OCF Behavior Therapy Institute

OCD Newsletter

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Funding Research: One of Our Most Important Missions

Dear Friends,

Our summer appeal for contributions to the OCF Research Fund raised more than $100,000. Your wonderful monetary gifts have made it possible to fund six of the research proposals that we received in response to our 2005 "Call for Proposals."

The total amount the Foundation will give out to investigators for the 2005 OCF Research Awards is $257,351.12. Most of these awards went to young researchers who are exactly the people that we want to attract to the field of OCD research. If we can attract talented people who are at the beginning of their research careers, we can eventually have a goodly number researching OCD. Young researchers usually gravitate to fields where research funding is available.

The OCF is one of the few funding sources available for supporting preliminary OCD studies. If we don't raise and give the needed money for these preliminary studies, who else will do so? Young researchers need to begin projects that will give them sufficient scientific data so that they become eligible for career research awards from the National Institute of Mental Health.

Unfortunately, in 2005 there were 36 projects that we were not able to fund. Any one of these may have led to development of more effective treatments for OCD and OC spectrum disorders. Since 1994, the OCF has given over $1.4 million to investigators in the OCD field, but compared to the funding for schizophrenia, major depression and bipolar disorder, this $1.4 million is miniscule.

Anticipating that you would respond generously to this year's Research Fund Campaign (as you did this summer), we just sent out hundreds of our "Call for Proposals," and we anticipate that we will get a great many wonderful research projects in response. Our goal this year is to raise and distribute $1 million so that we will be able to support most if not all of the projects we judge to be vital for finding better treatments for OCD.

As you are well aware, OCD can be as totally disabling as schizophrenia or paralysis. In addition, OCD does not just affect the sufferer, it negatively affects the patient's family, friends and co-workers. The only way to eradicate OCD is through research. There is still a staggering amount of research that needs to be done before we will have found and developed effective treatments for everyone who suffers from OCD. Please help us reach our goal of $1,000,000 by contributing to the OCF Research Fund now. The more you give, the more we can give.

Sincerely yours,

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

Continuing Our "Call For Proposals" for the 2006 OCF Research Awards

The OCF is seeking Research Proposals for the 2006 OCF Research Awards. The deadline for submission is January 13, 2006.

Topics of Interest

The OC Foundation is committed to finding and promoting "Effective Treatment for Everyone with OCD." To further this goal, the Foundation is interested in supporting research into the brain, its chemistry, structure and functioning; basic neurobiology; the genetics of OCD; its epidemiology, as well as all aspects of OCD and the OC Spectrum Disorders that will produce sufficient data needed to win a National Institute of Mental Health Career Award. Post-doctoral fellows are encouraged to submit proposals.

For more information on how to apply, contact Deputy Director Jeannette Cole at 203-401-2069 or at cole@ocfoundation.org.

IT'S A WRAP!

Production for the Obsessive Compulsive Foundation's first national public awareness campaign wrapped up recently.

The campaign, "My Name is Elizabeth," which centers around 18-year old Elizabeth McIngvale, an OCD sufferer from Houston, Texas, includes a 30-second public service announcement that will be distributed to 200 television stations across the country. A print public service announcement has been designed for distribution to national magazine and newspaper outlets. The television and print PSA's will be made available to local OCF affiliates to distribute to broadcast and print outlets in their area.

Research shows that public service announcements dealing with issues involving child and teen health receive more airtime from broadcasters. So, as the "My Name is Elizabeth" campaign was developed, the decision to focus on a teenager with OCD became an important factor. The theme of putting a beautiful "face" on OCD to represent all of the beautiful people who suffer from this terrible disease was paramount to compel the viewer or reader to stop and say, if she has it then it's okay to admit that my daughter, sister, best friend has it. The next action, of course, is for them to get help.

You can look forward to an interview with Elizabeth McIngvale in our winter issue of the OCD NEWSLETTER.

We now own the url "OCD GET HELP." It will be a direct connection to www.ocfoundation.org and will be working at the time of the campaign launch.

In This Issue

Please Support the OCF Research Fund

Bulletin Board

Body Dysmorphic Disorder Study

People with body dysmorphic disorder (BDD) worry about their appearance, thinking there's something wrong with how they look. BDD usually begins during childhood or adolescence but very little is known about what treatments help this age group. Research is greatly needed to answer this important question. We are studying the effectiveness of the medication fluoxetine for children and adolescents ages 10-16 with BDD who qualify for our study. This study is being done by BDD experts at the Mount Sinai Medical Center in New York, New York (Dr. Eric Hollander); Butler Hospital/Brown Medical School in Providence, Rhode Island (Dr. Katharine Phillips); and The University of Cincinnati School of Medicine in Cincinnati, Ohio (Drs. Brian McConville and Susan McElroy). People who qualify will receive free study treatment and are paid for their participation. Please contact us if you are interested in participating:

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Does your child or teenager take medication for OCD?

Many children and adolescents who take medication for OCD still suffer from OCD symptoms that can interfere with school, work, and relationships with family and friends.

Dr. John March at Duke University, Dr. Martin Franklin at the University of Pennsylvania, and Dr. Henrietta Leonard at Brown University are conducting a multi-site study evaluating the effectiveness of adding two different types of cognitive-behavioral therapy (CBT) to ongoing medication management for the treatment of pediatric OCD that does not respond completely to medication treatment.

Participants in this study will receive medication management free of charge. In addition, they may be assigned to receive CBT at no cost from a psychiatrist or a psychologist.

Children ages 7-17 with a diagnosis of OCD, who are taking fluoxetine (Prozac), sertaline (Zoloft), or fluvoxamine (Luvox), and who still have residual OCD symptoms may be eligible. Children taking citalopram (Celexa) or escitalopram (Lexapro) may also be eligible.

Participants must live within commuting distance of Raleigh/Durham, NC; Philadelphia, PA; or Providence, RI.

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Body Image Treatment Research Study

Do you dislike the way any part(s) of your body (for example, your skin, hair, nose, eyes, and genitals) look?

Do you think about your appearance for more than one hour per day?

Do you engage in any behaviors intended to check on, hide, or fix your appearance (for example, mirror checking, comparing yourself to others, excessive grooming behaviors)?

Or do you avoid any places, people or activities because of your appearance concerns (for example, do you avoid bright lights, mirrors, dating, or parties)?

Do your appearance-related thoughts or behaviors cause you a lot of anxiety, sadness, or shame?

Do you have problems with your work, school, family, or friends because of your appearance concerns?

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

Do you Suffer from Obsessive-Compulsive Disorder?

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

Dr. Sabine Wilhelm of the Massachusetts General Hospital OCD Clinic and Research Unit is seeking participants for a research study on the use of a medication in combination with behavior therapy to reduce the symptoms associated with

(continued on page 12)

OCD NEWSLETTER

The OCD Newsletter is published six times a year.

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

FACING FEARS

By Deborah Osgood-Hynes, Psy.D.

There are not many people who like to feel the body sensations and emotional discomfort that go along with high levels of anxiety: racing thoughts, increased heart rate, rapid shallow breathing, feeling dizzy or faint, sweating, shaking, nausea, fear, doubt and uncertainty. Whether this discomfort is triggered by external situations, places or objects, or whether the distress is due to internal triggers such as thoughts, images, memories, or anticipation of future events, emotional and bodily distress are something most people would rather do without. It's understandable why someone would avoid situations that trigger the anxiety or would do whatever they could to reduce the stress. Though understandable, this becomes problematic.

While OCD symptoms have a neurobiological origin, learning factors also contribute to symptom growth and maintenance. Anxiety and discomfort are aversive. Most of us will do whatever we can to avoid discomfort. However, any action that is done to reduce discomfort gets reinforced and strengthened because it made the discomfort temporarily go away. Avoidance and/or compulsions (both mental and physical rituals) reduce discomfort, albeit only temporarily, thereby strengthening the compulsions or avoidance behavior. It's as if you are teaching your mind and body that the only way to reduce discomfort is through ritualizing or avoidance.

Behavioral treatment follows a fairly simple principle. To reduce a fear you have to face a fear. This applies to all types of fears. If you fear flying, you need to start taking plane trips. If you fear public speaking, you need to give more lectures and presentations. If you fear open spaces, you need to go gradually to more open-feeling locations. If you fear elevators, you need to practice taking elevator rides. If you fear surfaces that you believe are contaminated, you need to touch those very surfaces. If you fear intrusive unwanted violent and/or sexual thoughts, then you need to deliberately think and face those thoughts. If you are afraid of the physiological experience of the anxiety itself, then you need to practice doing actions that trigger these feared body sensations. With repeated practice at facing what you fear, your fear will gradually be reduced (habituation). The way to reduce the fear, anxiety, distress and doubt is to face the fear, anxiety, distress and doubt. Keep in mind the phrase: "No pain, no gain." Short term pain (albeit sometimes very intense emotional pain) can lead to long term gain (OCD symptom reduction and reduced anxiety, fear and discomfort). Treatment can be set up so that you face fears gradually (systematic exposure and response prevention using a hierarchy of increasingly difficult feared situations) or done more rapidly through flooding (facing the highest fears on your fear hierarchy first instead of last). Treatment can be effective either way. Despite which method you choose, it can be a difficult journey that requires a lot of dedication, courage, persistence and support.

The two main treatments for OCD are: a) medication and b) exposure and response prevention (ERP) tasks. Cognitive therapy and dialectical behavior therapy can be useful adjuncts to supplement ERP work. If you are not familiar with exposure and response prevention treatment methods or with commonly prescribed medications for OCD, I would recommend you look to the many wonderful books on the market currently that can elaborate on this further as it is not the goal of this article to explain these treatment methods in detail. Suffice it to say that the goal of ERP tasks is to face your fears (exposure) and try not to do what the OCD is telling you to do (resist rituals and reduce avoidance behavior).

Facing your fears through exposure and response prevention tasks is more useful the more practice you can give to it. I know this is not easy but you can potentially reduce your symptoms faster. If you face a feared situation or thought once a week for 30 minutes, while it may be a very good "behavior therapy moment" as I like to call them, you will get much more momentum and gain out of your therapy if you could face your fears more often. After facing that same fear every day for 30 minutes a day, you will be that much further along. Remember that behavior therapy is about repeated practice at facing a fear. If you only face a fear once in a blue moon, your OCD has all that time in between to build and maintain its strength. Every time you ritualize or avoid, your OCD fears and symptoms are reinforced. There are different levels of practice intensity and I leave it up to you and your individual therapist to discuss the pace of therapy that is right for you.

Let me give you an example of what we do at the OCD Institute at Mclean Hospital in Belmont, Mass. The OCD Institute is a 20-bed residential treatment program for people with moderate to severe OCD or for people who would like to get OCD treatment but do not have access to qualified treatment providers nearby in their state or in their country. Many who come to the OCDI are considered treatment resistant, having been through numerous trials of medication and behavior therapy. The average length of stay is 1-3 months. At the OCDI, in addition to medication treatment, behavior therapy focuses primarily on exposure and response prevention tasks. Each resident is expected to follow through with a minimum of 4 hours of exposure and response prevention tasks every weekday. This includes 2 hours in the morning from 10-12 AM (which may be coached full time) and 2 hours again in the afternoon from 2-4 PM. On the weekends, we ask people to do at least 2 hours of ERP tasks. In addition to these 4 hours of ERP a day, many residents also have additional ERP plans that are specific to their morning wake-up routine, bathroom routines, going out into the community and bedtime routines since they get stuck with rituals at these times. Practicing ERP is very difficult. But therapists and counselors are available to lend support to help coach a person through his/her ERP tasks. We also include specific ERP tasks that are not coached (self-directed) to reduce the dependency on a coach in preparation for facing fears alone, such as, when the resident returns home. While it is important to practice ERP frequently, another important lesson is to live the philosophy of ERP outside of specific ERP practice times. The more you can incorporate a life philosophy of facing your fears and the more you can practice doing ERP tasks when spontaneous life behavior therapy opportunities arise, the more your therapy gains will grow and generalize.

As I said earlier, it takes courage to face your fears on a daily basis. Support to do this is important. First, it is helpful if you learn to praise and encourage yourself for your efforts. Praise yourself for your effort to fight the OCD even if you were not as successful at resisting rituals as you would like. Second, external support can come from many sources: an individual therapist, family, friends or group therapy, to name a few. Keep in mind that support is not asking others to accommodate to your OCD way of doing things nor is it having others offer reassurance to soothe OCD feelings of doubt and uncertainty. Good sources of support give you ideas and encouragement to face your distress and anxiety.

At the OCD Institute, in addition to meeting with a behavior therapist 2-4 times a week, the psychiatrist once a week, the social worker once a week and numerous counselor meetings, we have many types of group therapy for education and support. After a 2-hour block of time doing ERP tasks, residents meet as a group to publicly describe their distress level faced, rituals performed and percent of effort. Symptom specific groups for those struggling with issues of scrupulosity, body dysmorphic disorder, perfectionism and thoroughness, and intrusive violent and sexual thoughts offer specialized treatment and

(continued on page 11)

Message from The President

Dear Friends,

The same familiar thoughts and feelings came rushing back as I drove down the dirt road to Dr. Bill's office. How long had it been since my son and I had made this trip? I remember the first time. Both of us were quiet as we came closer to the doctor's home. We rang the doorbell, just hoping that the next hour would teach Jared coping skills that would help him function.

This time Jared called and made the appointment. He told me that his Obsessive Compulsive Disorder was making it harder for him to complete tasks in a timely manner. He was questioning his decisions, hesitating to let go and to move on. He was repeating tasks, each time hoping that this time would be the final one. Jared knew that he had to give the doctor a call and ask for another session. Jared had done this before and he knew that a few sessions with Dr. Bill would get him back on track.

An hour later, my son emerged from the therapist's office. He was actually smiling. One important difference between now and years ago is that he is able to talk about his obsessions and compulsions.

As we headed back to school, it occurred to me that the focus of my message in this newsletter should be about revisiting CBT. I asked Jared if he would write a piece that would provide insight into why he felt it necessary to return for another round of CBT, or, as he calls it, a "tune up."

Joy Kant
President, OCF Board of Directors

Here in his own words. . . .

When one of the attendees at the Nashville OCF Conference raised her hand and spoke about feelings of failure at having to return to cognitive-behavioral therapy/exposure and response prevention (CBT/ERP), I replied with an explanation that I still use today. What that girl had asked about was a "tune up," a necessary step in the ongoing struggle against OCD.

I, too, have experienced what others might call a relapse. I found myself facing the unpleasant reality that I needed to return to CBT to refine what I had learned in CBT many years ago. I'm currently a senior in college, less than a year away from my Bachelor of Arts in Creative Writing. Unfortunately, it is exactly at pivotal times that I'm most likely to experience an upsurge in my obsessions and compulsions.

For everyone, not just those of us with OCD, transitions are hard. That being said, the hardest sentence to speak aloud in the English language – as one of my professors once said – is "I need help." No matter how much we may find discomfort in asking for help; nothing can equal the discomfort of feeling that something you have worked on for eleven years slipping through your fingers and out of your grasp.

I don't have to tell any fellow OCD sufferers about how hard it is to live with Obsessive Compulsive Disorder on a day-to-day basis, because a great many of you already know this firsthand and would be bored to tears. All the same, I would like to dispel some misconceptions about therapy.

Cognitive-behavioral therapy, exposure and response prevention, pharmacology, and psychotherapy are all tools. CBT and ERP have lately proven themselves most effective in combating the potentially paralytic anxiety of OCD. But a tool is merely a device created to allow an individual to complete a certain task. It is not the solution in and of itself, not exactly. CBT, as a tool, is no different than the blade of a pocket knife. Because we use the skills learned in CBT every day, we are always employing this tool to get through the day; but we can start to lose our edge over time. The more we neglect our responsibility to keep the skills afforded us by behavioral therapy in tune, the more desperately they need to be sharpened, until one day, it's like trying to saw through a wooden log with a butter spreader. When we feel the OCD refastening its grip, this is when I would (metaphorically speaking) grab the proverbial whetstone and (literally speaking) call my doctor. It's time, then, for a "tune-up."

On the other hand, I refused to take my own advice this time around. One day, I was standing in a Virgin Megastore, sweating bullets, trying to remember the specifics of whatever it was my brain wanted me to do, for whatever reason it wanted me to do said task. I wanted to scream inside the store.

Still, though, I resisted getting help. It took me getting stuck in a loop inside my head in the public bathroom at a Home Depot when I was trying to buy light bulbs to break me again.

I just wanted these past two months of my life to appear semi-normal, whatever that is. That's why I was buying light bulbs in the first place. I was trying to be self-sufficient. I think you will all agree, however, that there is nothing self-sufficient, empowering or independent about getting stuck in a public toilet at 22 years of age.

Since the time I checked in with the doctor, I've felt a little edge return in my ability to recognize intrusive thoughts for what they are. I have no doubt in my mind that if I had called earlier, back when I first knew I should have, that my OCD would be in check by now. This is, however, neither here nor there. What's done is done. What matters is that I'm back in therapy, training myself to beat the disease. I'm confident because, when at its sharpest, CBT is like arsenic to OCD. It will take a little longer I'm sure; but I know I can beat this. I know this, because I have already done it once.

Jared Douglas Kant

New Copies of "OCD In The Classroom" Are Available.

To Purchase The Program, Call Leslie at 203-401-2070, ext. 14.

Why Am I Not Getting Better?

By Laurie Krauth, MA

An elderly patient's OCD began when Calvin Coolidge was president. Unfortunately the patient did not get a proper diagnosis or treatment for decades. Then this patient went to Dr. Penzel and was properly diagnosed and treated. Inaccurate diagnoses and ineffective treatments occur, even after patients consult with multiple therapists. Dr. Penzel identified nine reasons why people fail – but shouldn't.

Dr. Penzel

"There are many reasons why people appear to fail to recover, even after seeing four or five therapists," Dr. Penzel told his audience at the 12th Annual OCF Conference in San Diego. Dr. Penzel is the director of the Western Suffolk Psychological Services in Huntington, New York. He is on the OCF Scientific Scientific Advisory Board and has written widely on OCD. His books include *Obsessive-Compulsive Disorders: A Complete Guide to Getting Well and Staying Well* (2000) and *The Hair-Pulling Problem: A Complete Guide to Trichotillomania* (2003). The following are nine common reasons he gives for OCD sufferers' poor progress in overcoming their symptoms:

1. THEY WERE MISDIAGNOSED

Some people are diagnosed with OCD when they have another mental illness with similar symptoms. Others are told they have another disorder when they really have OCD. Many therapists lack the training and supervision to properly diagnose OCD, Penzel said. They fail to tease out the details that confirm or rule out the diagnosis. They may fail to distinguish how similar symptoms more accurately fit another disorder.

The proper diagnosis is essential to tailoring the right psychological and medical treatment to each person. To complicate matters, people with OCD may also have other disorders as well. So therapists may need to make more than one diagnosis to develop a treatment plan addressing all of a patient's problems.

For those who may have been misdiagnosed with OCD, he said, some of the disorders with similar symptoms that might fit them better include:

• **Autistic Disorder**. According to Dr. Penzel, characteristics of autistic disorder that are often mistaken for OCD include repetitive gestures or motions; lining up or organizing things in exact ways; saying things repetitively (such as words, phrases and sounds); and adhering to rigid schedules or ways of doing particular things that cannot be altered in any way." Parents may notice their children doing things repetitively but for a reason other than OCD. "Autism is a disorder of language and social relatedness, not of doubt and guilt. Autistics do things repetitively for sensory reasons, or to calm their nervous systems. They are stuck in loops of behavior intended to soothe themselves but they are not experiencing guilt and doubt the way people with OCD do," Penzel emphasized. Autistic people like sameness and order because it is reassuring and comforting, not for superstitious or perfectionistic reasons as OCD sufferers do, he added.

• **Asperger's Disorder**. Asperger's is similar to Autism but less dramatic in its presentation, said Dr. Penzel. It is a disorder of social relatedness: people with Asperger's may often be the odd-person out, explained Dr. Penzel. Features of Asperger's mistaken for OCD include "a focus on very specific, limited, and intense interests, which people with Asperger's often pursue to the exclusion of everything else, occupying many hours per day. They may lecture repetitively on favorite topics," he said, or "adhere to rigid schedules or ways of doing particular things that cannot be altered in any way." Unlike with OCD, people with Asperger's are motivated by pleasure, not anxiety, to spend excessive time on activities such as video games, math problems, on-line searches, and reading of numerous books on a subject of interest.

• **Tourette's and other Tic Disorders**. Tourettes's Disorder involves both multiple motor and vocal tics, though not necessarily at the same time. The tics occur many times a day, and cause marked distress or impaired functioning. Features of tic disorders that can be mistaken for OCD include repetitive motor or vocal acts, "evening up" things symmetrically, or repeating actions in order to get a "just right" sensation, said Dr. Penzel. Complex tics may involve a whole connected series of physical or verbal actions that resemble compulsions. However, "with tics, it's like the feeling you get before you sneeze – it just feels like you have to do it." He said people are not doing it to relieve bad feelings nor as protection against harm or embarrassment but to eliminate unpleasant sensations. For people with OCD who have "just right" compulsions, it is more anxiety driven, and less of a sensatory need.

• **Obsessive Compulsive Personality Disorder**. One of Dr. Penzel's "unofficial diagnostic criteria" for OCPD is met when a patient contacts him because "his/her back is against the wall because his/her job is threatened or his/her spouse brings him/her in for treatment," he said. "They don't want to change. They feel these things they do are an integral part of them and give them pleasure." Often their behavior doesn't cause them distress, even if it's messing up their lives, he added. People with OCD, however, "find their symptoms unpleasant or repulsive." Further, he notes that the difference between preventing someone with OCPD and OCD from behaving in these classic ways is that the first will likely become angry and the second, anxious.

Features of Obsessive-Compulsive Personality Disorder that are frequently mistaken for OCD, he said, are an insistence on perfectionism and exactness, having rigid routines, having to be very controlling of others, being meticulous and rule-governed, and hoarding useless or excessive numbers of things.

• **Schizophrenia**. Features of schizophrenia frequently mistaken for OCD include bizarre, extreme, and illogical thoughts and beliefs. People with schizophrenia believe their thoughts are true. If they have paranoid delusions, they are certain someone will be harmed. "They know it is true that, say, 'People in white cars are trying to kill me,' or 'my husband is trying to poison me.'" On the other hand, people with OCD are obsessed that someone will be harmed – by themselves or by others – but uncertain about it.

"Am I schizophrenic or do I have OCD? You can sum up OCD with two words: pathological doubt," said Dr. Penzel.

Schizophrenia has been one of the most common misdiagnoses for people with OCD due to the sometimes bizarre obsessions that can accompany OCD. Many people with OCD report family members once were hospitalized for schizophrenia who probably had OCD instead, he added.

• **Attention Deficit/Hyperactivity Disorder**. Ironically, some ADHD sufferers compensate with behaviors that can look like OCD, such as, extensive list-making, doing things in a certain unvarying order, repeating actions, counting while doing things, and double checking to avoid a reckless omission or error, said Dr. Penzel. A person with OCD, however, may be driven to do those things to reduce anxiety

(continued on page 10)

Research

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

Behavior therapy augments response of patients with obsessive-compulsive disorder responding to drug treatment

Journal of Clinical Psychiatry, 66:1169-1175, 2005, N.H. Tenneij, H.J.G.M. van Megen, D.A.J.P. Denys et al.

Most patients who benefit from serotonin reuptake inhibitor (SRI) medications obtain only a partial response and have residual OCD symptoms. Experts recommend combination treatment, medication and behavior therapy, as the best approach. Behavior therapy is expensive, time-consuming and not readily available for most patients; thus it is important to learn how beneficial the combination is. This study investigated whether addition of behavior therapy would increase the treatment response already obtained from medication. Ninety-six patients with OCD, who had responded to 3 months of treatment with paroxetine (Paxil) or venlafaxine (Effexor), were randomly assigned to receive either behavior therapy or continue on drug treatment alone for 6 months. Patients who received behavior therapy showed a greater improvement in OCD symptoms than those who continued on medication alone. Significantly, more patients who received behavior therapy were in remission (complete response) compared with those who continued on medication alone – 11% of patients in drug treatment only group and 53% in the combination therapy group. Results suggest that addition of behavior therapy is beneficial for patients who have responded to drug treatment.

This study did not address the alternative question: For those who have had behavior therapy, would adding an SRI improve that response. In the landmark study below, Foa and Liebowitz did not find the addition of clomipramine (Anafranil) increased the large improvement available from excellent behavior therapy. Nevertheless, the results from both of these group analyses do not answer the specific question about combination therapy for individual patients who may, or may not, respond according to these "average" results.

Randomized, placebo-controlled trial of exposure and ritual prevention, clomipramine, and their combination in the treatment of obsessive-compulsive disorder

American Journal of Psychiatry, 162:151-161, 2005, E.B. Foa, M.R. Liebowitz, M.J. Kozak et al.

This study compared the effectiveness of drug therapy, behavior therapy and the combination of the two therapies for OCD. In a randomized, double-blind design, 29 patients received behavior therapy (intensive exposure plus ritual prevention for 12 weeks), 36 patients received clomipramine (12 weeks with a maximum dose of 250 mg/day), 31 patients received both treatments and 26 patients received placebo. At week 12, the effects of all active treatments were superior to placebo pill. The effect of exposure and ritual prevention did not differ from that of exposure and ritual prevention plus clomipramine and both were superior to clomipramine alone. The study began in 1990 when the only U.S. FDA-approved medication was clomipramine. Now several SSRIs have been approved for OCD by the FDA and are usually used before clomipramine as it has potentially more serious side effects. Researchers state it is reasonable to assume these findings for clomipramine can be generalized to the SSRI. Exposure and ritual prevention (behavior therapy) is more effective than medications.

Effectiveness of intensive residential treatment (IRT) for severe, refractory obsessive-compulsive disorder

Journal of Psychiatric Research, 39:603-609, 2005, S.E. Stewart, D.E. Stack, C. Farrell et al.

Treatment outcome is reported on 403 patients admitted to the Massachusetts General Hospital/McLean OCD Institute, the oldest of the IRT centers in the U.S. All patients received 2 to 4 hours of cognitive-behavior therapy (CBT) daily, weekly medication assessments, meetings with social workers and group psychotherapy sessions. Measures of OCD severity, depression severity and psychosocial well-being were determined at admission, interim and discharge. The average treatment length was 66 days. Patients with longer treatment stays tended to have earlier ages of OCD onset and more severe OCD. Average Yale-Brown Obsessive Compulsive Scale (YBOCS) scores decreased by 30.1%, showing a meaningful improvement in OC symptoms. Additionally, psychosocial functioning, depression severity and self-report functioning indicated significant improvement. Treatment lengths up to 3 months were associated with significant improvement. Researchers concluded that IRT is an effective treatment approach for severe OCD that does not respond to standard treatments. It should be considered before the use of more invasive approaches, such as neurosurgery, for treatment resistant OCD. If substantial improvement does not occur within 3 months, further IRT is unlikely to help and another treatment strategy should be sought.

Tic or compulsion? It's Tourettic OCD

Behavior Modification, 29:784-799, 2005, C.S. Mansueto and D.J. Keuler

Coining the term "Tourettic OCD," authors describe a subgroup of individuals with OCD suffering a blend of OC symptoms and tic disorder symptoms. They propose that classifying this subgroup as Tourettic OCD (TOCD) would benefit the diagnosis and treatment of these individuals. Symptoms of TOCD include – (1) pronounced touching, tapping and repeating behaviors that relieve somatic discomfort or distress, (2) preoccupation with discomfort for nonperformance of the repetitive behavior, and (3) presence of unelaborated obsessional themes. Compulsions are associated with sensory phenomena such as localized physical tension, generalized discomfort and feelings of incompleteness. Usually these individuals receive standard treatment for OCD (or less likely Tourette's syndrome) that is often not effective. Three case studies are used to illustrate symptoms of TOCD and treatment. Behavior therapy with exposure plus ritual prevention can be more effective with the addition of muscle relaxation techniques, imagery, breathing exercises and substitution strategies. Additionally, greater response may occur if behavior therapy is given for longer periods of time and focuses more heavily on rote practice of therapeutic skills. Drug therapy with SSRIs can be

Digest

more effective with the addition of low-dose antipsychotics or alpha 2 agonists (antihypertensives) such as guanfacine (Tenex) or clonidine (Catapres; Clorpres).

Mental pollution: feelings of dirtiness without physical contact

Behaviour Research and Therapy, 43:121-130, 2005, N. Fairbrother, S.J. Newth and S. Rachman

Mental pollution refers to physical feelings of contamination (dirtiness) occurring without physical contact with a soiled substance/material/person. The dirtiness of mental pollution is experienced as being similar to ordinary "external" dirtiness – the dirtiness that can be seen, felt or smelt, and easy to identify. Researchers hypothesize that mental pollution can be induced by a thought, visual image or memory. In this study, 121 female college students were asked to imagine kissing someone at a party. Each participant was asked to imagine the scenes and events described in each of two audiotapes. One tape described a consensual (willing participation) kiss and the second a non-consensual (forced) kiss at a similar party. Three versions of the non-consensual kiss were used – a man forcing a kiss, a dirty and smelly man forcing a kiss and a man forcing a kiss in a situation where the participant is told she feels unable to get away. Imagining non-consensual kisses induced feelings of mental pollution, but imagining consensual kisses did not. Feelings of mental pollution were induced without physical contact and they were associated with feelings of shame and distress along with some urges to wash, and a few cases of actual washing. This research may have relevance for resistant cases of contamination/dirt phobias and OCD. Results are consistent with the feelings of mental pollution reported by victims of sexual assault and to cases of the onset of mental pollution and OCD subsequent to sexual trauma.

Attention-deficit hyperactivity disorder with and without obsessive-compulsive behaviours: clinical characteristics, cognitive assessment, and risk factors

Canadian Journal of Psychiatry, 50:59-66, 2005, P.D. Arnold, A. Ickowicz, S. Chen et al.

OCD behaviors were identified in 11.2% (15 of 134) children with attention deficit disorder with hyperactivity (ADHD). A comparison was made between the 15 children with ADHD plus OCD, 119 children with ADHD alone and 26 children in a normal control group. The children with both ADHD and OCD had increased perfectionism and a decreased likelihood of having a first-degree relative with ADHD. Based on parents reports, children with comorbid ADHD and OCD were more impaired and were more oppositional in the home setting. Research suggest clinicians should conduct comprehensive assessments for comorbid conditions, because a significant number of ADHD children will have OCD and their OCD was associated with increased impairment compared to ADHD alone.

Obsessive compulsive symptoms in schizophrenia: frequency and clinical features

Schizophrenia Research, 76:309-316, 2005, M. Byerly, W. Goodman, W. Acholonu et al.

Obsessive-compulsive symptoms occurred in nearly one-third of patients with schizophrenia or schizoaffective disorder. Of the 100 individuals evaluated, 30% reported two or more OC symptoms and 23% met full DSM-IV criteria for OCD. The OC symptoms were enduring; patients had experienced their OC symptoms for an average of 21.2 years (range, 1-47 years) at the time of the study. No association was found between occurrence of OC symptoms and severity of schizophrenia. The OC symptoms appeared to have little impact on psychotic symptoms or on patient's overall level of functioning. Patients were more likely to develop symptoms of their psychotic disorder before the onset of OC symptoms; only 28% of patients developed OC symptoms first. Several reports suggest that atypical antipsychotics may induce OC symptoms, but medication association with OC symptoms in this study was unknown.

Obsessions and compulsions in Asperger syndrome and high-functioning autism

British Journal of Psychiatry, 186:525-528, 2005, A.J. Russell, D. Mataix-Cols, M. Anson et al.

Obsessive-compulsive behaviors are common and disabling in autistic-spectrum disorders (ASD), which include autism and Asperger syndrome. Researchers compared the frequency and severity of obsessions and compulsions in 40 high-functioning adults with autistic-spectrum disorders (ASD) with those in 45 adults with OCD. The two groups had similar frequencies of OC symptoms, with only somatic (focus on body) obsessions and repeating rituals being more common in the OCD group. Obsessions and compulsions were more frequent and distressing in ASD than previously thought. Also, a quarter of the ASD group met full diagnostic criteria for OCD. A lower occurrence of somatic obsessions in the ASD group is of interest, especially as families often report that ASD individuals have difficulty reporting any physical complaints; instead agitation or behavioral distress may be seen. Clinicians need to consider the possibility of significant OC symptoms in ASD, rather than classifying repetitive behaviors as characteristic of ASD, since these individuals may benefit from standard treatments for OCD.

Posttraumatic obsessive-compulsive disorder: a case series

Psychiatry Research, 135:145-152, 2005, Y. Sasson, S. Dekel, N. Nacasch et al.

This paper describes 13 Israeli military veterans for whom the onset of OCD was clearly associated with a traumatic event. Posttraumatic stress disorder (PTSD) can occur after a traumatic event when symptoms persist for one month or longer after the trauma. These symptoms are re-experiencing the traumatic event, emotional numbing and avoidance behaviors, and increased arousal (becoming hypervigilant, watching for danger). A review of the literature linking OCD and PTSD is presented, followed by a discussion of the theory and implications of a relationship between the disorders. In the authors' opinion, this untypical course of OCD, triggered by a trauma, may be a distinct subtype of OCD.

An Interview with the OCD List Leader

The following is an interview with Wendy Mueller, who is the leader of the on-line "OCD-Support Group List" on yahoogroups.

NEWSLETTER: How would you describe the OCD-Support List to someone who had never heard about it or used it?

WENDY: The OCD-Support List is a huge on-line support group for people with OCD, as well as their family members and friends. It is a place for people with OCD to come to share their problems and feelings with others who understand what they are going through. The main purpose of this group is to have a safe place for people with OCD to come to "talk" with others or "listen" to others, regarding the difficulties of living with OCD.

NEWSLETTER: How did the OCD List get started? Who was the original list leader?

WENDY: This on-line OCD group was originally started about 11 years ago by Christina Vertullo, who is the mother of an adult child with OCD and a member of the OCF Board of Directors. Chris wanted to create a place on-line where people with OCD could share their thoughts and feelings and seek support from others. Chris' group was originally called the "OCD-L" group. Chris was able to get two of the top OCD doctors in the country, Dr. Michael Jenike and Dr. James Claiborn, to join her group; and they have been contributing their expertise to the group on a daily basis ever since it was formed. Chris "retired" from leading the group four years ago, and I took over as leader of the group. I had been an active member of the group for quite a few years prior to taking over as leader.

NEWSLETTER: How big is the OCD-Support List?

WENDY: We have 2,000 people in the group as of November 15, 2005.

NEWSLETTER: What subjects do list members discuss?

WENDY: List members discuss the daily problems of living with OCD. We discuss the problems we are having with obsessions and compulsions, and we talk about the treatments we are undertaking to help with our OCD. We talk about how to use behavior therapy to help with our obsessions and compulsions (Drs. Claiborn and Jenike are especially adept in helping us with ideas about how to apply ERP therapy to our difficulties). We talk about how our OCD affects our relationships with our family members and other loved ones. Those of us who have recovered greatly from suffering with our OCD try to give encouragement and support to those who are still struggling.

NEWSLETTER: What would a typical day entail? How many people would be posting? What topics do they discuss?

WENDY: The number of messages posted in a day varies from day to day, and from season to season. We always have a lower amount of postings during the summer (when people go on vacation), but we always have a big increase in postings right after the December holidays (when everyone is stressed to the max!). The number of messages posted per day by members averages about 35-37. Members can choose to receive these messages by private e-mail, or they can choose to just read the messages on the OCD-Support web site. This was set up this way so that members are not overwhelmed with 35+ additional e-mails each day. We discuss any topics related to living with OCD.

NEWSLETTER: Who are the people who make up the list membership? Sufferers, family members, treatment providers?

WENDY: Most of the members are people suffering with OCD, but we also have many family members and loved ones of people with OCD, who come to the group to learn how to help/support their loved one. We also have two of the top OCD doctors in the country, who contribute their knowledge and expertise on a daily basis – Dr. Michael Jenike from Boston, MA, and Dr. James Claiborn from Portland, ME. Also, Dr. Jon Grayson of Bala Cynwyd, PA, and Tom Corboy, MFT, of Los Angeles, CA contribute when they are able to do so.

NEWSLETTER: What kind of questions do the treatment providers answer?

WENDY: Dr. Jenike is our resident psychiatrist in the group. He offers general responses to questions about medications for OCD. He and Dr. James Claiborn, who is a psychologist, offer advice on how to apply exposure and response prevention therapy techniques to fight individual OCD problems.

NEWSLETTER: Is there a special topic that list members must stick to?

WENDY: Members must stick to the topic of discussing how OCD affects our lives. Off-topic messages are not permitted. I (and my list co-moderators) keep a close eye on all messages posted, so that off-topic messages are kept off the List. We also make sure that nothing offensive or hurtful is posted on the List. Anyone who posts an offensive or cruel message is immediately removed from membership.

NEWSLETTER: Are there any subjects that are forbidden?

WENDY: No off-topic "chatter" is permitted. I always encourage members to privately e-mail other members, if they wish to strike up conversations with someone else about non-OCD-related topics. However, all messages posted to the entire group of 2,000 people MUST be on the topic of OCD. No "flaming" of other members is permitted; no profanity is permitted; no cruel or derogatory remarks are permitted. If anyone violates these rules, they are immediately removed from the OCD-Support List.

NEWSLETTER: Do you also have active chat groups?

WENDY: We have a chat room available on the web site of the OCD-Support Group, which anyone can use 24/7. Members can "reserve" a time to meet with others in the chat room to discuss OCD issues in real-time.

NEWSLETTER: Who can join the list? Are there any requirements for membership?

WENDY: Anyone who has an interest in OCD can join the group. We have some college/graduate students who join the group because they are doing research on OCD and are seeking information. Treatment providers are also welcome to join to learn more about OCD and its treatment. The only requirement for membership is a true interest in learning more about OCD.

NEWSLETTER: How does one go about joining the list?

WENDY: All you have to do is send a blank e-mail to this address: OCD-support-subscribe@yahoogroups.com. You will need to briefly state the reason why you want to join the group. My co-moderators and I usually approve memberships within a couple of hours – sometimes within a few minutes.

NEWSLETTER: Why should somebody join the list?

WENDY: People with OCD should join the List to learn how to best fight their OCD by learning about behavior therapy and medications, through peer support with others suffering from OCD and by sharing their own struggles and problems with others who understand. Loved ones of people with OCD should join to gain a greater understanding of what it is like to live with OCD and how they can help their loved one with OCD to lead a better and more productive life.

NEWSLETTER: What do you think are the benefits of belonging and participating in the OCD list?

WENDY: The benefits for people with OCD are TREMENDOUS! You will have a place where you can talk about your OCD among hundreds of people who understand exactly what you are going through. You will have a place to vent your frustrations and get understanding support from others who know what you are experiencing. You can strike up friendships with other OCD people from around the world, who might become long-term pen pals. (We have many List members from Canada, England, Australia and other foreign countries in the group.) You can be kept informed about the latest medications and behavior therapy treatments for OCD through our expert doctors. And – last but not least – you will get to hear Dr. Michael Jenike's ridiculously bad jokes at least a few times each month!

I hope to see more of you as members of our OCD-Support List! Please contact me if you have any questions. Wendy Mueller, List Leader, OCD-Support List
wmueller@adelphia.net

Your Thoughts Revealed – Answers to Dr. Grayson's Challenge

By Jonathan Grayson
Bala Cynwyd, PA

This last summer, a member of the newsletter staff approached me about starting a column in which OCD sufferers could share their own thoughts about important concerns and issues. I accepted and thought the column would be more interesting if it focused upon a theme for each issue. With this in mind, *Your Thoughts Revealed* is an adaptation of how meetings of the Philadelphia GOAL support group begin. A question is posed for members to discuss thoughtfully some aspect of OCD or how OCD affects their lives. Adopting this approach allows this column to offer OCD sufferers a place to share their thoughts on important issues regarding OCD, whether it be coping with family members, careers, faith, symptoms, or any other of the endless issues to which OCD gives rise.


Dr. Grayson

The question posed in the summer issue was: **Have you or haven't you accepted uncertainty as a part of life? What does this mean to you? How has this affected your recovery?**

Below are responses we received, followed by my own reflections. In some cases, the original responses may have been edited or shortened for publication demands. The following are the answers the Newsletter received.

From D.

As for the question about accepting uncertainty in my life, I have only been able to accept it in some areas. Sexual identity, the significance of everyday aches or pains, the meaning of most thoughts that come into my head, and the possibility of harm coming to me if I travel somewhere are some areas where uncertainty is no longer a problem for me, thanks to therapy.

The uncertainty of what is right and what is wrong has been a constant in my life since I was ten years old. I grew up in a family which valued being right. None of my five siblings could stand being wrong. It would be your fault if you had the directions wrong, or if you had read the movie time incorrectly. Intellectually, I know this to be an absurd expectation. But, emotionally it has fueled my OCD. Somehow, I still feel I am a failure if I don't know something for sure.

This uncertainty too has decreased significantly with the help of Fr. Thomas Santa who used to write the *Scrupulous Anonymous Newsletter* and more importantly held a retreat for people such as myself. The tools he gave us were in line with Dr. Cirocchi's talk on scrupulosity at the OCF National Conference. Their advice about telling priests of the need to apply "epeika" when administering the Sacrament of Reconciliation to those of us with scrupulosity has made a tremendous difference for me in accepting uncertainty in this area.

Being sure that I know as much information as possible and know as many different techniques as needed to perform to the very best in my profession are still problems for me. Along with this, I still ruminate about whether I have said things correctly, so that people understood them as I meant. I also get tied up in determining the honesty of my remarks and how people perceive what I have said.

Having succeeded in accepting uncertainty in some areas makes me believe that further improvement is possible. Things that once tortured me now don't bother me at all. When I think about this sometimes, I think that it is quite amazing. To get this far I have had to really work on my recovery, but the changes that have occurred give me hope for the future.

From A.

Intellectually, yes; emotionally is another question. I will go to extremes to ensure that all is right and there is nothing left to chance. The thought of something falling through for which I am responsible is intolerable. On the other hand, the rational me knows something will be forgotten or fall through. Discovered the phrase "good enough" about five years ago at age 60 (!) and am trying to incorporate it into my thinking. Sometimes I even succeed!!

From R.

Yes, I have accepted uncertainty in my life to a much more comfortable degree than during my past 43 years. Success was achieved by hard cognitive work, consulting diagnosis and medication. My diagnosis is OCD (checker) with overfocused ADD. Tolerance in navigating life was achieved using 80 mg of Prozac, the SSRI contribution, and 25 mg of Ritalin for neurotransmittal control. As a result I have a

(continued on page 14)

Why Am I Not Getting Better?

(continued from page 5)

caused by obsessional thoughts that they may have made an (unlikely) error. "ADHD is a disorder of attention and concentration, not of doubt and guilt as in OCD," Dr. Penzel pointed out.

These are just some of the other mental health issues that resemble features of OCD. The plethora of such possible diagnoses can overwhelm someone eager to nail down the right one for him/her. Some end up saying, "Doc, I'm suffering from the "DSM," said Dr. Penzel. The bottom line is that if you suspect you have OCD, you need to be diagnosed by someone who specializes in treating it.

2. THEY HAVE A MOOD DISORDER THAT ISN'T UNDER CONTROL

OCD sufferers may be pursuing appropriate treatment, but be waylaid by a mood disorder. If they're experiencing a major depressive episode, their mood is depressed or they have lost interest in nearly all activities, according to DSM-IV. It may be a reactive depression caused or exacerbated by living with OCD, or a biological depression that persists even as your OCD improves, said Dr. Penzel.

They may be stymied by crushing fatigue, which makes even the smallest effort seem impossible. They may lack motivation due to extreme negative thinking, believing that they will be unsuccessful in treatment, that they do not deserve to recover, or that nothing can help them, he said.

At the other end of the mood spectrum, sufferers who are experiencing a manic episode, will display, according to the DSM IV, "an abnormally and persistently elevated, expansive, or irritable mood" which may be accompanied by inflated self-esteem or grandiosity, a decreased need for sleep, a pressure to keep talking, flights of ideas, increased activity or even agitation, or excessive involvement in pleasurable activities with a high potential for negative consequences. Some of these sufferers may have impulses to throw their medications away as a result of feeling "too good," as if they have suddenly been cured without having done the necessary therapeutic work, noted Dr. Penzel.

In either case, patients need to stabilize their mood disorder with medication and therapy so they have the motivation, energy and persistence to follow through on treatment.

3. THEY'RE GETTING THE WRONG TREATMENT

Cognitive-behavioral therapy (CBT) and antidepressant therapy are the treatments of choice for OCD, said Dr. Penzel. He said he has not seen scientific evidence supporting other treatments, although individuals may cite success with one or more of them. Some of these the alternative treatments that have been used for OCD but not extensively researched include relaxation training, biofeedback, hypnosis, diet changes, homeopathy, psychoanalysis or other non-specific talk therapy, and EMDR (eye movement desensitization reprocessing).

4. THEY'RE NOT GETTING COMPREHENSIVE TREATMENT

Dr. Penzel cautions that even where people have gotten a proper diagnosis and CBT treatment, they may still "get watered down assignments that don't sufficiently challenge their symptoms."

- Cognitive-Behavioral Therapy

Assignments involve a behavioral component – exposure and response prevention – as well as a cognitive component – "recognizing the illogical thinking of your OCD," according to Dr. Penzel.

- Medications

Medications, specifically the SSRIs, such as Prozac and Zoloft, or the older tricyclics, such as Anafranil, can help. He said there is some scientific evidence suggesting some benefit in the B vitamin inositol, and uncontrolled evidence showing promise in the herb St. John's Wort. But, he added that the potency of commercially available brands of this herb can be unreliable and may vary widely, even within the same brand.

- Life balancing

"Health comes from a state of balance – work, school, volunteering, and helping at home; exercise; sleep; eating well, and socializing," said Dr. Penzel. People with OCD benefit from reducing the extremes of stress and excessive free time.

5. THEY'RE GETTING WEAK AND INEFFECTIVE TREATMENT

Dr. Penzel cautions that even where people have gotten a proper diagnosis and CBT treatment, they may still "get watered down assignments that don't sufficiently challenge their symptoms."

"I'm an industrial strength therapist," said Dr. Penzel. "You have to be to get the job done. You must experience anxiety up to the level you can tolerate and stay with the anxiety (until you habituate to it) Every week I want you to know you have done something better than the week before. Warm, fuzzy therapists don't challenge the patients enough."

This doesn't mean "rocking and socking people with their anxiety at a level they can't tolerate," according to Dr. Penzel, but finding assignments that are demanding enough to produce change. They also need cognitive therapy that "challenges the illogical in their own thinking."

6. THEY DON'T ACCEPT THAT THEIR OCD IS A PROBLEM

To succeed in treatment, said Dr. Penzel, "sufferers need to accept that:

- They have OCD
- It's a chronic problem like asthma or diabetes
- They will never "perfect" their OCD
- They cannot keep on compulsively protecting themselves and others and still recover
- There are tasks they will have to accomplish on their own, in order to recover. The only way out is through, not around (the symptoms)."

7. THEY'RE SUCCUMBING TO LOW-FRUSTRATION TOLERANCE

"The 'shoulds' that frequently accompany low frustration tolerance are:

- I should not have to work hard at getting the things I want – these things should come easily to me.
- I should never have setbacks, but always make continual progress.
- Getting recovered should happen very quickly.
- Treatment for my symptoms should not make me uncomfortable in any way. and, above all, should not make me anxious."

Added Dr. Penzel, "It's like saying you should get surgery without getting cut or getting stitches."

8. THEY'RE BEING SABATOGED BY OTHERS

Family members and friends are profoundly affected by a loved one's OCD. They may be drawn into the sufferers' pain and rituals, make decisions for them, take over responsibilities. When the sufferers begin to get better, loved ones react in different ways – not all helpful.

Certain kinds of "help" do not help, said Dr. Penzel. They include:

- Intentional sabotage. "In one case, the sufferer's husband undermined her progress because he made all the family decisions and he liked it that way. His temper got worse and he made nasty comments."

Impatience. Family members become invested in seeing rapid progress and get too invested in each step of the therapeutic

journey. Someone overcoming a contamination fear may be able to "open a door knob without a paper towel" yet a family member might wonder why the person cannot make even more progress.

Dr. Penzel noted how much family members often suffer in watching and responding to loved ones with OCD. Nevertheless, he encouraged family members to step back and allow sufferers to do what they have to do on their own, even if they have occasional lapses, or even if they lose their momentum and quit altogether.

9. THEY'RE COMFORTABLE IN THEIR DISCOMFORT

"They are living with their symptoms full blast, with multiple compulsions, and everyone else has to accommodate their symptoms. Being a patient has become their full-time job," Dr. Penzel said. Maybe they are suffering from one or more of the other eight obstacles, such as severe depression, inadequate medication, or simply feeling demoralized by several failed treatment efforts. The bottom line is that they are not willing to get help and do the work they need to do to get better. Until they do, no one else can make them better. Dr. Penzel encourages family members not to take responsibility for their loved ones' recovery. If the OCD sufferers live at home, he said, family members can make staying there conditional on their continued efforts to get better. Otherwise,they can live in community-supported housing until they are ready to return to doing the work to improve.

Despite those who are not ready or able to sustain the work to get better, many sufferers can and do get better, even after multiple tries. The woman who lived with OCD for several decades was successfully treated by Dr. Penzel. "I don't like the terms 'refractory OCD' (unremitting symptoms) or 'treatment resistant,' (not responsive to therapy)," said Dr. Penzel. Many people given those labels could succeed under the right conditions. "The worst thing is to take hope away from you."

Success depends upon an OCD sufferers' proper diagnosis, treatment plan, and own effort. So Dr. Penzel's elderly patient lived over four decades with the fear of being contaminated by others. "She didn't know what it was or that anything could be done about it," said Dr. Penzel. Then one of her daughters read an article about OCD that described her elderly mother's symptoms. "Actually, it went rather quickly, once she started working on it. She was very diligent about her doing her [ERP] homework," said Dr. Penzel. And her life changed.

Laurie Krauth, MA, is a psychotherapist in Ann Arbor, Michigan, treating OCD and other anxiety disorders. She can be reached at LKrauth@comcast.net or through her web site, www.LaurieKrauth.com. She is also on the Advisory Board of the OC Foundation of Michigan.

Facing Fears

(continued from page 3)

support. Symptom specific groups allow people to discuss issues that they may not feel comfortable discussing in a larger group context with others that are not experiencing those symptoms. In these groups it is not uncommon to hear people say that for the first time they have met someone struggling with issues just like them and were able to face issues of shame or embarrassment. Some groups focus on teaching coping strategies to supplement ERP tasks such as cognitive therapy or affect management (distress tolerance). Yet other groups focus on methods to maintain motivation, relationship issues relevant to OCD struggles, relapse prevention, support during transition, support for completing behavioral assignments given within the skills groups, and teaching ways to generate small manageable ERP goals above and beyond ERP tasks already established with the behavior therapist. The first group in the morning helps people track daily appointments and personal goals, and the last group of the day offers a check-in and support regarding daily goals. Outside the OCD Institute, there are not as many OCD support groups available for people as I would like to see. Groups can be a wonderful source of treatment and support. Check to see if there is an OCD support group near you that can help reinforce your efforts to fight your OCD.

There are many modes of treatment intervention, all of which can be beneficial in the effort to reduce OCD symptoms, regain quality of life and increase the possibility of pursuing life goals. Typically, individual outpatient treatment is once a week for a 50 minute session. Occasionally, outpatient treatment offers 80 minute sessions once a week. Some locations offer home-based sessions. Group treatment is typically once a week for 80 minutes. Intensive outpatient treatment varies across locations and can meet from 2 to 5 times a week for 2-4 hours per meeting. Longer sessions provide more opportunity to practice exposure and response prevention tasks. Day treatment typically involves coming to a program 5 days a week for 5-8 hours a day and includes a combination of individual therapy and group therapy. Residential treatment requires living at the treatment facility and includes both individual and group therapy.

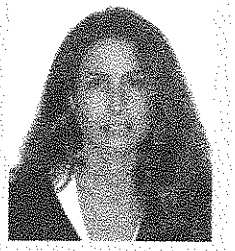
Regardless of which treatment modality you choose to pursue, as you work on facing your fears to reduce OCD symptoms, it is important to hang onto your life goals and dreams. OCD treatment is not just about reducing your emotional reactivity to feared situations and reducing your rituals and avoidance behavior. Treatment is also about getting back in touch with who you are beyond your OCD symptoms. Therapy can help you regain your life and self-worth. There are lots of ways to get support to do it. The OCF has Referral Lists that you can ask for. So, face the fear, do it often and get support.

Dr. Osgood-Hynes is the director of Psychological Services and Training at the OCD Institute at McLean Hospital.

Sixth Research Award Given to Dr. Fama

The OCF was able to give another OCF Research Award this year. The sixth 2005 OCF Research Award was awarded to Jeanne M. Fama, Ph.D., for her study, *"Critical sessions and sudden gains with cognitive therapy for OCD: Identifying mechanisms of change."*

It is Dr. Fama's hypothesis that research into the mechanisms by which cognitive therapy effects change will give clinicians and researchers insight into how to modify cognitive therapy (CT) to increase its effectiveness. According to Dr. Fama, "there is some evidence to suggest that CT works at least in part, by its hypothesized mechanism of change, namely, by eliciting and modifying the maladaptive beliefs thought to engender and maintain OCD symptoms."



Dr. Jeanne Fama

In doing her research on this issue, she will be monitoring by session symptom severity. It is her belief that by doing this she will be able to identify patients who make sudden gains following a critical session. In reviewing audiotapes of patient sessions, Dr. Fama has learned that patients evidenced more cognitive change in critical sessions than in sessions proceeding critical sessions in a course of treatment.

This project, according to Dr. Fama, will track whether or not patients who experience "sudden gains" will have a better treatment outcome than patients that do not experience sudden gains in the therapy. She believes that she will be able to show that "critical sessions" will be characterized by greater cognitive change and that sudden gains will precipitate an "upward spiral effect" and positively impact subsequent in-sessions gains.

Dr. Fama is a Clinical Fellow in Psychology in the Department of Psychiatry at Massachusetts General Hospital/Harvard Medical School and was recently awarded her Ph.D. in psychology from Harvard University.

Bulletin Board

(continued from page 2)

obsessive-compulsive disorder (OCD). To be eligible, you must: have OCD, be between 18 and 65 years old, be able to commute to the Boston area, be able to participate for 10 weeks, not be pregnant or breastfeeding. If you are interested in this study and believe you are eligible, please contact Dr. Ulrike Buhlmann at (617) 726-5374 or e-mail her at ubuhlmann@partners.org.

Do You Have Obsessive-Compulsive Disorder?

Do you still have symptoms?

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

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

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

Research Study on the Genetics of Obsessive-Compulsive Disorder (OCD)

Do you have obsessive-compulsive disorder? We are doing a research study to find genes associated with OCD. We are looking for children and adults with OCD and their family members. Family members are welcome to participate whether or not they now or in the past have experienced OCD symptoms. Family members who can participate include any biological relatives of the person with OCD, such as parents, siblings, children, grandparents, aunts, uncles and cousins.

Your involvement in this study and any information given will be kept confidential. Participants will be offered a modest cash honorarium to compensate for time spent participating in this study. This study is being conducted by Drs. Paul Arnold, James Kennedy and Peggy Richter, at the Centre for Addiction and Mental Health in Toronto, Ontario, Canada, and is part of a larger project including centers in Michigan and Florida. Our research was partially supported through the generosity of the OCF in the form of an OCF Research Award.

For more information, please contact our research coordinator, Eliza Burroughs at
Tel: 416-535-8501, ext.4829
Email: eliza_burroughs@camh.net
Address: 250 College Street
Toronto, Ontario, M5T 1R8, Canada

University of Florida Research Study

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

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

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

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

Are you an African-American Suffering from OCD?

If you have ever been diagnosed with Obsessive-Compulsive Disorder or suspect that you might have it – WE NEED YOU!

Are you:
- An African-American who grew up in the United States?
- Between the ages of 18 and 50?

If your answers are "yes," in just ONE HOUR you can receive $25 for your help.

It's as simple as filling out some questionnaires (by mail) and answering a few questions about your tendency to worry or doubt (over the phone).

For more information or to sign up for this study, contact Emily at (814) 937-9438 or send an e-mail to: anxietystudy@peernom.org

A Family Research Project

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

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

Where? In your own home. No hospital or school visits are necessary.

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

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

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

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

Your participation will help us understand family functioning in children and adolescents with OCD.

Principal Investigator: Marco Grados M.D., M.P.H.

Pediatric Obsessive-Compulsive Disorder

Is Your Child's OCD Medication Not Helping?

If your child (ages 7 to 17 years old) currently has moderate to severe Obsessive-Compulsive Disorder (OCD) and has not benefited from his or her present medication, your child may be eligible to participate in a research study

at the National Institute of Mental Health in Bethesda, MD. We are investigating adding riluzole, an FDA-approved medication to the child's current medication(s). We expect that riluzole will decrease obsessive-compulsive symptoms.

Participants will have a day-long assessment that includes comprehensive psychiatric, physical and laboratory evaluations. Children will then have follow-up evaluations every two weeks for 12 weeks, and again at 4, 6, 9 and 12 months, so they must live within a reasonable commuting distance of Bethesda, MD. Children should continue to be followed by their own physicians while in this study. Research evaluations are free of charge and most travel expenses to the NIH are provided.

The name of this study is "An Investigation of the Efficacy in Childhood Obsessive-Compulsive Disorder of Riluzole: An Antiglutamatergic Agent." Dr. Paul Grant, MD, a board-certified child psychiatrist, is the Principal Investigator.

For further information, please contact Ms. Maggie Pekar, M.A., or Ms. Lorraine Lougee, LCSW-C, at 301-496-5323; or email OCDNIMH@intra.nimh.nih.gov

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

RESEARCH STUDY - OBSESSIVE COMPULSIVE DISORDER

DO YOU HAVE OBSESSIVE COMPULSIVE DISORDER (OCD)?

- Have thoughts or feelings that don't make sense but still make you feel bad?
- Have to do things over and over again?
- Wash excessively or avoid touching things for fear of contamination?

This is a randomized, double-blind study in which there is a 1 in 2 chance of being assigned to either active medication and placebo or two active medications.

UCLA Anxiety Disorders Program is looking for people with OCD to take part in a study that is providing:

- Diagnostic Evaluation
- 18-30 weeks free medication for OCD

Study conducted by Alexander Bystritsky, M.D., Ph.D.
UCLA Anxiety Disorders Program
UCLA Neuropsychiatric Institute
For more information, call (310) 794-1038

PLEASE GIVE TO THE OCF RESEARCH FUND

Call for Conference Presentations

The 13th Annual Obsessive Compulsive Foundation Conference is scheduled for July 21 through 23 at the Hilton Hotel, Atlanta, Georgia. Anyone interested in putting on a seminar, workshop, presentation or support group must submit his/her presentation proposal to the Conference Committee by February 3, 2006.

Past OCF conferences have offered workshops and presentations on the etiology of OCD, the Genetics of OCD, treatment for symptom specific OCD, compulsive hoarding, family therapy, treatment resistant OCD, and new and emerging research. There have been GOAL support groups, parent support groups, workshops for children, adolescents, parents, caregivers, sufferers and mental health professionals.

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

For more information, please contact Jeannette Cole, deputy director, at 203.401.2069 or e-mail her at cole@ocfoundation.org for an application.

SUBMISSION DEADLINE IS FRIDAY FEBRUARY 3, 2006.

Behavior Therapy Institute

Sign Up For The Obsessive Compulsive Foundation's Behavior Therapy Institute

February 11-13, 2006

at the

University of California, Los Angeles

Los Angeles, CA

The BTI is a three-day intensive training course in cognitive-behavior therapy for mental health professionals who are treating individuals with obsessive-compulsive disorder and the OC spectrum disorders. It features:

- Direct clinical instruction from leading OCD experts
- Small faculty-to-student ratio
- Development of actual treatment plan
- Follow-up phone consultations

BTI Faculty

Eda Gorbis, Ph.D.
John Piacentini, Ph.D.
C. Alec Pollard, Ph.D.
Gail Steketee, Ph.D.
Gerald Tarlow, Ph.D.
Sanjaya Saxena, M.D.

For more information, contact OCF Deputy Director, Jeannette Cole, at (203) 401-2069 or e-mail her at cole@ocfoundation.org

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

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

BTI Attendee

Your Thoughts

(continued from page 9)

new and better life! I enjoy smoother work and play behaviors, new interests, and enhanced awareness to some joys of authentic life. Basically, my recovery is successful because I accept uncertainty as a part of life with much more ease now.

From B.

Dr. Grayson, I am a 43 year old woman, I have been struggling with OCD since the age of 17. Over the years, my illness has manifested itself with checking and both sexual and violent intrusive thoughts. I am a special education paraproffessional at a high school. In response to your question I haven't accepted uncertainty as a part of my life. It really bothers me whether the obsessive-compulsive behavior is concerned with an appliance, the stove, taking meds, or even thoughts about harming others. I still struggle with doubts about my sexual behavior in regard to my nephews, students and staff. I would really like to be certain that these things haven't happened. My behavior therapist says that I have a very high level of doubt. I am also quite emotionally reactive to the OCD. At some other times I have to sit with the doubt. However, this can be extremely difficult for me and other OCD sufferers. That is when the rituals, mental ones, come into play, or I try to use cognitive therapy or coping statements. I guess I'm more on the side of not accepting the uncertainty as a part of my life. This means to me, that I do need to work on this to allow myself to get healthier. It causes me an insurmountable amount of anguish in my everyday life. One also needs reassurance which I am aware can be detrimental to one's recovery and progress. In response to how has this affected my recovery, it probably has not allowed me to move forward in my life, profession, family, and social life more easily. It probably also hinders my chances of recovery. I have a very hard time with uncertainty. Many times it feels like a double life. I am loved by all family members, friends, and fellow coworkers. On the other side, I'm struggling with this debilitating disease. Everyone has some degree of uncertainty in his/her life, I just need to try and find productive ways to deal with my high levels of uncertainty.

From K.

I've always been some who likes to be in control in life and my OCD. In regard to my recovery, I kept thinking that if I could just work hard enough, master the behavioral techniques just right that ultimately I could "cure" myself of the disorder. I'm finally learning that being in recovery means accepting uncertainty. While there is treatment, there is no cure. Some thoughts may always be with me. Accepting that possibility has allowed me to embrace my assignments, doing them not to rid myself of the thoughts but to reduce my anxiety about them which is really the goal. Finally, I'm working to give up such tight control over the rest of my life and enjoying the twist and turns of my journey. It's allowed me to enjoy my husband and baby even more and treasure each moment life brings.

From J.

I thought I'd respond to the "Thoughts Revealed" section of the last newsletter related to uncertainty.

1. I have accepted uncertainty as an inescapable part of life, and this makes the "duties" of life much more tolerable.

2. This acceptance means that whenever I sense that I am overdoing the checking of my work, or putting an "extra" effort in making "certain" that my work is "perfect" I challenge the belief that these exhausting efforts will have a positive effect on the end result. Usually I conclude that the compulsions are preventing me from completing my work and going onto other endeavors. While refusing to continue the compulsive pursuit of certainty/perfection leads to an inital increase in anxiety, the anxiety is temporary, and a "good enough" job is completed with less effort.

3. The realization and acceptance that uncertainty in life must be accepted and can never be eliminated has helped give me with the strength to not give into compulsive behavior.

DR. GRAYSON'S RESPONSE

I want to thank everyone who responded for sharing their thoughts. When I posed this question, I noted that with OCD's many different presentations, the common factor that makes all of these manifestations a single disorder is that every sufferer has an areas in which s/he feels the need to be absolutely one hundred percent certain. And the resulting problem is that absolute certainty does not exist; there is always some slim, infinitesimal chance that the seemingly impossible may occur. OCD is not the inability to be certain; it is the desperate anxious attempt to achieve the impossible, to be absolutely certain.

What strikes me most about the responses is how they demonstrate the connection between OCD and non-OCD behavior. D. writes of an overly judgmental family that believes every problem that arises is someone's fault and that someone should be blamed. A. writes to say that while intellectually she can accept uncertainty, she's having difficulty with emotional acceptance. Sufferers and non-sufferers all accept the logic that achieving absolute certainty is impossible. And everyone has difficulty with emotional acceptance in some areas. It is part of human nature to want to believe that all problems are solvable and/or avoidable. And it is true, but only in theory. The reality is Murphy's Law – something will always go wrong. We try to teach our children to be safe and not to do anything dangerous. But they do. And if they don't, then that's also a problem, because we also tell them that it is important to take risks. And that is the issue: few rules, if any, work all of the time.

For example, in quality control work, factories don't demand 100% quality. And the reason is simple. A high degree of quality 90 to 97% is profitable and makes a good product. But the cost of reaching 100% makes a great product at a cost that no one can afford. Do you want to spend $200 for a piece of furniture that has a one in 20 chance of having a flaw, so that you will have to return and exchange it? Or are you willing to pay $10,000 for the same piece, but you definitely won't have to return it (assuming there is no damage in shipping, although we could add another few thousand to cover this)?

So there is no perfection. One day I was working with a patient in my office, who despite my urging checked under the couch cushions before leaving my office. He found a quarter and triumphantly handed it to me as proof that this checking was worthwhile. I gave it to him and told him to keep it, to stare at it and to remember that this is the fruit of his checking, that his lost years, lost jobs, failed relationships, the public humiliation of having others see him circle a car five times have all led to this twenty-five cents. Twenty-five cents for a life.

There is no perfection or certainty. But if we can learn to get up and move forward, we can learn to be confident enough to handle all that life will throw at us. As I have said before, freedom from OCD means learning to live with uncertainty. And although each of the respondents was at a different point in being able to accept uncertainty, they all had made some progress and they like all of you can keep learning until they reach the point of being able to enjoy, in D.'s words, "good enough."

NEXT ISSUE'S QUESTION:

When someone has OCD, it affects the entire family. Demands may be placed upon family members. They want to help, but they don't know how. Some of you have families that have been very helpful, others tell me about families that just don't understand. With this in mind, my question has two parts:

What would you like your family to understand most about your OCD?

What could your family do that would best help you with your OCD?

Compliance with Solicitation Regulations

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

A copy of OCF's most recent financial report is available upon request and may be obtained at no cost by writing to OCF at P.O. Box 9573, New Haven, Connecticut 06535-0573 or by contacting its Executive Director at (203) 401-2074. If you are a resident of one of the following states, you may obtain information directly as follows: Florida: A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE FLORIDA DIVISION OF CONSUMER SERVICES BY CALLING TOLL FREE WITHIN THE STATE (800) 435-7352, OR (850) 488-2221 IF CALLING FROM OUTSIDE FLORIDA. OCF's registration number in Florida is CH8507. Maryland: A copy of the documents and information submitted by OCF pursuant to the Maryland Charitable Solicitations Act are available for the cost of copies and postage from the Secretary of State, State House, Annapolis, MD 21401, Telephone (401) 974-5534. OCF's registration number in Maryland is 5015. Mississippi: The official registration and financial information of OCF may be obtained from the Mississippi Secretary of State's office by calling (888) 236-6167. OCF's registration number in Mississippi is C1143. New Jersey: INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING (973) 504-6215. OCF's registration number in New Jersey is CH1461800. New York: A copy of the most recent annual report filed by OCF with the New York Secretary of State may be obtained by writing to Charities Bureau, 120 Broadway, New York, NY 10271, Telephone (518) 486-9797. OCF's registration number in New York is 66211. North Carolina: A COPY OF THE LICENSE TO SOLICIT CHARITABLE CONTRIBUTIONS AS A CHARITABLE ORGANIZATION OR SPONSOR AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DEPARTMENT OF HUMAN RESOURCES, SOLICITATION LICENSING BRANCH, BY CALLING (919) 733-4510. OCF'S REGISTRATION NUMBER IN NORTH CAROLINA IS SL002059. Pennsylvania: A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling toll free within Pennsylvania (800) 732-0999. OCF's registration number in Pennsylvania is 15687. Virginia: A copy of the OCF's most recent financial statement is available upon request from the State Division of Consumer Affairs in the Department of Agriculture and Consumer Services.
Washington: Additional financial disclosure information may be obtained by contacting the Secretary of State toll free within Washington at (800) 332-GIVE. OCF's registration number in Washington is 6363. West Virginia: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, West Virginia 25305.

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