester Minnesota;
- **Evaluation of Exposure and Response Prevention with or without Parent Management Training for Children with Obsessive Compulsive Disorder and Disruptive Behavior**, Denis Sukhodolsky, Ph.D., Yale University Child Study Center, New Haven, Connecticut; and
- **Augmentation of Behavioral Exposure Therapy for Obsessive Compulsive Disorder with D-Cycloserine**, Matt Kushner, Ph.D., University of Minnesota Medical School, Minneapolis, MN.

The 2005 OCF Research Awards will range from \$25,000-50,000. Please call Jeannette Cole at 203.401.2069 or e-mail her at cole@ocfoundation.org for more information and an application.

**The submission deadline is
January 15, 2005.**

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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 treatment providers; and the distribution of books, videos, and other OCD-related materials through the OCF bookstore; and other programs.

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

How I Treat OCD – A Forum

In this issue of the OCD Newsletter we continue our series focusing this time on how prominent clinicians treat hypochondriasis.

Health Anxiety and Hypochondriasis: Diagnosis and Treatment of These Serious and Debilitating Illnesses

By John Hart, LCPC, Thorstur Bjorgvinsson, Ph.D., and Joyce Davidson, M.D.
The Menninger OCD Treatment Center
Houston, TX



Hypochondriasis is a disorder that is characterized by a fear or belief, based on misinterpretations of bodily sensations, that one has a serious illness and is not swayed by reasonable and, therefore, appropriate medical reassurance that no medical condition is present. According to the DSM-IV, a diagnosis is made when the above conditions are present for at least six months, is not the result of delusional thinking or other psychiatric disorder, and creates significant distress in a person's life (American Psychiatric Association, 1994). A co-existing medical illness may be present but the concerns and preoccupations are disproportionate to the gravity of the diagnosed illness.

Hypochondriasis belongs to the somatoform class of disorders with Somatization Disorder, Undifferentiated Somatization Disorder, Pain Disorder, Conversion Disorder, and Body Dysmorphic Disorder (BDD). What this group of disorders has in common is distress from persistent bodily symptoms that cannot be explained medically. The exception is BDD, which is an excessive preoccupation with an imagined defect in appearance.

This disorder differs from other disorders in this class because sufferers do not focus on unexplained illness. However, the intense bodily focus of a person with this disorder is the commonality shared with the other somatoform disorders.

Individuals struggling with these disorders are typically first encountered not by mental health practitioners, but in physical medicine settings. When individuals are faced with serious physical symptoms that cannot be adequately explained, the high level of distress can motivate individuals to seek repeatedly more evaluations and further treatments that are often unnecessary and perhaps dangerous or harmful. Referrals are often made to various specialists, which frequently result in more uncertainty or in an initially promising solution that turns into another dead-end treatment.

When the physician is unable to find a cause for a patient's complaint, then the focus of the interactions becomes one of containment of the help-seeking behaviors, which can lead to erosion of the doctor-patient relationship (Looper & Kirmayer, 2002) in which the patient either leaves the doctor's practice or the doctor terminates the patient. In an effort to find explanations, people suffering with unexplained physical symptoms may get into a pattern of "doctor shopping," moving from doctor to doctor to find an answer.

Often a frustration with the medical community will prompt the sufferers to investigate his or her symptoms on their own through medical books, television programs, the Internet and other means. The Internet has become a popular medium for the exchange of medical information, sometimes of limited veracity, through websites and chat rooms. The term "cyberchondria" has even been coined to describe the phenomena (Taylor & Asmundson, 2004). Moreover, people may turn to alternative medical practitioners or new age treatments. Unfortunately for many with unexplained physical symptoms, they begin to feel misunderstood and invalidated and their quest for a solution to their problems becomes less important than being vindicated that there is something truly physically wrong.

In primary care or medical settings, the diagnosis of a somatoform disorder is

usually made on the basis of ruling out known medical disorders. When a diagnosis can't be reached, a psychiatric referral is possibly the next step. Individuals in this position will often believe that they are being told that their distress is "all in their head" or that they are making up their symptoms. Earlier diagnosis is difficult because patients are frequently adverse to the idea, and many physicians are unfamiliar with the diagnostic criteria and their primary task is not diagnosing psychiatric disorders.

In addition, the diagnostic criteria for somatoform disorders have been criticized as being too restrictive or excessively overlapping (Phillips, 2001; Fink et al., 2004; Looper & Kirmayer, 2002). In hypochondriasis cases, the DSM-IV requires that a diagnosis be given only if "preoccupation persists despite appropriate medical evaluation and reassurance" (p. 224). This criterion is very subjective and the demarcation between appropriate and inappropriate will differ between patient and doctor. Many illnesses, such as multiple sclerosis, develop slowly over time. This situation – diagnosis by elimination over a long period of time – can easily play into the fears of someone with unexplained physical symptoms. Some medical illnesses themselves are difficult to diagnose as a result of ambiguous diagnostic criteria. Other illnesses are of controversial validity. It is the uncertainty and ambiguity that is truly the basis for the patient's frustration and anxiety.

Because of the difficulty with the diagnosis, in recent years there has been a push to use the term health anxiety, with hypochondriasis being its extreme form. The term health anxiety also includes: 1) abridged hypochondriasis in which not all the conditions of full-blown hypochondriasis are present; 2) disease phobia in which a person fears contracting a specific illness much in the same way a person fears snakes or spiders; and 3) somatic delusions in which a person's belief is so extreme that, despite overwhelming evidence to the contrary, the belief continues to be held (e.g., belief that one's skin is infested with bugs or that a terribly foul odor is being emitted from one's body) (Taylor & Asmundson, 2004). Categorizing these problems as health anxiety disorders seems useful in

Interviews with the Presidents of the Metro Chicago OCF Affiliate, the Central New Jersey Affiliate and the Puerto Rico Affiliate

Interview with Jeanne Ettelson, president of the Metro Chicago OCF Affiliate.

OCD NEWSLETTER: What activities and programs is the Metro Chicago Affiliate involved in now? What programs has it been involved in since its formation?

ETTELSON: Here at OCF Chicago, we offer practical information and resources to people with OCD. We provide treatment referrals and current information about OCD and its management and advocate for equitable treatment of mental illness. By working with the media, we help to disseminate accurate information about OCD and



reduce the stigma of this illness. For example, two of our Board members were recently featured on a Chicago Public Radio program on OCD. We also supply speakers to schools and public forums to improve understanding about OCD. Volunteers staff a "help line," and personally answer all calls from people searching for help and information on OCD. In the coming year, we are launching a program to disseminate information about OCD through clergy in the Chicago metropolitan area. We are also planning a school program to help educators deal with OCD in the classroom.

Our printed materials are designed to be effective and compelling. This year, we published a booklet on OCD for teens and preteens. The booklets are being distributed through treatment providers and treatment centers, as well as to the public by request.

Through the years, our expanding programs have served to inform and connect people with one another. We have produced consumer and professional conferences for large numbers of people, and also pride ourselves on giving personal attention to every single person asking for help.

OCD NEWSLETTER: Does Metro Chicago have a website? What is the address?

ETTELSON: OCF Chicago has just created a brand new web site to provide people searching for knowledge about OCD with

comprehensive, up-to-date information in a user-friendly style. We are proud of our new site and hope that you will visit it at www.ocfchicago.org. There is even a special section for people to share their personal stories.

OCD NEWSLETTER: Who started the Metro Chicago Affiliate and when?

ETTELSON: This year, OCF Chicago celebrated its 10-year anniversary. It was founded in 1994 by Susan Richman and Jane Bodine, who recognized an opportunity to bring resources that were not yet in existence to families in the Chicago metropolitan area. OCF Chicago has continued to innovate, as the only Chicago area non-profit organization dedicated to helping people affected by OCD.

OCD NEWSLETTER: Over the years, Metro Chicago has been very innovative about children's programs. What are some of the young people's programs that you have sponsored?

ETTELSON: We have sponsored a variety of events, from picnics to painting parties. A couple of years ago, we sponsored the world premiere of "OC ME," an award-winning stage play written and produced by Jessica Carleton, a talented teenager with OCD. At past conferences, we have included full day children and teen programs which featured art, filmmaking, and mostly lots of fun and friendship. Next year we are planning a bowling party. Our aim is for kids with OCD to meet one another and take comfort that they are not alone. We take the time to connect kids whenever we receive a request, whether or not an event is planned. We pride ourselves on personalized service!

OCD NEWSLETTER: Can you describe the programs the affiliate has put on in the local schools? Who designed these programs? Who did the presentations?

ETTELSON: In past years, a successful school program was conducted for elementary and secondary school personnel who, with proper training, can represent the first line of support in the identification, assessment and treatment of childhood and adolescent OCD. Our Board of Directors and members of our Scientific Advisory Board, A. J. Allen, M.D., Ph.D., and Gail Adams, Ed.D., developed the program and educational materials for attendees. Drs. Allen and Adams provided the in-service training

in 37 school districts. Over the years, Board members and volunteers have made many presentations upon request. Currently, our outreach committee is planning a new program for school personnel.

OCD NEWSLETTER: Does the Metro Chicago Affiliate have a newsletter? How does someone subscribe to it?

ETTELSON: A "News Update" is published during the year to alert supporters to issues. A copy of the most recent "News Update" is also posted on our web site.

OCD NEWSLETTER: Does Metro Chicago sponsor Support Groups? Where are they held? Are they mutual support groups or therapist-led groups? When are they held? Can anyone participate?

ETTELSON: The Chicago metro area has over a dozen support groups operated by volunteers and professionals. We promote these valuable meetings but do not organize or endorse them. Dates, times and locations vary; we always suggest calling prior to attending to confirm meeting details.

OCD NEWSLETTER: The Metro Chicago Affiliate has held several conferences on OCD. Can you describe them for our readers?

ETTELSON: Consumer and professional education is an important part of our work. OCF Chicago has held conferences every several years since the first one in the year of our founding. Topics included the most current information from experts throughout the U.S. We are reviewing various options for the next conference with a keen awareness that the public has learned to access information quite differently.

OCD NEWSLETTER: The Metro Chicago group has held several successful fundraisers. Can you describe them and how they were organized?

ETTELSON: Our approach to raising funds consists of having a good relationship with our constituency. We keep in touch with our public and, in the last several years, have held an annual benefit dinner with entertainment. All our services depend on the generosity of people willing to make a contribution to help transform someone's life.

OCD NEWSLETTER: Who can join the Metro Chicago Affiliate? How can they go about joining?

Please Support the

ETTELSON: Any interested person may join. Simply get in touch by email or regular mail and send \$45 for a regular membership or \$85 for a professional. Membership in our local affiliate includes membership in the national organization.

OCD NEWSLETTER: What kinds of volunteer opportunities does the Metro Chicago Affiliate offer?

ETTELSON: Our committee structure offers many opportunities—from taking telephone calls, to researching issues, and to giving presentations. We are always happy to talk with people who wish to volunteer.

OCD NEWSLETTER: If someone is interested in joining the Metro Chicago Affiliate, how can s/he contact you? Can you give our readers a contact phone number or e-mail address?

ETTELSON: E-mail: info@ocfchicago.org

OCF Chicago

Attn: Ellen Sawyer - Executive Director

2300 Lincoln Park West

Chicago, IL 60614

Office Telephone: 773-880-1635†

Interview with Ina Spero, President of the New Jersey Affiliate of the OCF

OCD NEWSLETTER: When was the New Jersey Affiliate of the OC Foundation started?



SPERO: 1998

OCD NEWSLETTER: Who started the New Jersey Affiliate? How did the founders get together? What inspired them to start the New Jersey Affiliate?

SPERO: Ina and Julian's son has OCD and OCDP.

OCD NEWSLETTER: Does the New Jersey Affiliate sponsor Support Groups? Where are they located? Who runs them? Are they mutual support or therapist-led groups? When are they scheduled?

SPERO: The New Jersey Affiliate helps organize support groups throughout the state lead by individual sufferers and professionals. The groups are held in hospitals, churches, public buildings.

OCD NEWSLETTER: What activities and programs does the NJ Affiliate sponsor?

SPERO: We have a 24/7 referral hotline, quarterly meetings and an annual Conference.

OCD NEWSLETTER: Does the New Jersey Affiliate have a website? What is the address?

SPERO: Yes. www.njocf.org.

OCD NEWSLETTER: Does the New Jersey Affiliate have a newsletter? How does someone subscribe to your newsletter?

SPERO: Yes, we have a quarterly newsletter which is mailed on request to anyone. The suggested donation is \$5 per year.

OCD NEWSLETTER: Does the New Jersey Affiliate have any formal relationship with a particular treatment center or research group?

SPERO: No.

OCD NEWSLETTER: How is your affiliate structured? Is it a non-profit corporation?

SPERO: Non-profit.

OCD NEWSLETTER: Where is your office located? Where and when do you have meetings?

SPERO: The office is located at 60 MacAfee Road, Somerset, NJ. Meetings are held quarterly March, June, September, and December at Robert Wood Johnson University Hospital, New Brunswick, NJ.

OCD NEWSLETTER: The NJ Affiliate has a one-day Conference every year. Can you describe it for our readers? What topics have the Conferences covered in the past? When is this year's Conference? Where is it? Who will be the speakers?

SPERO: This year's Conference was October 10. The Keynote Speaker was Dr. Jonathan Grayson who spoke on "Using Scripts to Counter the Voice of OCD." Past Conference topics included: "Flying Towards the Darkness," "Living with Someone with OCD," "Freeing Your Child from OCD," and "OCD: Biological Basis and Pharmacotherapy Treatment."

OCD NEWSLETTER: What area of New Jersey does your affiliate serve?

SPERO: Officially, central New Jersey, but we're available for everyone.

OCD NEWSLETTER: What opportunities for volunteering does the New Jersey Affiliate offer?

SPERO: We need volunteers to distribute newsletters, take videos of meetings, help fundraise, and assist with mailings. Being computer-savvy would be a plus.

OCD NEWSLETTER: If a national OCF member living in your area wants to get involved with the New Jersey Affiliate, whom should s/he contact? Can you give our readers a contact phone number or email address?

SPERO: Contact Ina at (732) 828-0099 or via e-mail: julina@patmedia.net

Interview with Millie Court of the OCF Affiliate of Puerto Rico

OCD NEWSLETTER: What kinds of programs and activities is the OCF of Puerto Rico involved in?



COURT: We have two support groups. One in San Juan and the other on the west-side of Puerto Rico which is Mayaguez. Both groups meet the second Saturday of each month at 1:00 p.m. Our group is a mutual support group and it's open

to individuals with OCD, family and friends. I have volunteers who help me with the groups. On occasion, we have a therapist come to our group. Once a month we bring a therapist who does yoga for relaxation. Our support group is like a small family; they all like to come to the group.

OCD NEWSLETTER: You recently brought Dr. Brad Riemann from Rogers Memorial Hospital to Puerto Rico to put on a program. How did you set that up? Who was the target audience? How did you attract participants? How did you raise money to underwrite it?

COURT: One of my goals was to have Dr. Riemann come to Puerto Rico and give a two day symposium for mental health professionals on how to treat individuals with OCD. Since, I was a board member of the Association of Psychologists of Puerto Rico, I suggested that they invite Dr. Riemann to come. The board members of the Association of Psychologists of Puerto Rico were very interested in this and they got involved in the process. Also, the Mepsi Medical Center donated their conference room and theater for the activity.

OCD NEWSLETTER: Does the OCF of Puerto Rico have a website? What's its address?

COURT: The OCF of Puerto Rico does not have a website. However, if people are interested in contacting me they can do so by calling me at (787) 780-7789 or they can write to: OCF-PR, PMB 564M, P.O. Box 607061, Bayamon, Puerto Rico, 00960-7061.

OCD NEWSLETTER: Does your affiliate have a newsletter? How can people subscribe to it?

COURT: Currently, we don't have a newsletter.

OCD NEWSLETTER: Has the Puerto Rico affiliate been able to promote books, pamphlets and articles in Spanish on OCD and the OC Spectrum Disorders?

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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

Today, several medications and cognitive-behavior therapy have been proven effective treatments for OCD through rigorous scientific studies. Yet, many individuals with OCD do not seek professional help and try to treat their OCD with unproven complementary medicines, such as, vitamins, herbs and nutritional supplements supported largely by personal testimonials. This lingering and often misguided trust permits a continuation of the nickel-in-the-slot patent medicine hucksterism of past centuries that helped the charlatans selling their concoctions. Consider the promises from Dr. Chaise's nerve and brain pills, sold by Sears Roebuck and Company more than a century ago: "This will cure you if you feel generally miserable or suffer with a thousand and one indescribable bad feelings, both mental and physical, among them low spirits, nervousness, weariness, lifelessness, weakness, dizziness, feelings of fullness, like bloating after eating, or sense of gone-ness." It goes on to warn: "BEWARE OF QUACK DOCTORS who advertise to scare men into paying money for remedies which have no merit."

As P.T. Barnum said, "There's a sucker born every minute." So, those who choose to believe unfounded claims, rather than learning what science has proven, should use these remedies and when going to the dentist for a root canal, rub a herbal ointment on their gums rather than having the dentist use FDA approved novocaine.

The first article below provides a balanced review of complementary and self-help treatments for anxiety disorders. The other research presented in this end-of-year Research Digest covers what is arguably the most beneficial of treatments proven effective for OCD cognitive-behavior therapy. (JHG)

Effectiveness of complementary and self-help treatments for anxiety disorders

Medical Journal of Australia, 181(7):S29-S46, 2004, A.F. Jorm, H. Christensen, K.M. Griffiths et al.

This article reviews evidence for the effectiveness of 108 complementary and self-help treatments for anxiety disorders. Treatments specific to OCD will be summarized first, followed by a few other

treatments reviewed for anxiety in general. In a small study, inositol (an isomer of glucose that occurs in the normal human diet and also one of the B-vitamins) was found to be superior to placebo in treating OCD, but it did not augment the effects of selective serotonin reuptake inhibitors (SSRIs) in another study. There is some evidence that an amino acid, 5-hydroxy-L-tryptophan (5-HTP), which is a precursor of serotonin, might be effective for OCD. However, some supplies of 5-HTP caused a sometimes fatal eosinophilia-myalgia syndrome, which led to its withdrawal from the market in the U.S. There is only weak, uncontrolled evidence supporting St. John's wort for OCD. Bibliotherapy, the use of written educational materials, by itself, has had little effect on symptoms of OCD. Relaxation therapies have been found to be inferior to behavior therapy for OCD. For anxiety disorders in general, there is no evidence supporting the use of Bach flower remedies, Berocca, ginger, gotu kola, lemongrass or licorice. There is little evidence supporting the use of magnesium, passionflower, valerian, or vitamin C. Despite reasonable evidence supporting kava for general anxiety, rare cases of liver toxicity advise against its use. Regarding physical treatments, there is evidence that acupuncture and meditation can reduce symptoms of anxiety. Exercise has demonstrated strong effects for mild to moderate anxiety, but further studies are necessary to determine its effects on specific anxiety disorders. Exercise is a highly promising treatment. Currently there is little support for aromatherapy, hydrotherapy, massage therapy or yoga. For individuals with alcohol-use disorders, eliminating alcohol use may reduce anxiety. There is some evidence that caffeine increases anxiety levels.

Post-treatment effects of exposure therapy and clomipramine in obsessive-compulsive disorder

Depression and Anxiety, 19:225-233, 2004, H.B. Simpson, M.R. Liebowitz, E.B. Foa et al.

Researchers tested their hypothesis that patients receiving behavior therapy (exposure plus ritual prevention) or behavior therapy with medication (clomipramine [Anafranil]) would be less likely to relapse after treatment discontinuation than patients receiving medication alone. After receiving 12 weeks of one of four treatments (behav-

ior therapy, clomipramine, behavior therapy plus clomipramine, or pill placebo), 46 adults with OCD who responded to one of these treatments (18 behavior therapy, 11 clomipramine, 15 behavior therapy plus clomipramine and 2 placebo) were followed after treatment discontinuation for 12 weeks. Behavior therapy and behavior therapy plus medication responders, compared to medication alone responders, had a significantly lower relapse rate (12% versus 45%) and a significantly longer time to relapse. A lower relapse rate (12%) after discontinuation of behavior therapy is consistent with other study findings, showing that beneficial behavior therapy effects (with and without medication) persist after treatment discontinuation.

Cognitive-behavioral family treatment of childhood obsessive-compulsive disorder: a controlled trial

Journal of the American Academy of Child and Adolescent Psychiatry, 43:46-62, 2004, P. Barrett, L. Healy-Farrell and J.S. March

In the treatment of childhood OCD, the effectiveness of individual cognitive-behavioral family-based therapy (CBFT) was compared to group CBFT and to a wait-list control group (no treatment received). Conducted in Australia, the CBFT program used was based on the cognitive-behavioral therapy (CBT) program developed by Dr. John March (OCD in Children and Adolescents: A Cognitive-Behavioral Treatment Manual. New York: Guilford Press, 1998). As expected, results demonstrated that CBT, including an active family component, was effective in treating OCD and the treatment gains were maintained up to 6 months of follow-up. Surprisingly, contrary to previous findings and expectations, group CBFT was as effective in reducing OCD symptoms as individual CBFT. It is suggested that group therapy is an attractive treatment delivery option for children and adolescents and might have added benefits. Therapists reported increases in self-confidence as a result of the peer-learning experiences. Also, group CBT would be helpful for adolescents who often report feeling embarrassed, ashamed and guilty about their OCD symptoms.

Research Digest

Cognitive-behavioral therapy for medication nonresponders with obsessive-compulsive disorder: a wait-list-controlled open trial

Journal of Clinical Psychiatry, 65:922-931, 2004, D.F. Tolin, N. Maltby, G.J. Diefenbach et al.

Cognitive-behavioral therapy (CBT) is a recommended treatment for patients who fail to respond adequately to serotonin reuptake inhibitor (SRI) medications. However, few studies have evaluated the effectiveness of CBT for patients who have not responded to medications. Here, 20 adult OCD patients with a history of poor response to adequate doses of multiple medications received 15 sessions of outpatient CBT. Efforts were made to ensure the patients were truly medication refractory and clinically challenging (most patients had comorbid disorders and many had poor insight into their OCD). Of the 15 patients completing the study, 53% (8/15) responded and 40% (6/15) maintained their response at 6-month follow-up. Researchers speculated on why fewer patients (53% versus 74% to 80% in other CBT studies) responded possibly multiple failures to respond to medications are due to more severe OCD; possibly a lack of insight into the OCD leads patients to put forth less effort during CBT treatment; possibly the small response from multiple previous medication trials led to negative expectations and little motivation for CBT; and possibly CBT beyond 15 sessions is needed for these patients. This study suggests that CBT is helpful for some OCD patients with a high frequency of comorbid disorders who have failed to respond to adequate trials of multiple SRI medications.

Cognitive-behavioral therapy for the treatment of anxiety disorders

Journal of Clinical Psychiatry, 65(Suppl 5):34-41, 2004, M.W. Otto, J.A.J. Smits and H.E. Reese

Evidence supporting cognitive-behavioral therapy (CBT) for anxiety disorders is reviewed. Additionally, the combination of medication with CBT and issues with maintaining response after treatment discontinuation are discussed. Research has shown that CBT is effective, is an acceptable treatment as judged by patient preference and lower patient dropout rates in

studies, and can be cost effective. However, despite strong research supporting CBT, it is lamentably underutilized in clinical practice.

Fluoxetine, cognitive-behavioral therapy, and their combination for adolescents with depression: Treatment for Adolescents with Depression Study (TADS) randomized controlled trial *JAMA, 292:807-820, 2004, Treatment for Adolescents with Depression Study Team*

Although OCD is not discussed and only 12 of the 439 adolescents in this study had OCD, the study findings are important. Depression is a common co-occurring illness for individuals with OCD. Of the treatments compared (medication, CBT and medication plus CBT), the combination of medication (fluoxetine [Prozac]) with cognitive-behavioral therapy (CBT) produced the greatest improvement in depressive symptoms. Fluoxetine alone was effective, but not as effective as fluoxetine with CBT. Most importantly, this study evaluated the presence of suicidal thoughts. There is now convincing evidence that antidepressants, including selective serotonin reuptake inhibitors (SSRIs), such as fluoxetine, are associated with an increased risk of developing suicidal thoughts or acts. In general, research with adult patients has failed to find a relationship between antidepressant treatment and increased risk of suicide or suicidal thoughts. The U.S. Food and Drug Administration (FDA) is requiring new warnings about this risk and recommending that physicians closely monitor all depressed patients for worsening of depression or the development of acute suicidal thinking or behavior. This study found a clear superiority of medication combined with CBT in reducing depression and suicidal ideation. This study's findings are consistent with work suggesting that CBT has a specific beneficial effect on suicidal thoughts. CBT, combined with medication, may provide a protective effect against suicidality.

Seasons Greetings From the Foundation

Thank you for your support, participation and generosity this year and best wishes for a happy and OCD-free 2005.

The OCF Staff

Affiliate Interviews

(continued from page 5)

COURT: I have been fortunate to have a volunteer who works in public relations and is able to translate and edit some pamphlets on OCD. I also have appeared with Dr. Rafael Garcia Barcena, M.D. who treats OCD, in several TV interviews, radio, newspaper articles and some of the best published magazines of Puerto Rico. Most recently Dr. Ohel Soto, M.D., who did his practice in psychiatry with Dr. Wayne K. Goodman in Gainesville, Florida, has joined me in several TV interviews.

OCD NEWSLETTER: What volunteer activities do you have available for people who would like to work with the affiliate?

COURT: Anything they would like to do from staffing a booth at the health fair, to passing out brochures in their local mental health communities and help with our support group. I have been fortunate to have many volunteers in the Foundation and we even have volunteers who would cook for any activity we have. Any help they can offer will be much appreciated.

OCD NEWSLETTER: When was the OCF of Puerto Rico formed?

COURT: Our affiliate was formed in April 2000.

OCD NEWSLETTER: What was the inspiration behind the formation of the OCF of Puerto Rico affiliate?

COURT: My inspiration in forming the OCF of Puerto Rico was my son. He was diagnosed with OCD that same year; and in Puerto Rico, there were no resources and information regarding the disorder. Many of the doctors I spoke with didn't know how to treat OCD the correct way.

OCD NEWSLETTER: What were some of the obstacles you faced in setting up the OCF of Puerto Rico? How did you overcome them?

COURT: I had no obstacles in forming our affiliate. Many people supported my decision to form an affiliate.

OCD NEWSLETTER: What kind of support have you been able to get from the local mental health establishment?

COURT: I am the Vice President of Counseling and Planning in Mental Health of Puerto Rico, board member of the University of Puerto Rico in Mental Health for Children and Adolescents in Rio Piedras, and Vice President of Advocacy of Mental Health. These titles help the Foundation of Puerto Rico in many ways.

OCD NEWSLETTER: Is the affiliate connected with any local treatment or research center?

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How I Treat OCD

Health Anxiety and Hypochondriasis

(continued from page 3)

that it speaks to the terrible anxiety people feel when they are struggling with these issues. Another benefit to the health anxiety term is that over the years hypochondriasis evokes negative connotations demonstrated by statements, such as, "He's a real hypochondriac."

Individuals with hypochondriasis often have some features in common with sufferers of Obsessive Compulsive Disorder (OCD). The ruminations and preoccupations in hypochondriasis are similar in their ability to increase anxious arousal and to capture the attention of the individual. Additionally, excessive checking and reassurance behaviors characterize both disorders. However, there are significant ways in which the two disorders differ. The preoccupations and concerns of the hypochondriasis sufferer are experienced as a sensible and rational line of thinking. On the other hand, OCD sufferers for the most part see their obsessions as senseless, irrational, and will expend a great deal of effort to keep their obsessive thoughts out of their awareness. OCD sufferers also tend to keep their obsessions and compulsions private and often regarded them with shame. In contrast, people with hypochondriasis typically tell other about their symptoms and expend a great deal of effort in trying to convince others that their symptoms are real or that there is a yet to be discovered medical explanation (Barsky, 1992).

It is clear that people suffering from hypochondriasis experience a great deal of anxiety. This anxiety can be triggered in a myriad of ways, such as, watching a television program or receiving news that a family friend just dropped dead of a heart attack. The thoughts underlying the anxious reaction are likely to be similar to, "What if that happened to me?" or "Maybe that is what is wrong with me." As previously mentioned, television and the Internet as well as other media are rich sources of information and misinformation.

Internally, a person's anxiety can be triggered by his or her interpretation of bodily sensations. The human body is often considered "noisy." A healthy body contains "noises" in the form of gurgles, twitches, aches, tensions, itches, etc (Taylor & Asmundson, 2004). Variations in functioning, such as, energy levels, memory, or digestive processes can also be misinterpreted. If a noisy bodily sensation

is misinterpreted as a sign of serious illness, then a stream of catastrophic thoughts will be accompanied by an increase in anxiety and physiological arousal causing the body to make more noise. Misinterpreting ambiguous and unexplained situations as being more threatening than they are has long been known to be one of the major underlying factors in serious anxiety problems (Beck, Emery, & Greenberg, 1985). In health-anxious people, threats from physically uncomfortable bodily sensations are likely to be misinterpreted as signs of serious illness. Through repeated misinterpretations and increasing anxious arousal, a person's belief that one may be acquiring or already has a serious illness becomes more fixed and troubling. An individual with a serious illness belief will begin to seek reassurance from, not only the medical community, but from friends, family and the media, that he or she is physically all right. Unfortunately for people with extreme health anxiety and hypochondriasis, the reassurance works for only a very short time or not at all.

The experience of reassurance-seeking in health anxiety and hypochondriasis is similar to OCD and other anxiety disorders in that it serves to reinforce the fear, particularly if reassurance works even temporarily. Unfortunately, as people's fears intensify, they will often, not only seek reassurance that they are okay; but they will also seek confirmation that there is something physically wrong. This is particularly true of individuals who are convinced that there is something wrong and have put a considerable investment into being "sick." A person can find him/herself in a "sick" role through a variety of factors. People whose physical discomfort becomes so intense that they begin to start missing responsibilities and productive activities are prone to fall into a pattern of maladaptive illness behaviors. Family members, friends, and co-workers may inadvertently reinforce these illness behaviors by taking over responsibilities, canceling activities, or making excuses when the person with health anxiety is sick. In addition, avoidance of strenuous activities can lead to a state of physical deconditioning, which can lead to further noisy body symptoms. Ironically, people with severe health anxiety and hypochondriasis often have poor health habits (e.g., smoking, poor diet, lack of exercise) because they avoid anxiety-reducing behaviors. Unfortunately, maintenance of

sick role behaviors and repetitive, inappropriate reassurance do not allow a person with health anxiety to process new information that may dissuade him/her from his/her fear beliefs and assumptions.

The beliefs and assumptions that serve to maintain health anxiety and hypochondriasis can be influenced in a multitude of ways, including family attitudes toward illness, prior experience with illness personally or observed in others, cultural background or negative information about the medical community. These assumptions can be translated into maladaptive health rules. For instance, "any body sensation has to have an explanation" or "every uncomfortable physical feeling must be a sign of serious illness" or, perhaps, "being normal is being totally free of discomfort." People with health anxiety based on illness rules and assumptions find themselves setting inappropriate goals for themselves, i.e., ones based on a physical or mental feeling rather than effective behavioral goals. For instance, a person with health anxiety may miss work because his or her stomach may hurt. It is likely that his/her stomach will hurt at home as well. Staying home at the first tinge of illness can cause more problems. It allows the person to become isolated and give him/her more time to focus on his possible stomach pain. Someone with health anxiety has more time to focus attention on his/her body, more time for rumination and worry, and, therefore, his/her discomfort is amplified.

How We Treat Hypochondriasis and Health Anxiety at the Menninger OCD Treatment Center

Cognitive-Behavioral Treatment (CBT)

CBT and related interventions have been demonstrated through controlled studies to be effective in treating health anxiety and hypochondriasis. In addition, specific components of CBT have been shown to be beneficial, including psychoeducation, exposure and response prevention, and stress management. The initial task facing the therapist treating a person with these difficulties is to make the treatment acceptable to the person. In achieving that, their health worries, ruminations, obsessional thinking, and illness behaviors are con-

sidered just as problematic as their physical discomfort or any yet undiagnosed medical illness.

When a patient enters the Menninger OCD Treatment Center, our first task is to do a complete psychiatric and medical assessment. Patients with health anxiety and in its severe form, hypochondriasis, often feel that this assessment is not nearly comprehensive enough because of their tendency to be too detailed and over inclusive when giving their medical history and symptoms. This is based on the belief that if they could be clearer or more thorough, then a solution could be found for their difficulties. This can make relationship-building between therapist and patient problematic. In addition, the therapist, in the same way as previous health-care professionals, can easily get mired down in the minutiae of the patient's symptoms. We (the multidisciplinary team at Menninger) strive to foster trust with a patient by showing empathy and understanding for the patient's problems. We do give the assurance that, even though the psychological aspects are going to be explored, the patient's physical health will not be neglected.

Additionally, we assure patients that their physical discomfort will be taken seriously. Many patients feel that no one takes them seriously and that their family and previous healthcare providers believe that the patients' complaints are "all in their head" or that they are merely imagining their symptoms. Purely medical approaches in the past have failed for these patients and it is likely that an overly aggressive psychological approach may be doomed for failure as well (Lautenbacher & Rollman, 1999).

Through the assessment process, the multidisciplinary team gains a better perspective of the patient's experience. For instance the DSM-IV states that a patient must have "fears of having, or the idea that one has a serious disease" (p. 224). Whether patients fear getting a disease, fear that they already have a disease, or are convinced that they have a disease will have a bearing on treatment planning. It is important to identify the patient's beliefs, assumptions, and behavior patterns involving his health and illness concerns. This information is used to formulate the treatment interventions. We usually interview family members to get other perspectives on the patient's struggles. Additionally, we often ask patients to self-monitor their symptoms. Patients are instructed to keep written track of when their symptoms occur, what thoughts they had at the time, rate their emotional experience, and describe what their behaviors were as a way to discern patterns for their symptoms.

An initial stage in the treatment for health anxiety and hypochondriasis is psychoeducation. Our program offers daily psychoeducational groups that we utilize to inform patient about, among other things, various aspects of their treatment, symptom presentation and relapse prevention. It is possible that mild forms of the problem may be helped with just psychoeducation, including learning real and appropriate medical facts and the role of stress (Taylor & Asmundson, 2004). Patients with a mild form of health anxiety usually do not need intensive specialty hospitalization. So, at Menninger, we focus on patients who have failed previously in outpatient treatment or have severe and debilitating health anxiety or hypochondriasis.

Many health-anxious people, particularly those who are disease phobic, are woefully under-informed about health and illness. In our specialty hospital treatment program, in addition to basic health and illness facts, we utilize psychoeducation to give patients information about the connection between thoughts and beliefs in anxiety and other emotional experiences, misinterpretation of noisy body sensations, the role of selective attention in amplifying symptoms, how various forms of checking and reassurance-seeking are factors in maintaining health anxiety, the role that stress and loss play in physical problems, and the consequences of falling into the "sick role."

Through groups and individual sessions, patients are encouraged to challenge their prevailing beliefs and assumptions about their situation. Initially, we ask our patients - at a minimum - to at least consider a new competing hypothesis: that, in addition to their firmly held beliefs that there is something medically wrong, psychological factors can offer another reasonable explanation to account for their physical discomfort. Since they have been struggling, in some cases for several years, to find medical answers, maybe it is time to set aside the frustration for a new strategy. We then ask our patients to begin challenging their ineffective thoughts and behaviors, generating more adaptive thought patterns and engaging in more useful activities. Patients are asked to generate evidence for and against the possibility that they have a diagnosable medical illness. The evidence itself may be in need of critical scrutiny. Asking patients the following questions, "How do you know your assumption is true?" "What other assumptions could be true?" "What would you do if it were true?" can be useful in helping to generate more effective and adaptive responses. There are a variety of other CBT tech-

niques that help patients reframe ineffective thoughts into healthy and more productive ways of looking at things.

Exposure and response prevention therapy (ERP) for health anxiety is used in a similar fashion as it is used to treat OCD. The process of ERP exposes the patients to increasingly stressing triggers and helps them to prevent safety behavior or ritual-like responses. During exposure to their triggers, patients' distress, usually in the form of anxiety, will increase dramatically. Without the safety behaviors (e.g., escape, avoidance, checking, reassurance-seeking) as their usual form of distress reduction, patients learn that they habituate to their distress over time. Through habituation, they find a new source of information that begins to diminish their beliefs that a catastrophic result will occur if they face a feared situation without employing their safety behaviors. Since many of our patients have failed ERP when they tried it in an outpatient situation, we usually have one particular staff member designated to work with a specific patient to help him or her complete the exposures. As patients progress in treatment, our staff will support patients as they work independently to complete their ERP exercises. And, as patients progress in treatment, they usually start to accumulate evidence that weakens their beliefs in the inability to tolerate negative emotional states. Patients develop a hierarchy of fears in which they will work their way up to challenging themselves to habituate to their most feared situations. With some challenges, it can be difficult to arrange actual feared situations. In these cases, we often do an imaginary exposure by having the patient either repeatedly writing or listening to a recorded message that describes the fear until habituation occurs.

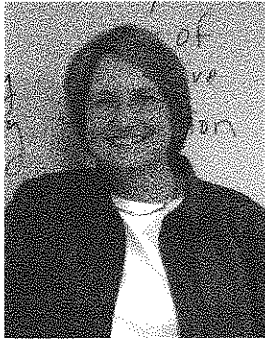
Another form of CBT intervention that we have used effectively for health anxiety is the behavioral experiment. In a behavioral experiment, the patient and therapist agree to a set of behaviors or a goal after which the results will be analyzed to determine what has been learned. It can be used as an information-gathering tool for assessment. For instance, a patient who fears having a heart attack may be asked to exercise for 10 minutes and then record how many times he checks his pulse for the rest of the day. In the same situation, a behavioral experiment could be used to help the patient gather contradictory evidence that a heart attack will occur if she or he exercises and does not check her or his pulse. Behavioral experiments can be short exercises (e.g., asking the patient to hold her/his breath to increase heart rate) or take place over a longer period of time (e.g., negotiating

My OCD Notebook

Tackling OCD: Talk Is Not Cheap!

By Christina J. Taylor, Ph.D.
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While ERP is the main behavioral tool to manage OCD, there are also cognitive skills to assist in your efforts to fight OCD. Cognitive therapy is based on the idea that our thoughts - what we say to ourselves, our "self-talk," - determine our feelings and our actions. It is the essence of the biblical statement, "As you think, so shall you be." It's a simple idea with profound implications for what



guides all behavior - we are like puppets on the strings of our own thoughts. Even the act of reading these words was based on a simple thought such as, "I'll take a look at the newsletter and see what the contributors have to say about OCD." And, there may have been further thoughts, such as, "I'll read this article and learn something that will help my OCD."

Simple statements, what amounts to our self-talk, guide our actions, effort, and feelings. The person who says, "I will read this and learn something that will help my OCD," has clearly got a different mindset than someone who says, "I'll read the article, but it probably won't help much." How we talk to ourselves can certainly affect our motivation and effort, and, dealing with OCD, the willingness to engage in finding help for OCD.

Cognitive therapy offers techniques to help identify ways and patterns of thinking that produce distress, negative behavior, and poor motivation. With regard to OCD, cognitive techniques can help improve an individual's motivation to tackle her OCD, help change her reaction to and interpretation of her obsessions, and help her to cope with the anxiety she experiences when she carries out an exposure and response prevention regimen. It can certainly do helpful things and can be a useful tool in the treatment of OCD.

I have been a college teacher for 30 years. I have seen students with the exact same ability excel, while others fail precisely because of how they "talked" to themselves about their ability to succeed - which in turn determined their motivation. Some years ago, I learned this lesson very clearly when I returned exams to students in an introductory psychology course. It was the first test the students took in the course so the students were very keen on reviewing their exam. When the class finished going over the questions, a student who had done poorly complained to me about the difficulty of the test questions. The implication was, of course, that the test was unfair. In contrast, another student who had also done very poorly looked at me with steel in her eyes and resolve in her heart as she exclaimed, "Now I know what it is that you want." Interestingly, at the end of the course, the student who complained that the questions were unfair ended up with a "C" average on the exams, while the student with resolve and determination achieved an "A" average. Why should students of similar capabilities perform so differently? It is really a matter of self-talk.

If you say that your poor performance is due to the impossibility of a task, it is understandably a very unmotivating situation. Why would you even try to succeed? Where is the motivation to try if you perceive the questions, job, therapy, or life problem as too hard? On the other hand, if you say to yourself that although the questions are hard, "I can redouble my effort, regroup, and try harder," then you will be motivated to put in the effort to succeed. This seems to be what my steely eyed and determined student did. This is called "self-efficacy." Self-efficacy refers to our belief, expectation, knowledge, or confidence that we can do what is necessary to achieve a goal. My student who asserted that she knew what the teacher expected demonstrated strong self-efficacy - confidence in her ability to do what was necessary to succeed. In contrast, my other student, whose self-talk said, "the teacher was too tough and the questions too hard," appeared to be low in

self-efficacy. If you think you have a shot at succeeding, that you can figure it out, then you will give it a try, doing whatever it takes to succeed.

How you talk to yourself about your own ability to tackle OCD reflects your self-efficacy and is a key ingredient to your motivation. If you think you can do it, then you greatly increase your chances of trying. In regard to challenging your OCD, you will be determined to learn what you need and get the tools and resources to do it. On the other hand, if you don't think you can, or if you are unsure, which is probably most often the case when undertakings involve making tough changes, then you will need to build your self-efficacy and motivation.

Resistance to change or ambivalence about making change are common reactions people have when confronting changes of all types, including quitting smoking, losing weight, stopping drinking as well as stopping compulsive rituals. Change is a difficult undertaking even when the behavior we want to eliminate is hurting us and preventing us from living life more fully and happily. In the case of OCD, there can, indeed, be very strong resistance and ambivalence about change because the obsessions seem so real and the compulsions appear to offer protection from some very awful consequences. It may, therefore, appear almost impossible to stop the compulsions. How do you build motivation and self-efficacy to take on such a challenge? Remember that self-efficacy is at least partly a reflection of self-talk. Cognitive techniques are a means of overcoming this obstacle. Changing irrational and self-defeating self-talk can set the stage for embarking on the journey of gaining control over the OCD. To help yourself with this, check out some of the self-help books on OCD. Look over the discussion and exercises on how to change distorted and irrational thinking, especially statements that interfere with trying to work on your OCD. Someone who has been working on her OCD for some time and who has become discouraged, as well as someone who does not recognize that she has a problem, or someone else who does not think that there is any particular hope for her problem, may all benefit from using cognitive therapy techniques to build self-efficacy and hope.

The most important point to keep in mind is that you can learn the tools needed to control OCD. Remember the Little Engine that Could! You can too!

How I Treat OCD

Health Anxiety and Hypochondriasis

(continued from page 9)

with the patient to not take her/his blood pressure for one week). The patient and therapist frequently assess each behavior experiment to determine what was learned and what further experiments need to be conducted.

In addition to these CBT interventions, we utilize family therapy, relapse prevention, stress management in attempts to get the patient out of the sick roles by developing empathic ways to encourage patients to learn to reduce reassurance-seeking. We have observed that trying to totally eliminate reassurance-seeking is not an attainable goal. What we try to do is to develop useful ways to give reassurance without reinforcing obsessive ruminations and dysfunctional behaviors. Family therapy receives significant attention in our center since it is often an essential part of helping patients to maintain treatment gains after they leave the program.

Establishing and maintaining other relationships, in addition to family relationships, post-hospitalization is very helpful in sustaining recovery and preventing relapses. In many cases, it can be very beneficial to work with primary physicians whether the physician is a psychiatrist, a family doctor or specialist to help a patient in recovery to make good decisions about future health care. For instance, a patient may make a contract not to seek further evaluation or treatment without first making a collaborative decision with a designated medical professional. This must be a person whom the patient trusts and from whom he has agreed in advance to accept reasonable and appropriate reassurance despite thoughts and feelings to the contrary. Regular appointments for a period of time with this trusted professional might be warranted.

Since symptoms of health anxiety and hypochondriasis often increase in difficult times, stress management can be a useful auxiliary to a patient recovery program. Components of a stress management program will typically consist of self-monitoring of stressful situations and one's reactions, increasing problem-solving skills, and learning applied relaxation (Barsky et al., 2002).

Pharmacological Treatments

Several antidepressants have been studied for effectiveness in treating health anxiety and hypochondriasis. These medications include the tricyclic medication, clomipramine and imipramine, and the SSRIs: fluoxetine, fluvoxamine, and paroxetine. Precisely why these medications work on health anxiety and hypochondriasis is speculative. A reasonable assumption that since these medications have been proven effective for many in getting symptom relief from anxiety and depression, that this relief reduces the amplification of symptoms. SSRIs have been shown to help with pain syndromes in patients who do not have reported anxiety and depression.

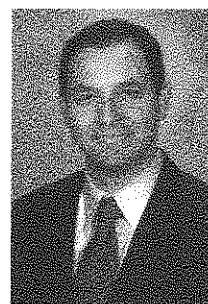
There are some pitfalls in using pharmacotherapy in treating patients with health anxiety and hypochondriasis. Initially, there is no medication that works for everyone in the same way. This means there is some trial and error involved in the process, as is the case with most psychiatric problems. In addition, some patient's health anxiety is related to past side effects from previous attempts to treat their condition with medication. The phenomenon of the "nocebo effect," which is the opposite of the placebo effect, is frequently encountered in the pharmacological treatment of patients with health anxiety and hypochondriasis. The nocebo effect happens when a patient experiences the negative side effects through expectation. (Barsky et al., 2002). As a consequence then, a medication may be prescribed in an effort to give relief to a patient, but may unfortunately result in increasing the distressing symptoms.

Conclusion

Health anxiety and hypochondriasis are serious and debilitating conditions that are poorly understood by the general public as well as by healthcare providers. Fortunately, there are beneficial treatments available; CBT and pharmacology have demonstrated effectiveness. However, the goal should not be simply symptom relief, but rather the focus should be on improving the quality of a person's life through increased productive and functional activities and improved relationships.

Cognitive-Behavior Therapy for Hypochondriasis: An OC Spectrum Disorder

By Jonathan S. Abramowitz, Ph.D.
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Jeremy can't fall asleep. As he lies in bed, he can't take his mind off the fear that he has throat cancer. Even though his doctors reassure him that everything is fine, he can't get past the fact that from time to time, it feels like his throat

is "closing in." What could be going on that modern medicine can't explain it? Surely, there must be something terribly wrong that the doctors can't figure out. Jeremy feels so anxious that he decides to check the World Wide Web for more information on throat cancer. Since his doctors stopped taking his calls, he had amassed quite a collection of books and articles on cancer. Some of the descriptions of what throat cancer feels like seem to overlap with what he is experiencing; but then again, there are other symptoms that he doesn't have. The urge to call the doctor grows more and more intense.

Jeremy has hypochondriasis, which involves a preoccupation with the belief that one has, or is in danger of developing, a serious illness. Many people with hypochondriasis are disabled because of their problem. They can't function very well in work, school, or family settings. People with hypochondriasis usually focus on bodily functions (e.g., breathing, heartbeat), minor physical abnormalities (e.g., skin blemishes), or physical sensations (e.g., headaches, stomach aches). The person might also worry about a specific organ or disease (e.g., fear of having cancer). Unfortunately, many people with hypochondriasis are reluctant to seek mental health evaluation since they

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How I Treat Hypochondriasis

CBT for Hypochondriasis

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believe they have unexplained medical illnesses. Our OCD and anxiety clinic evaluates and treats many people with hypochondriasis. So, in this article I will discuss how we think about hypochondriasis, where we observe overlaps with OCD, and how we treat people with hypochondriasis.

Hypochondriasis as Severe Health Anxiety

Anxiety serves an adaptive function: it protects us from harm by activating the "fight or flight" response, the body's automatic danger detection mechanism. But it is important to understand that the anxiety response is activated by the perception of threat, even if true danger doesn't really exist. Research, including our own, shows that a main problem in hypochondriasis is that people are actually misinterpreting as dangerous, their otherwise normal bodily perturbations and sensations. That's right, humans have "noisy bodies" that create all kinds of sensations that probably have some physiologic or metabolic purpose (which we might not be aware of), but which aren't at all dangerous. These normal symptoms might include changes in visual acuity, in heart rate and blood pressure, in saliva levels, depth of breathing, balance, and muscle tone, to name just a few. These are normal and harmless bodily changes. But when a person misinterprets them as symptoms of some terrible disease, it (naturally) makes them worry. This explains why medical tests come out negative: the sensations are real, but they are not symptoms of a disease.

Why do people misinterpret body sensations when there is actually no need for concern? Probably because of their basic assumptions about health and illness. For example, the idea that "hurt equals harm" or that "my father died of cancer, so it's only a matter of time until I get it too." People with hypochondriasis hold rigid definitions of good health, perhaps believing that any discomfort whatsoever means "bad health."

Why does Health Anxiety Persist Despite Reassurance?

If people with hypochondriasis are incorrect about their fears, why doesn't reassurance from doctors help them? Unfortunately, it's not so easy. As I mentioned above, when we become anxious,

we experience the fight-or-flight response which involves an increase in symptoms, such as, rapid heart rate, difficulty catching your breath, and sometimes dizziness, the sweats, and seeing spots. Although these sensations are not dangerous in the least, if they happen to occur right when you're anxious about your health (as what happens in hypochondriasis) – wham! It just adds fuel to the worry fire.

Certain behaviors that people with hypochondriasis do can also prevent a person from realizing that they are not really sick, for example, seeking reassurance from a doctor or other expert source. This habit leads the person to rely upon such reassurance to obtain relief from health worries. Checking one's body also makes a person preoccupied and likely to notice subtle sensations that most people simply ignore. So, a vicious cycle develops of noticing a sensation, misinterpreting it as threatening, becoming anxious, and seeking reassurance, which leads to further preoccupation and worry with the essentially harmless sensation.

Hypochondriasis and OCD

OCD, of course, involves intrusive thoughts (obsessions) and urges to perform rituals (compulsions) that reduce obsessional anxiety. As you might notice from the case description of Jeremy above, there are definite overlaps in the clinical picture of hypochondriasis and OCD. Specifically, persistent fears about illness in hypochondriasis (HC) are similar to obsessional thoughts in OCD. Similarly, attempts to seek reassurance in hypochondriasis are akin to compulsive checking rituals in OCD. That is, checking behaviors in hypochondriasis are an attempt to reduce illness fears much as compulsive rituals are an escape from obsessional anxiety (e.g., checking to make sure I did not make a mistake). However, there are also some important differences. In particular, people with hypochondriasis show more fears of bodily sensations and less awareness that their fears are senseless compared with people with OCD. In my mind, hypochondriasis is a form of OCD. In fact, as I describe below, I tend to use the same treatment techniques as I would use to help someone with OCD.

Cognitive-Behavioral Treatment

Understanding hypochondriasis as I have described above, we can see that effective

treatment requires that a person (a) corrects his threatening interpretations of certain body sensations and (b) eliminates behaviors such as compulsive checking and reassurance-seeking. This treatment approach, termed cognitive-behavioral therapy (CBT), involves the following steps that require a skilled therapist's assistance.

1) Proper Medical Evaluation

Prior to CBT, the prospect of actual medical problems must be ruled out through a thorough physical exam. Information from this exam should be reviewed (one time only) and accepted as evidence of good health.

2) Education

Education about bodily symptoms is a vital component of CBT. Patients are provided with non-threatening explanations for the bodily sensations they frequently misinterpret as threatening symptoms of underlying diseases. Of course, this is not the same as providing reassurance. The patient is required to use this knowledge for him or herself, rather than asking the doctor over and over for the same information.

3) Cognitive Therapy

Cognitive therapy techniques are used to help modify unrealistic interpretations of harmless physical sensations. It is a form of guided discovery wherein the therapist helps the patient explore the evidence for and against the threatening misinterpretation.

4) Exposure Therapy and Response Prevention

Exposure therapy is a set of techniques designed to help correct mistaken beliefs. For hypochondriasis, exposure involves gradually confronting the situations and bodily sensations that the person avoids because of the fear of illness. During exposure, patients also learn to tolerate uncertainty about whether or not a sensation is really a symptom. Even though at first people become anxious when they do exposure practice, the distress is temporary – it subsides by a process called habituation. As a result of habituation, the person learns that they do not need to fear these situations and sensations because their distress does not go on forever.

Response prevention is used in tandem with exposure. It involves resisting the urge to seek information or reassurance about health and illness. In other words, once exposed to the feared sensations, the person is taught to use healthy coping strategies (such as, examining the evidence), rather than calling doctors or running to the web.

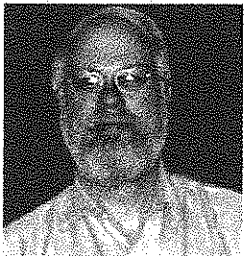
Conclusions

Although research is helping us to understand and treat hypochondriasis more effectively, the main obstacle to successful treatment is that many patients are reluctant to view their problems as anything other than physical. Our experience, though, is that helping patients appreciate the role that their thoughts and behaviors play in generating health anxiety allows them to engage in treatment and reduce their symptoms.

How I Treat Hypochondriasis

By James Claiborn, Ph.D.
Portland, ME

Hypochondriasis is a disorder characterized by preoccupation with fears of having a serious disease, or the idea that one has such a disease based on misinterpretation of sensations, body changes and similar evidence. This preoccupation persists in spite of negative



medical findings and reassurance. There are other diagnoses that present with very similar complaints such as disease phobia and these types of problems can be lumped together as health anxiety. Some sources will argue that hypochondriasis is on a spectrum with OCD or is really just a variation of OCD where the seeking of information about diseases, checking of one's body for signs of illness, and doctor visits constitute the compulsions. These ideas while interesting are irrelevant to the question of how to treat health anxiety since small distinctions in presentation don't change the core ideas about how to treat health anxiety.

Treatment begins with conceptualizing health anxiety in terms similar to the cognitive conceptualization of OCD. The

central idea is that everyone experiences thoughts that they might be ill or that some change in their body or some sensation may represent a problem. Such thoughts will produce some anxiety or at least discomfort. Most people manage to let such concerns pass, tolerating the uncertainty; and then the thought is quickly forgotten. The health-anxious individual, however, is not willing to accept the uncertainty and allow the thought to pass on its own. But, instead, he is most likely going to try to prove the thought wrong, try to be certain he is safe and try to get reassurance to reduce the anxiety.

These efforts to control anxiety are partially successful in that the distress is reduced for at least a short time. When the search for information leads to suggesting the feared disorder is not there or the doctor says the test results are normal, anxiety is reduced and the compulsive information and reassurance seeking is reinforced. This means that next time a scary thought comes up or a sensation seems odd and the anxiety appears the individual will want to do the same thing that worked to reduced his/her anxiety before.

When this idea is explained, the health-anxious individual will say, "But how do I know when to go to the doctor? How do I know this time it isn't something serious? What if I ignore a symptom and this time it is cancer? Isn't it something I should be sure about?" The answer is that the health-anxious individual needs to live with uncertainty. A critical part of treating health anxiety is learning how to deal with the thoughts and signals that trigger the anxiety.

As a part of dealing with these triggers, I introduce two strategies. One is the "Noisy Body" theory. We know everyone has sensations and thoughts about things being wrong with their bodies; but the health-anxious individuals seem to have more. Maybe this is because they just have noisy bodies; and in part they are paying much more attention to and are more vigilant about sensations that might signal illness. Some sources have argued that people prone to health anxiety may have noisy bodies that send out more signals. With this in mind, it seems a little more sensible to pay a little less attention to the signals.

The second strategy is to look at the activity of others as it impacts health anxiety. This often includes the primary care doctor, other health care providers and family. Typically the primary care

doctor recognizes what is going on and is open to some ideas about how to handle the hypochondriac patient. I get permission to talk to the primary care physician. I explain to both the patient and doctor how health anxiety functions and how tests and reassurance actually perpetuate the problem. I encourage the doctor to stop ordering unnecessary tests and stop trying to convince the individual that s/he can be certain about their health status.

In treating health anxiety, I also apply the same principles of behavioral treatment that I use for OCD, including the familiar methods of exposure and response prevention. Exposure using imagery often recorded on a loop tape is a useful method for doing exposure to fears of having a particular disease and the associated consequences. In designing these exposures, I find it is important to carefully identify what it so frightening about having the feared disease. Sometimes this is death; but often it involves being helpless or dependent on others.

Another common theme is the impact on others of having the disease or dying. Sometimes the fear is of being irresponsible. This may be explained as "If I have this disease and don't find out about it, I would be irresponsible." When the health-anxious individual says the worst consequence of having a particular disease is death, there are more questions to answer. Fear of death often involves some odd ideas about what it would mean to be dead. When these ideas are spelled out, they can be used as the focus of specific exposure and response prevention exercises. The response prevention part of this aspect of treatment involves inhibiting information and reassurance-seeking and inhibiting self-provided reassurance, such as, patients telling themselves that the therapist is sure they are OK or that the feared consequences could never really happen.

The Holidays Are Coming!

Please shop for all of your holiday gifts at GreaterGood.com. For whatever you need, go to the OCF website, www.ocfoundation.org. Click on the OCF Shopping Plaza and shop at the hundreds of retailers listed on the GreaterGood.com Shopping Mall.

The OCF is a partner with GreaterGood.com and when you shop at GreaterGood.com up to 15% of every purchase automatically goes to the Obsessive Compulsive Foundation. This amount is donated by the merchants in the Shopping Mall.

SSRIs and Children

(continued from page 1)

sertraline (Zoloft). In addition, the FDA is preparing a Patient Medication Guide (MedGuide), which will be given to patients receiving the drugs to advise them of the increased risk of suicidal thoughts and behavior ("suicidality") when taking antidepressants. The category of "suicidality" was created from chart reviews and is not equivalent to, but may include, suicide attempts, and other self-injurious behaviors. "Suicidality" may be related to several reactions to antidepressant use in children including: a) behavioral activation (excitability, impulsivity, restlessness); b) asynchronous improvement (energy improves but not mood or suicidal ideation); c) general improvement (depression improves but life-situation does not improve); d) mania; e) covert discontinuation (children stopped medication for unclear reasons and not documented). More research is needed to understand the underlying mechanisms of "suicidality" in the setting of antidepressant use in children.

In FDA terms, all physicians prescribing antidepressant medications to children and adolescents are now given the highest level of warning for possible "suicidality" when using these drugs to treat children with depression. While fluoxetine (Prozac) also has a "black box" warning, it is FDA-approved for treating depression in children given its efficacy in controlled trials.

Several observations with respect to this recent warning, although preliminary, are necessary. The risk of increased "suicidality" did not lead to completed suicides in any of the more than 4,000 children in the 24 trials that were examined. The assessment of "suicidality" was an *a posteriori* "after the fact" data gathering exercise; the main outcome measured in all these trials were improvement of depressive symptoms. The antidepressants examined included five SSRIs (Celexa, Prozac, Luvox, Paxil and Zoloft) and four "atypical" antidepressants (Wellbutrin, Remeron, Serzone and Effexor XR). The "suicidality" signal observed in the trials of the 9 antidepressants did not emerge from individual trials; they were only noticed after doing a meta-analysis (a grouping of all trials as if they were one large trial with over 4,000 children) so that weak signals were invariably magnified several-fold by this method. The grouped meta-analysis data show a "risk difference" increase of 2-3% for suicidality when comparing children who took active medication to those children that took pill placebo ("sugar pill"). The "suicidality" occurrence of 2-3% in the active drug group represents almost a two-fold increase with respect to the

placebo rate (1-1.5%).

What are the implications for the treatment of children and adolescents with OCD? Several main points can be stated:

- 1) CBT remains the treatment of choice for children and adolescents with OCD, if children are eligible. Medication can also decrease OCD symptoms, ameliorate anxiety and reduce depression often associated with the disorder (up to 70% of children with OCD may have depression). In practice, most children with moderate-severe OCD generally benefit from medication use.
 - 2) There are no separate trials in children with OCD that examine rates of "suicidality" when taking SSRIs. The antidepressant trials treated children with depression (and not OCD), where "suicidality" is often part of the clinical picture before medication use. More research on children with OCD using SSRIs is needed in order to determine whether increased "suicidality" signals seen in the depression trials also occur in OCD.
 - 3) The use of fluvoxamine (Luvox), sertraline (Zoloft) and fluoxetine (Prozac) in children with OCD is still supported by FDA guidelines. There is no current data on the emergence of "suicidality" when treating children with OCD (see #6-7 below).
 - 4) The need for close monitoring of children, especially in the first 12 weeks, after starting an SSRI is not changed and is of even greater relevance. Behavioral activation (excitability, impulsivity, restlessness) can occur in 10-20% of children and can readily improve with a reduction in the dose of the medication.
 - 5) The published controlled trials using fluvoxamine (Riddle et al., 1998), fluoxetine (Liebowitz et al., 2002) and sertraline (March et al., 1999) in children with OCD show little to no data on "suicidality" leading to the possibility that this adverse event is rare or non-existent in use of SSRIs in children with OCD.
 - 6) In the above OCD trials, "agitation" was observed in the fluvoxamine trial (12% vs. 3%), "outburst of anger" in the fluoxetine trial (19% vs. 14%) and "agitation" in the sertraline trial (13% vs. 2%). Only the adverse event "agitation" in the sertraline trial reached a statistical significance level.
 - 7) In the setting of the recent FDA warning, the risk of not treating depression in children and adolescents, with medication or therapy, needs to be emphasized to parents.
- OCD remains a serious and disabling disorder in children. Only the close collaboration of informed parents and medical care providers will ensure that children receive the most efficacious and safe treatment in order to defeat OCD.

CALL FOR CONFERENCE PRESENTATIONS

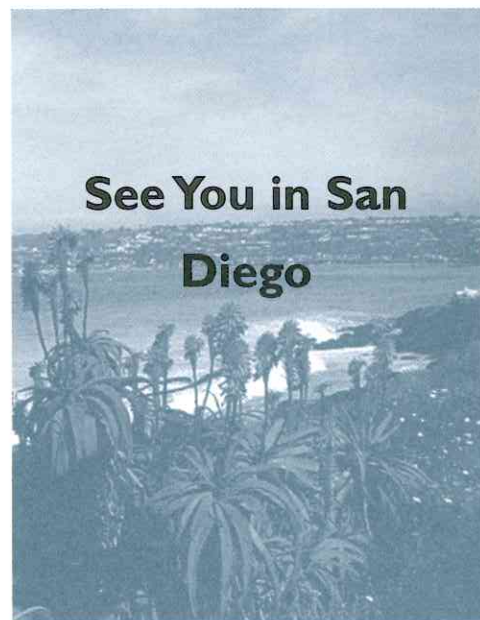
The 12th Annual Obsessive Compulsive Foundation Conference is scheduled for July 29-31st at the Town and Country Resort and Convention Center in San Diego, CA. Anyone interested in putting on a seminar, workshop, presentation or support group must submit his/her presentation proposal to the Conference Committee by February 15, 2005. Past OCF conferences have offered workshops and presentations on symptom specific OCD, compulsive hoarding, family therapy, treatment resistant OCD, sessions on new and emerging research, G.O.A.L. groups, parent support groups, workshops for children, adolescents, siblings, parents, caregivers, sufferers and professionals.

We invite and encourage clinicians, researchers, sufferers and support givers to submit proposals that will help us reach our goal of "Effective Treatment for Everyone with OCD."

Please contact Jeannette Cole, deputy director at 203.401.2069 or email her at cole@ocfoundation.org for an application.

Submission deadline is
February 15th, 2005.

See You in San
Diego



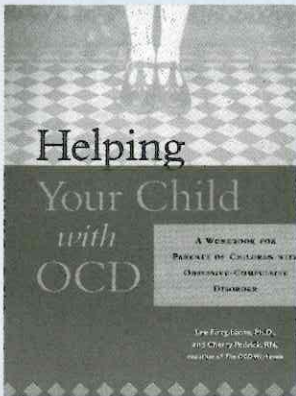
Book Review

Helping Your Child with OCD: A Workbook for Parents and Children with Obsessive-Compulsive Disorders

by Lee Fitzgibbons, Ph.D. and Cherry Pedrick, RN

Review by Barbara Van Noppen, Ph.D.
Brown University
Angell Street Wellness Collaborative
Providence, RI.

Helping Your Child with OCD is cleverly organized in three parts: 1) Does my Child have OCD? 2) Selecting Treatment and Seeking Help, and 3) What the Parent Can Do. In Part I, Fitzgibbons and Pedrick provide a descriptive overview of OCD. The diagnostic criteria and an explanation of the cycle of OCD



from a cognitive-behavioral perspective are presented. The cognitive theme of intolerance of uncertainty is highlighted. This is followed by demographic statistics on the prevalence of OCD in children and theories of etiology, including information about PANDAS-related OCD. Seven cases of childhood OCD (children ranging in age from 7-16 years) are described to convey the different forms of OCD and how they affect children's and parents' functioning.

The authors recommend that parents begin by "unmasking OCD," i.e., "bring the OCD out in the open without shame or fear." Since these are common feelings for parents, the authors provide relevant descriptions of the various presentations of OCD so that parents can identify their child's symptoms and begin the unmasking process. Worksheets in the book help parents to identify what is OCD and what is not, a frustrating dilemma for parents. Part I concludes with an exquisitely sensitive section on the impact of OCD. The authors lay out the many forms of interference caused by OCD for both children and family. Though the impact of OCD on a child is extremely distressing for parents to acknowledge, the authors provide hope that there is effective treatment to promote recovery from OCD.

Part II, Selecting Treatment and Seeking Help, is a thorough two-chapter overview of treatment options and what they involve. The authors outline medication strategies, cognitive-behavioral therapy and the combination of both. Techniques such as exposure and response prevention and cognitive restructuring are described in a "user-friendly" way. Tips on finding a qualified psychiatrist and therapist are provided.

The last part of the book, What the Parent Can Do, is the heart of the workbook. It is in this section that questions about parents' roles and responsibilities are addressed. The authors prepare families for what can be a long journey of recovery from OCD. An emphasis is on changing negative or overly involved attitudes to constructive partnership-like ones. The authors stress that it is not a parent's job to fix or solve the OCD. Parents can empower and support their child in his/her treatment to learn strategies to manage their symptoms. Helpful suggestions are made for parents to become advocates for their children in schools. In addition, the authors underscore the importance of parents taking time to care for themselves and families working together to normalize routines. This section is very goal oriented, providing numerous worksheets for families to use to outline goals, establish timelines, create privileges, develop family contracts, and brainstorm about expectations and limits. The book concludes with an extensive resource guide and list of publications of interest to children and teens, parents, educators, and therapists.

In short, this book is an invaluable resource. The authors' presentation of information is simultaneously frank and direct while empathetic and compassionate. The practical suggestions and worksheets help families to support and implement CBT techniques in the home. Many thanks to Lee Fitzgibbons and Cherry Pedrick for their contribution to the OCD community, which includes persons afflicted with OCD and the professionals who are always looking for therapeutic resources to help improve the quality of lives.

Available through the OCF Bookstore.

Dr. Jenike

(continued from page 1)

ble negative impact. First, the lack of funding means that the best young researchers are not initially attracted to the field. Secondly, because there is so little first-level OCD research, the federal government through the National Institute of Mental Health does not give anywhere near as much funding to OCD as it does to schizophrenia, major depression and bipolar disorder.

At the Annual OCF Conference this past summer, Dr. Thomas Insel, the Director of the National Institute of Mental Health and an old friend of mine, was the Keynote Speaker. Tom was one of the early pioneers in the field of OCD research. In his eloquent talk, he outlined the numerous possibilities for progress in OCD research and pledged to help with funding from his organization. However, to obtain federal funding, young investigators must first have completed pilot studies demonstrating the feasibility of their ideas. The OCF Research Awards are one way they can start working toward obtaining NIMH grants. Interestingly, in 1994, Tom chaired the OCF Research Awards subcommittee. That year, we awarded three grants totaling \$70,768. Since then, the OCF has given or pledged \$1,143,089 to fund 48 projects.

I heartily thank those of you who have given in the past. However, we need more help. If we could raise even one dollar per sufferer (approximately, 6,000,000 people in the USA have OCD), we would be able to fund enough research to be well on our way to finding effective treatment for everyone with OCD. Any amount you can spare will help us greatly.

Now that the Foundation has set up the OCF Genetics Collaborative, we also need to raise money to fund the research being done by its members, who are the world's finest researchers in the field of OCD genetics. If genes can be identified for OCD and related disorders, researchers can eventually find out what these genes do and perhaps correct the deficit. This research would also help identify children who may be at high risk for developing OCD.

Other advocacy organizations, such as, NARSAD, the Tourette Syndrome Association and the Alzheimer's Association, have raised hundreds of thousands to millions of dollars to support research in their respective areas of interest and have thus attracted many of the world's best researchers. The OCF needs money to compete with these organizations to attract great researchers to our cause – finding effective treatment for everyone with OCD. We can do it with your help. Please send in your contribution today.

Sincerely,

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

Thoughts From The President

Dear Friends,

Since I joined the OCF Board, I have had the privilege of reading the research proposals and participating in deciding which ones would be chosen for the upcoming year. I have found that as the topics and the proposals have become more sophisticated, the amount of money needed to fund these studies has increased as well. Thanks for your support when we have asked for your help. Below are the quarterly reports from the 2004 OCF Award winners. You will notice that many of the projects are in the introductory stage of the research. One particular research project met opposition from the hurricanes that swept the Florida coast. Hopefully, the delay will be only temporary.



Genetic Studies of the Glutamate System in Childhood OCD Including Gene Interaction

In this study, Drs. Paul Arnold and James Kennedy, the principal investigators from the University of Toronto, working with co-investigators from the University of Florida Medical School and Wayne State University, are studying the glutamate system because there is evidence that the genes that affect glutamate neurotransmission might be involved in OCD.

Our project investigating the glutamate system genes in childhood OCD has progressed well during these past three months. This report will summarize recent work in the areas of recruitment and genotyping.

Recruitment: Our current sample size has grown to 86 families, which represents over 50% of our recruitment goal of 157 families (containing 264 individuals). To date, all of our complete families have been collected from our Toronto and Michigan sites. We believe that this sample already represents one of the largest samples of childhood OCD families available for genetic studies in the world. An additional 36 probands have been collected from Wayne State University, and collection of blood samples from family members in this sample is being initiated.

All of the aforementioned subjects (probands and family members) have received detailed assessments including semi-structured interviews and YBOCS questionnaires. Our sample size would be even higher if not for setbacks at our Florida site, where the unforeseen impact of the hurricanes has delayed initiation of recruitment.

Genotyping: With the funds provided by the OCF grant, we were able to hire an experienced and highly competent technician, who has been actively genotyping our current sample since beginning work on the project in mid-August. We have completed genotyping of a total of eight markers in our three NMDA receptor genes (GRIN1, GRIN2A, and GRIN2B) in our current sample using automated genotyping technology. Assays are being ordered for seven additional markers in these three genes, and we anticipated completing the genotyping of all fifteen markers in our current sample over the next month. We believe this represents good progress towards our objective of genotyping the glutamate candidate genes in our sample in the first six months. In addition, we have genotyped one marker in 5HT2A in the current sample, which will enable us to do some preliminary analysis of gene-gene interaction.

A major priority of the next three months will be continued recruitment of new families, particularly at the University of Florida and Wayne State. Genotyping of the remainder of the variants within glutamate genes (GRIN1, GRIN2A, GRIN2B, and SLC1A1) will also likely be completed during this period. We will then be able to perform analysis using the Family Based Association Test to look for associations between OCD and our glutamate candidate genes in this sample of child OCD families. We anticipate having publishable results based on investigation of NMDA receptor genes this period.

Family Genetic Studies of Obsessive Compulsive Disorder

Dr. Carol A. Mathews, an Assistant Professor at the University of California at San Diego and a member of the OCF Genetics Collaborative, believes that there are multiple causative factors for OCD. In this study, she is investigating whether there is a genetic predisposition for OCD. According to Dr. Mathews, identifying the susceptibility genes for OCD, which is the

purpose of this study, will improve our understanding of OCD and could lead to improved diagnosis and treatment.

In the first quarter of our grant award, we have obtained clinical information and DNA on a number of additional family members in three of the large OCD extended families that are part of the group that we have been studying. We have interviewed nine additional family members and have obtained blood samples for seven additional family members in the overall sample set. In addition, members of our research group attended the 11th Annual OCF Conference in Chicago this summer, where we identified five new families with more than one member affected with OCD who would be appropriate for our studies.

We have completed the best estimate diagnoses on 15 subjects. Genotyping of the original core of families (not including the new family members described here) is slated to begin within the next two months. We anticipate that the results of those genetic analyses will be available by March and will guide our genotyping efforts in the additional subjects collected as part of this research award.

Adjunctive Glycine for OCD

In this study, Dr. William M. Greenberg of the Nathan S. Kline Institute for Psychiatric Research is adding glycine to the current anti-obsession medication for patients with OCD who have not experienced a satisfactory remission of symptoms. It is his hypothesis that the addition of glycine will significantly improve these patients' symptoms.

Since receiving the grant, our first priority was to have the study medication and placebo formulation prepared, have it packaged and labeled in blinded fashion. This has been completed.

We have also started advertising for the study. We have posted on the OCF Foundation's website and we are currently in the process of submitting advertising to the local OCF affiliates in New Jersey and New York. On October 10, 2004, we attended the Central New Jersey Affiliate Chapter's Annual Conference, where we had a table for informational and study recruitment purposes. We spoke with interested parties and distributed fliers regarding the study.

We have currently screened several patients through these efforts. None of whom meet criteria to participate in the study at this time. In the coming months, we have made appointments to travel to several local consumer and professional groups to give lectures and talk about the study; and we will have submitted advertising for this study in local professional newsletters. On October 13, we presented this study to another local institution's IRB (a county community mental health center), and we will be seeking out participants from other community mental health centers in coming months.

Measuring the Effects of Cognitive Behavioral Treatment on Neurochemical Compounds in Pediatric OCD Utilizing Proton Magnetic Resonance

In this research study, Dr. Stephen Whiteside and Dr. John Port of the Mayo Clinic are testing the theory that dysfunctions in the cortical-striatal brain circuitry are associated with OCD symptoms. The aim of the study is to show through proton magnetic resonance spectroscopy that cognitive behavior therapy changes irregularities in neurochemical compounds in children and adolescents with OCD. These changes have already been recorded in adults with OCD.

Over the past three months, we have completed the planning and training stage of our study and have received approval from our Institutional Review Board to proceed with the project. We have begun the process of recruiting participants with OCD as well as recruiting healthy controls. We have trained two additional CBT therapists and have put into place the structure for and begun the process of supervising these therapists. We are now ready to begin enrolling participants.

Evaluation of Exposure and Response Prevention (ERP) with or without Parent Management Training (PMT) for Children with OCD and Disruptive Behavior

The goal of this study being conducted by Dr. Denis Sukhodolsky, Associate Research Scientist, at Yale University Child Study Center, is to examine the effectiveness of a 12-session ERP intervention augmented by a 6-session parent management training in six children with OCD and disruptive behavior. The study utilizes a single subject design, and obsessive compulsive symptoms and disruptive behavior are monitored using the weekly ratings by a blinded clinician.

I am pleased to let you know that we have enrolled and randomized one subject, who is now in week seven of the study. The study has been implemented according to the protocol and no adverse events has been reported. Dr. Diane Findley and I meet weekly to review the issues related to treatment implementation. In addition to monitoring adherence to the treatment manuals, we document information that is relevant to the integration of ERP and PMT in a flexible and clinically sensitive manner.

We are also actively recruiting new subjects through our specialty OCD clinic at the Yale Child Study Center and through outreach to the local clinicians. As part of our recruitment efforts, we have reviewed charts of nearly 300 children who have been seen at the Yale TS/OCD clinic during the past two years. Based on this review, we mailed 29 letters to the families who may be potentially interested in participating in this study. We also carefully monitor new patients at the clinic, and families who may be potentially interested are informed about the study by the TS/OCD clinic doctors. The information about the study is also available on the Yale Child Study Center web site at <http://info.med.yale.edu/chldstudy/research/behavior/index.html>.

Augmentation of Behavioral Exposure Therapy for Obsessive Compulsive Disorder with D-Cycloserine

In this project, Dr. Matt G. Kushner and his team at the University of Minnesota Medical School, Department of Psychiatry, are studying whether an experimental medication, D-Cycloserine, can improve the effectiveness and efficiency of exposure and response prevention therapy (ERP) for OCD. The study's hypothesis is that subjects with OCD will benefit more from 10 ERP session when each session is preceded by a 250 mg doses of D-Cycloserine.

Since formally launching this study in July, we have completed an initial organizational phase and have recently started recruitment and data collection. In the initial phase, we hired staff, obtained the study drug, commissioned our investigational pharmacy to create placebo pills, obtained approval from our Human Subjects Committee for several minor protocol modifications and collated subject/experimenter protocol packets to guide data collection and other study activities. In this early recruitment phase, we have completed initial phone screening interviews with 41 individuals. From this group, we have invited 12 individuals for further in-person

assessment, eight of which have been completed to date (the other four are scheduled for initial appointments). We have enrolled three of these eight subjects to date; and there are five new candidates being reviewed for eligibility.

We are also happy to report that the study has generated a fair amount of interest in the local media. To date, we have done interviews for both a local TV and radio station and have been featured on the University of Minnesota's website and have had an article in the University's newspaper. We use these opportunities to help recruit participants and also to educate the public about the Obsessive Compulsive Foundation and its mission.

As you read the quarterly reports, I am sure that you were struck by the amount of time that it takes to get a project in motion and how much money is necessary to pay for the equipment and the people who help the investigators with their research. In this Newsletter, Dr. Michael Jenike is asking for our help to fund the 2005 OCF Research Awards. Please join me and members of the OCF Board in supporting the OCF Research Fund. Thank you.

Joy Kant
President
OCF Board of Directors

Affiliate Interviews

(continued from page 7)

COURT: Yes, Mepsi Medical Center, which is located in San Juan. Even though they don't treat OCD, they donate their facilities for our support group and any other activities of the Foundation without limits.

OCD NEWSLETTER: Do you have a Treatment Provider Referral List for sufferers in you affiliate area?

COURT: Currently, we have only two doctors in our list. I have been working hard to grow the referral list. However, many of the doctors here in Puerto Rico don't have the experience and training necessary to treat OCD. That is why I have been trying to work with the doctors first in training them in how to treat the disorder.

OCD NEWSLETTER: How can people who need information or are interested in joining the affiliate contact you?

COURT: Anyone interested in contacting the OCF of Puerto Rico can call me at (787) 780-7789 or (787) 244-7279.

PANDAS: A Subset of Pediatric OCD

By Marie Lynd Murphy, M.D., Elmwood Pediatric Group, LLP, Rochester, NY
Eileen Lynd-Balta, Ph.D., St. John Fisher College, Rochester, NY

For many years, it has been known that *Streptococcus*, the germ which causes the "strep throat" illness so common in school-age children, stimulates the body to make antibodies to the strep germ. In certain individuals, these antibodies will attack a person's organs, such as the heart (rheumatic fever), kidney (glomerulonephritis), and brain (Sydenham's chorea). More than a century ago, children with Sydenham's chorea were described as having a "perseverativeness of behavior," which would now be known as OCD. Prevention of these secondary problems is the reason for treating a strep throat illness with antibiotics.

In the 1980's, Susan Swedo, M.D., began her work investigating the link between strep disease and OCD in children. She studied children who experienced an explosive onset of OCD and explored their history of strep throat exposure. Working with her colleagues at NIMH, she coined the term PANDAS: Pediatric Autoimmune Neuropsychiatric Disorders Associated with Group A *Streptococcus*. The landmark paper by Swedo, describing characteristics of the first 50 patients with PANDAS was published in 1998. The working criteria for the diagnosis used by clinicians and researchers in the field include:

- * Pediatric onset
- * Evidence of Group A *Streptococcus*
- * Acute onset / episodic course
- * OCD and/or tic
- * Motoric hyperactivity/choreiform movements

Outside of the patients with long-standing OCD and Tourette Syndrome studied at NIMH, does PANDAS exist? We sought to answer that question at the Elmwood Pediatric Group, a private primary care practice in Rochester NY. We identified 12 patients with their first episode of a sudden, explosive onset of new OCD symptoms. All patients had symptomatic strep infection and evidence of the strep germ. The onset of severe OCD symptoms could often be pinpointed to a particular day. All of these patients had been entirely free from these symptoms in the past, were active, healthy, well adjusted children successful in their academic and social lives. We observed that during standard treatment of strep throat with antibiotics, elimination of not only the strep germ but also of the OCD symptoms occurred. Half of these children had an abrupt onset of OCD symptoms again associated with a new strep infection; and each again improved during the course of

antibiotic treatment.

What does PANDAS look like? How does a typical child with PANDAS appear to their parents and physician? Most children with PANDAS are between the ages of 4 and 12 with a peak at 8 or 9. Boys outnumber girls. We summarized the presenting symptoms of 25 patients with PANDAS at our practice and found that less than 5% called because of a sore throat or other typical strep symptoms. What patients reported were "needing to schedule a behavioral conference" to discuss such issues as washing, ritualistic behaviors, hoarding of worthless objects, or the new onset of severe and age inappropriate separation anxiety. Parents called to have their children's eyes checked due to excessive blinking (a tic behavior). They also called with a concern of excessive daytime urinary urgency and frequency, wondering about a bladder infection or kidney damage. Their children would suddenly develop a need to go to the bathroom to urinate 10 times in an hour, especially before leaving the house for the bus in the morning or before bedtime. Some had a complicated urinary hygiene ritual involved as well. None had pain on urination or evidence of urinary tract infection when tested.

No parent called to report that their child had developed OCD overnight. Physician recognition of these types of symptoms as evidence of OCD is essential. The description of an EXPLOSIVE onset of these OCD symptoms helps identify the small subset of PANDAS patients from the rest of those with OCD. If indeed there is an explosive onset of OCD and/or tic and there is evidence of current or recent strep infection, the diagnosis of PANDAS should be seriously considered.

With the generous support of the Obsessive Compulsive Foundation, we have continued investigations about PANDAS in Rochester, NY. We have enrolled children in a study to gather further information about the onset of PANDAS. If a school age child has an explosive onset of OCD symptoms, it does make sense to see if there is evidence of strep infection. This can be done in the primary care doctor's office with a simple throat culture. For just under half of the children we studied, strep was present at the time of OCD diagnosis.

In our study, we also obtained blood tests for ASO and AntiDNaseB, the antibodies which indicate the presence of recent strep infection. Those who simply carry strep on the tonsils do not make an antibody response and do not show the increase in blood level. We found that patients with sudden onset of OCD had a positive antibody response; they were not simply carriers of the germ. At the onset of the symptoms, standard tools like the CY-BOCS (Children's Yale-Brown Obsessive Compulsive Scale) revealed severe disease symptoms,

often affecting the children for the majority of their waking hours. After an eight-week course of antibiotics to treat the strep, the same children were re-evaluated. Strep had cleared from their throats and we documented significant reduction of OCD scores to the subclinical levels. In addition, blood samples before and after treatment were analyzed for the presence of antineuronal staining. Dilute serum samples were incubated with thin serial rat brain sections and immunocytochemically detected. Antineuronal staining was localized to specific areas of the brain. Further characterization of the brain circuits which may underlie OCD behaviors is necessary.

PANDAS is not only new; it is controversial. Critics have dismissed the concept, in part, because strep and strep carriers are so common. They consider the strep infection as a co-occurrence, not a cause. While some studies indicate that up to 20% of school age children are strep carriers, in our own practice, the rate is less than 5%. Skeptics warn that the overuse of antibiotics is dangerous and unwarranted, and they are correct. In a time when the injudicious overuse of antibiotics is leading to serious patterns of resistance by dangerous germs, it is important not to "give them a try and see if it helps" when OCD is diagnosed. Isolated serum strep titers in the absence of other diagnostic criteria should not be treated. But what should be done?

Does it make sense to treat every child with OCD with antibiotics? Should parents, as advocates for their children, demand a course of antibiotics? Of course not. Most OCD symptoms evolve slowly and are revealed slowly over time. The majority of patients with OCD do not report the explosive, overnight onset that is a hallmark of the PANDAS subgroup. Although antibiotic therapy given at the first evidence of OCD appeared to be helpful in the small group described, there has not been enough evidence gathered to make universal recommendations. Ongoing studies, such as ours which received a 2003 OCF Research Award, allow patients to receive safe care and allow researchers to gather data which will be most helpful for treating others.

If you suspect a child has new, sudden onset of OCD symptoms characteristic of PANDAS, it is appropriate to see your doctor who can make the diagnosis of OCD, perform a physical examination of the throat, and obtain a throat culture. If an active strep throat infection is diagnosed, the standard of care for all patients with strep throat is to treat with antibiotics. For some patients, the next step may be to do a blood test to look for evidence of previous strep infection. For all patients, the recognition and accurate diagnosis of OCD is the first step towards effective treatment.

For more information about PANDAS, the NIMH website is an excellent starting point: <http://intramural.nimh.nih.gov/research/pdn/web.htm>.

Treatment of Pediatric OCD

(continued from page 1)

group has completed and just recently published the primary outcome paper from a large randomized controlled trial that points to efficacious treatments – both medication and psychotherapy – for OCD in children and adolescents. We are now taking the next step – how to help children who are on medication for OCD who still have clinically significant residual OCD symptoms even after an adequate trial of a selective serotonin reuptake inhibitor (SSRI). A summary of our recently completed comparative treatment study and a description of our ongoing study of augmentative treatment is provided below.

Previous research on the treatment of OCD in children and adolescents supports the efficacy of short-term OCD-specific cognitive-behavior therapy (CBT) or medical management with a selective serotonin reuptake inhibitor (SSRI). However, little was known about their relative and combined efficacy. Accordingly, the aim of our initial research project was to evaluate the efficacy of CBT and medical management with the SSRI, sertraline (Zoloft), alone and in combination as initial treatment for children and adolescents with OCD. The project was funded by the National Institute of Mental Health in 1997, and the project's Principal Investigators were Edna B. Foa, Ph.D., and John S. March, M.D., M.P.H.; mid-way through the study Brown University was added as a clinical site (Henrietta L. Leonard, M.D., Principal Investigator at the Brown site). A volunteer sample of 112 outpatients between the ages of 7-17 inclusive with a primary diagnosis of OCD and with significant clinical impairment was recruited. Participants were randomly assigned to receive one of the three active treatments (CBT, sertraline, or CBT plus sertraline) or pill placebo for 12 weeks. We measured change in symptom severity and impairment over 12 weeks using the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS), which is the primary outcome measure used in most pediatric OCD outcome trials conducted to date; scores on the CY-BOCS range from 0 to 40, with most studies reporting pre-treatment mean scores in the low to mid 20s for clinical samples. Importantly, blind raters conducted all evaluations during the study to minimize the possibility of rater bias. We also classified patients as "excellent responders" if their post-treatment scores on the CY-BOCS were equal to or less than 10, which is thought to reflect minimal OCD symptoms.

Our statistical analyses indicated a significant advantage for all three active treatments – combined treatment, CBT, and sertraline

– compared to placebo. With respect to comparisons of the active treatments, overall combined treatment was particularly effective; it proved superior to CBT and to sertraline, which did not differ from one another. With respect to "excellent response," approximately 54% of the patients who received combined treatment and 39% of those who received CBT alone achieved excellent response, in comparison to approximately 21% of those who received sertraline and 3% who received placebo. We also detected site by treatment effects on the CY-BOCS such that CBT alone at the University of Pennsylvania was superior to CBT at Duke University, whereas the reverse was true for sertraline alone; notably, no site by treatment effects were found for combined treatment or for placebo.

Based on these results, we recommend that children and adolescents with obsessive-compulsive disorder begin treatment with either the combination of CBT plus an SSRI, or with CBT alone. The addition of medication to CBT alone may be particularly important when CBT is attenuated for some reason; subsequent studies from this same dataset will be aimed at determining whether patient factors, therapist effects, or differences in implementing the protocols underlie the observed site effects.

Our study findings emphasize the potential utility of CBT, either alone or in combination with SSRIs. CBT, however, is a limited commodity in the community at large. The usual treatment received by children with OCD is medication management alone prescribed by a primary care clinician. The medication used is typically an SSRI such as sertraline, fluoxetine, or fluvoxamine, each of which is FDA approved for pediatric OCD. The chances for excellent response are lower with medication alone – for example, the results of our completed study indicate that rates of excellent response in children treated only with sertraline is just 21%. Therefore, our next phase of research addresses the issue of treatment augmentation (adding an additional treatment to a current treatment) as well as treatment transportability (bringing a treatment developed in a research setting to the community). The current study, funded by NIMH, will evaluate the effectiveness of two 12-week treatments that will be added to ongoing medication management for childhood OCD: either full CBT by a psychologist, or instructions in CBT by a psychiatrist in the context of medication management. The aim of the study will be to determine (1) what is the most effective treatment to add to medication management, and (2) whether a more transportable treatment, in the form of psychiatrist-delivered instructions in CBT, is as effective as full CBT by a psychologist. We are currently recruiting children aged 7-17 who are taking an SSRI for OCD and

who still experience clinical impairment from OCD.

Help us to determine the best way to help children and teenagers with OCD who are still struggling with clinically significant symptoms even though they have received an adequate trial of an SSRI! If you think your child may be eligible for the study, and if you live within commuting distance of Duke University (Durham, NC), Brown University (Providence, RI), or the University of Pennsylvania (Philadelphia, PA), please contact one of our study coordinators below. Your child may be eligible to receive treatment from leading OCD study centers at no cost.

Contact information:

Brown University, Providence, RI:
Janet Ng, (401) 444-2178 jng@lifespan.org

University of Pennsylvania, Philadelphia, PA:
Radhika Pasupuleti, (215) 746-3331, radhikap@mail.med.upenn.edu

Duke University, Durham, NC
Rebecca Dingfelder, (919) 416-2447, dingf002@mc.duke.edu

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BTI Faculty

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Martin Franklin, Ph.D.
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Charles Mansueto, Ph.D.
Fred Penzel, Ph.D.
C. Alec Pollard, Ph.D.

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