

FROM THE FOUNDATION

Join Us in Minneapolis for the 16th Annual OCF Conference

By Michael Spigler, OCF Program Director



OCF is proud to announce that its 16th Annual Conference will be held August 7-9 at the Hyatt Regency in Minneapolis, Minnesota. Known as the “City of Lakes,” Minneapolis is home to many exciting attractions including the nation’s largest shopping and entertainment complex, the Mall of America. We are happy to bring the event back to the Twin Cities area, which was the host of the first ever Annual Conference in 1994.

As the only national conference dedicated to OCD and OC Spectrum Disorders, the Annual Conference provides a wide range of topics for everyone in the OCD community – adults and children with OCD, their families, treatment providers, and researchers.

People with OCD and their loved ones have always been the primary focus of the Conference and this year’s program will feature presentations on nearly every aspect of OCD and its treatment, including perfectionism, scrupulosity, contamination, and intrusive thoughts. Also, because parents and families play such an important role in the treatment of OCD, this year’s schedule features a mini-program of presentations specifically designed for family members.

Our evening programs also include more than ten support groups, as well as Jonathan Grayson’s 9th Annual OCF Virtual Camping Trip. This experiential workshop gives participants the chance to experience the exhilaration of conquering OCD fears in a group. This is an extremely popular workshop that has helped hundreds of people over the years – don’t miss it!

For the children and teens who attend, we will once again offer Art and Activity Rooms. These rooms will be staffed by Jenifer E. Waite Wollenburg and Katy Peroutka, art therapists from Rogers Memorial Hospital. The therapy rooms will offer a variety of activities such as

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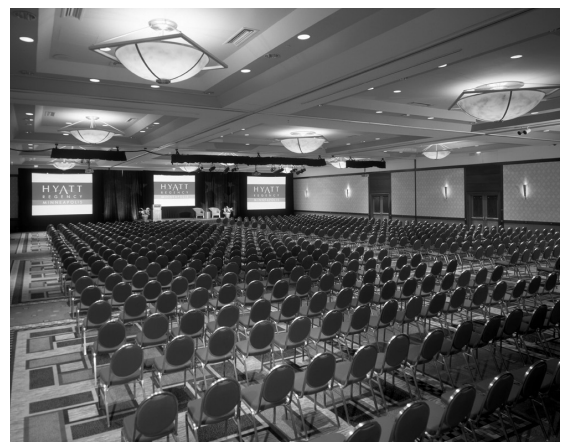
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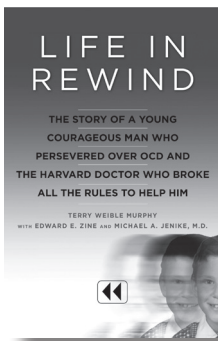
(Join Us in Minneapolis, continued)

jewelry making, social games, and the creation of the Annual OCF Conference Mural. Adolescents (13 and older) and children (6-12) will have many chances to socialize and make friends who they can keep in touch with after the Conference.

There will also be several sessions targeting treatment providers. Physicians, psychiatrists, psychologists, social workers, professional counselors, and nurses in attendance can earn up to 22.5 continuing education credits. These providers can also benefit from the optional pre-conference Advanced Behavior Therapy Training Institute, featuring Dr. Michael Twohig. Dr. Twohig will cover Acceptance and Commitment Therapy (ACT), which teaches individuals with OCD to step back from and make room for inner experiences such as obsessions and anxiety. The aim of the treatment is to encourage individuals with OCD to continue to do what is important to them while the obsessions and anxiety are present. These skills may be useful for many types of OCD and can be used on their own or along with other behavioral procedures. Although Dr. Twohig's Advanced Behavior Therapy Training Institute is for professionals only, user-friendly presentations on ACT will also be made available throughout the conference that will be designed for individuals with OCD and their families.

Back by popular demand, this year's expanded Poster Session will again highlight current and innovative research into OCD and OC Spectrum Disorders. These posters give researchers the chance to interact with attendees in a relaxed and informative setting. In addition, we will be recognizing three outstanding poster submissions this year by acknowledging these researchers at the conference and presenting them with a travel award for the following year's conference.

To help keep you motivated and to continue your learning long after the conference, Mimi and Bob Doan will again be available to you in the OCF Bookstore to recommend titles and topics that meet your needs.



Last but not least, we are excited to announce that this year's Keynote Address will feature Dr. Michael Jenike, Terry Murphy, and Edward Zine. This Keynote Address will detail Dr. Jenike's work helping Ed Zine free himself from a trapped world of endless repetitions and rewinding, counting and checking rituals. Terry Murphy chronicles the years during which Dr. Jenike would meet with Zine in his basement and how they came together with Terry to write "Life in Rewind," which will be published on April 14 by HarperCollins.

At the Keynote Address, the OCF will honor Dr. Michael Jenike with a Lifetime Achievement Award. Dr. Jenike, Chairman of the OCF's Scientific Advisory Board and member of the OCF Board of Directors, has been a longtime supporter of the OCF's mission. Dr. Jenike's leadership and commitment to the entire OCD community has directly improved the lives of thousands of people affected by OCD and their families. We hope that you'll join us in honoring Dr. Jenike!

To view the entire conference schedule and to register online, please visit www.ocfoundation.org.

OCD NEWSLETTER

The OCD Newsletter is published by the Obsessive Compulsive Foundation, Inc.

President, OCF Board of Directors: Diane Davey, R.N., M.B.A.
Chairman, OCF Scientific Advisory Board: Michael Jenike, M.D.
Executive Director: Jeff Szymanski, Ph.D.
Newsletter Editor-in-Chief: Rebecca L. Cyr
Newsletter Editors: Michael Spigler, CHES & Jeff Szymanski, Ph.D.

Phone: (617) 973-5801
Fax: (617) 973-5803
Email: info@ocfoundation.org
Website: www.ocfoundation.org

The Obsessive Compulsive Foundation (OCF) is a not-for-profit organization whose mission is to educate the public and professionals about OCD in order to raise awareness and improve the quality of treatment provided; support research into the causes of and effective treatments for OCD and related disorders; improve access to resources for those with OCD and their families; and advocate and lobby for the OCD community.

DISCLAIMER:

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

Message from the President



Dear Friends,

First of all, I would like to thank all of you who have contributed and are still contributing to our Year-End and Research Campaigns. In these difficult and uncertain economic times, I know that charitable giving can sometimes take a back seat to other needs. We are so grateful for your ongoing contributions and support of OCF programs and research. Your donations are the cornerstone of all that we do. We simply could not continue without you!

Our research proposal review team, headed by Dr. Sabine Wilhelm at Massachusetts General Hospital, is in full swing reviewing our 2009 proposals. We received a record number of submissions this year and we will be able to

announce our grant recipients on our website later this spring and in the next issue of the OCD Newsletter. It is so gratifying to see the quality of the submissions that we have received. I'm sure that the eventual recipients will significantly impress you all!

The planning for this summer's conference in Minneapolis is also well under way. Following up on last year's hugely successful conference in Boston, we are again looking to raise the bar this year for both consumer and professional attendees. Given the success of the Research Poster Session last year, we will be offering one again this year with expanded hours. It is clear that OCD research is of enormous interest to everyone, both consumers and professionals alike! Also, to highlight the research funded by your generous contributions to the OCF Research Fund, we will be having a special presentation by previous OCF grant recipients to report on the outcome of their research. For those of you who have attended the conference in the past, you know that it is an amazing and incredibly rewarding experience. If you have never attended, I strongly encourage you to do so! It is THE place to get the most up-to-date information about OCD treatment and research.

OCF staff has also been in the process of updating and redesigning our informational brochure on OCD. This updated version includes information about OCD, treatment options, and information for parents and families. Many thanks to Denise Egan Stack, Michael Stack and an anonymous donor for their generous contributions to help underwrite some of the costs of this new brochure!

In the coming months, I also hope you will check out our new website due to "go live" sometime in May. Our office team has been hard at work making changes to the site to make it more user-friendly and easier to navigate with new search tools!

As you can see, 2009 has gotten off to an extremely busy start for us all. Again, we thank you so much for your ongoing contributions and support.

Diane Davey

President, OCF Board of Directors

OCF to Rename its OCD Newsletter!

The OCF is planning to rename this newsletter, and we would love to hear your ideas! If you have a suggestion for a new name for our quarterly publication, please email it to editor@ocfoundation.org with the subject reading, "New Newsletter Name," or mail it to:

Editor-in-Chief
O.C. Foundation
P.O. Box 961029
Boston, MA 02196

Be sure to include your name and mailing address, because the creator of the winning title will receive a \$50 gift card to Amazon.com!

FROM THE FRONT LINES

Dancing Queens

By Mary Lou Shields

Mary Lou Shields is the author of Sea Run: Surviving My Mother's Madness, a memoir of her five-year psychoanalysis at McLean Hospital under the aegis of the Boston Psychoanalytic Society and Institute.

What a wonderful opportunity for them.

That was my first response last July when my daughter Liz told me that she had signed up for the three-day OCF Annual Conference at the Renaissance Waterfront Hotel in Boston. For them. Won't it be great, I thought to myself, "they" being my daughter, granddaughter Madison, and son-in-law Russ. (Madison, age nine last summer, has been in treatment for OCD since she was six or seven.)

By August 1st, when I found myself on the Red Line train at 5:45am on my way to join Liz and Madison for the opening day of the conference, I was hoping that the conference would be a breakthrough for them.

Even though Liz lives in Boston, she took a room at the Renaissance so that she and Madison could easily be on time for the 8am Parents and Children Orientation, co-chaired by Patti Perkins and Katy Peroutka.

From the moment Patti had us move the chairs from theater-style to a circle, she created a welcoming atmosphere. Needless to say I was unaware that Patti is a co-founder of the OCF and an inspiration to all. I and my little family could not have been in better hands but, at the time, I didn't know this. More than a few of us were nervous and shy but by deftly including us all, the young people took center stage in a natural way.

Over the next three days as the conference continued, I would learn that OCD is frequently part of a constellation of behaviors, which can include hoarding and relying on things to develop a sense of self. Thanks to the excellent speakers and the overall cordiality of the attendees, I gradually moved from observer to participant. By seeing myself on the OCD spectrum, I unwittingly moved closer to my daughter and granddaughter.

As I learned about thoughts, behaviors, and feelings along "the perfectionist triad," I began to understand what Liz had been telling me about my granddaughter's cognitive behavioral therapy.

I understood how important it was for Madison to learn to outwit OCD. I saw how my own impatience with Madison thwarted some of her therapy. Understanding my past mistakes created the space for new skills.

As I learned about hoarding and clutter, I realized that I leave papers and files stacked up on my desk and my shelves because I'm afraid I'll lose them if they're out of sight. I'm not sure if this would ever be diagnosed as visual and spatial fugue but, as I began to see my own traits verge on what's called a disorder, I saw myself more like Madison. I began to wonder what else I had missed.

I think it's Dr. Edward Hallowell, author of *Driven to Distraction*, who said, "I think of ADHD as a trait, not a disability, and the people who have it as having a difference - not a disease."

In Dr. Roberto Olivardia's workshop, I learned that ADHD can be a co-morbid disorder with OCD and, for the first time in my life, I saw both tendencies in myself. Dr.

Olivardia encouraged us to find the positive features of ADHD such as the ability to multi-task and think creatively. "People with ADHD are drawn to their passion. They have to do what they have to do," said Olivardia, a description that describes me to a tee.

Whereas I had known about my ADHD tendencies, I hadn't ever thought I had any OCD traits so, for me, Dr. Olivardia's seminar proved to be the most revelatory. For example, I never connected my inflated sense of responsibility with my obsessive attention to detail. Both can coexist alongside an obsessive commitment to complete a project. In the larger sense, these might be considered positive aspects of OCD but, nonetheless, these traits have long bogged me down.

In the pool later that afternoon, we all took a break and I helped chaperone the young girls who by then had become friends, Emily, Rielly, Mimi, and Madison.

On Day Three, the girls all went to Virtual Camp and I stationed myself outside the door so that Liz and Russ could go off to their own workshop. Can you imagine my surprise when kids in groups burst from the seminar room searching for trashcans into which they could put their hands?

"Where are you going now?" I asked Madison (who calls me Louie.)

"Oh Louie," she answered as she and the others rocked with laughter, "we're going to sit on the bathroom floor to prove no one dies."

Off they all went and I had been introduced to ERP, or Exposure and Response Prevention.

By the last day of the conference, I was drawing more inferences about myself than about Madison. I also connected some missing behavioral links to my whole family.

Without awareness, people can't change. Without resilience, change can be difficult. Watching the girls in their brightly colored clothing as they romped on the carpets of one of Boston's newest waterfront hotels, I saw not their shared "disorder" but their shared zest for life and friendly affection.

"A life changing event for Madison," said Liz.

Perhaps for me, too?

If our identity and confidence depend on the stories we tell ourselves about who we are, how great is it that, at age nine, Madison has a new story to tell herself? And I, the author of two memoirs, one published and another, not quite, am developing a new story to tell at age seventy-three.

On the last night of the conference I was simply too tired to stay on for the wonderful party with its shiny decorations, fabulous buffet, and loud, happy music. In the crowded ballroom, I bid my farewells to the score of *Mama Mia*. As I turned to blow a last goodnight kiss to Liz, the only ones on the dance floor were Rielly, Emily, Mimi, and Madison happily twirling to the strains of Abba's "Dancing Queen."

Back out on the Red Line Sunday night, I couldn't get either the song or the image of the girls out of my mind so, all the way home, I smiled and silently sang,

*See that girl,
Watch that scene,
Diggin' the dancing queen....*

Picturing You

by Margaret Eckman

Your picture haunts me,
caught in a photoclip next to my desk.

You're three, maybe four,
leaning out your castle window,
blue eyes wide under
your blueberry hat (my favorite),
head tilted, like your smile,
so happy, so pleased, so proud
of your plastic palace.

This morning, years later,
you struggle
as you do each day
to battle the demon
that lurks by the sink
that attacks, right on schedule,
that knows your weakness,
that hisses its lies:
Wash more, you're filthy,
you'll never be clean.

You look so weary
as you fall into your chair
and ask for my help.
"You're clean," I tell you,
knowing I shouldn't get caught in the battle,
that my words reinforce the cycle of washing.

You turn with a sigh,
pull your cereal bowl close,
and lose yourself in the comics.

Then your dad arrives home
from his morning bike ride
with a treat, just for you,
from Starbucks, your favorite.
You're surprised, you're pleased,
your eyes widen: "Really? For me?"
And that sweet, crooked smile
breaks through the clouds,
a picture I'll keep for years to come.

FROM THE FRONT LINES

I Changed My Mind: Gamma Knife Surgery for Treatment-Resistant OCD

By Gerry Radano, LMSW

Gerry Radano was one of a handful of people chosen to receive Gamma Knife, a very rare experimental brain surgery for OCD, that enabled her to make a miraculous recovery. She wrote a book, Contaminated, My Journey Out of Obsessive Compulsive Disorder, to raise awareness of this neurological brain operation that gave her back her life. If anyone would like more information on Gamma Knife, you can go to www.freeofocd.com or contact the writer at gerryradano@aol.com.

At the age of five I knew exactly what I wanted to be when I grew up: a stewardess/flight attendant. Since I had always been strong willed and extremely determined, I held fast to that goal and at the age of 20 brought it to fruition. In addition to flying, I was just getting started as a real estate entrepreneur when I met my future husband Michael, an aspiring accountant. We seemed to have it all: a home in an affluent community, a thriving real estate business, we were financially very well off, had a busy social life, traveled extensively, we had a beautiful little girl and another baby on the way. Suffice it to say, we were living the American Dream.

However, during my second pregnancy our whirlwind storybook life suddenly was no longer looking at happily-ever-after. With my mother dying of cancer and my hormones raging, overnight I had gone from a force to be reckoned with to simply a wreck. I had somehow become obsessed with germs and contamination issues. I was terrified of just about everything in my life I came in contact with, including my husband and my child. I spent every waking moment washing, showering, spraying Lysol, changing my "contaminated" clothes, and suffering from panic attacks while crying over the devastation taking place, which I felt powerless to stop. I had developed a case of Obsessive Compulsive Disorder (OCD) tantamount to that of Howard Hughes in the film *The Aviator*.

After my son's birth, I became a veritable recluse. Despite a myriad of medications, countless therapist visits, hours of cognitive behavior therapy sessions, and 3 psychiatric hospitals, I was unable to function. I was told by numerous psychiatrists that I was incurable. After 10 years of battling with this invisible mental monster, I had lost everything that meant anything to me including my friends, relatives, career, my husband, and almost my children.

The one thing I never lost was my hope/belief that I would one day recover from this endless ocean of madness. And so I continued obsessively to pray each day that God would give me back my brain and my life. By chance, or what I call Divine Intervention, I found out about an experimental non-invasive brain surgery known as Gamma Knife (GK). The good thing about GK is that the prognosis for this procedure is remarkable: 50% very much improved, 30% moderately improved, and 20% slightly improved, or showed no improvement. On the bad side, however, at that time GK was only available at two places in the world, Rhode Island and Sweden, it cost \$30,000 (not covered by insurance), and you had to be approved by a fastidious review board in order to be considered for it.

Despite these caveats, a year-and-a-half later through much self-advocacy and the grace of God I was approved to have this rare procedure. I became the 32nd person in the US to receive GK. I was also the first person, again through obsessive perseverance and self-advocacy, to have it paid for by an insurance company. Miraculously, I was able to make a full recovery and take back my life.

A thumb-nail description of how the GK works is: Neurosurgeons use the Gamma Knife Machine to make 4-mm lesions. This is done by focusing 201 thin beams of cobalt-60, which emit gamma rays, at a target in the patient's brain. The target for OCD is two small groups of nerve fibers deep in the brain called the anterior capsule. These fibers connect areas of the brain that are thought to be involved in causing OCD. When these beams are focused, it allows the neurosurgeon to target an extremely small area in the brain and lesion/

damage it without affecting surrounding nervous tissue. It is this concentration of radiation that damages the tissue and forms a lesion, which can take anywhere from 3 months to a year to develop. These lesions are assumed to block the activity from the areas of the brain that are thought to be involved in causing OCD.

I had the GK surgery on November 10, 1999, a day I now celebrate as my new birthday, or as I like to call it my Brain-Birthday! Besides the birth of my two children, GK was the best thing that ever happened to my life. But my journey back to sanity and humanity did not take place overnight. For me, it took about 8 months for the lesions to develop and 4 *long* years after that to bring about this transformation, which I still look upon as a work in progress. Essentially GK gives people suffering from treatment resistant OCD the ability to “lower the volume” and begin to utilize the cognitive behavior and other therapies necessary to function again, or begin to take back their lives.

Since my life at that point had been completely ravaged by OCD and I had lost everything/body that had meant anything to me, I had to start over from ground zero. Basically what I did was put together a plan, which I simplistically entitled my “Take Back Your Life Plan,” and started writing down all the things I would have to do to bring this plan to fruition. These goals included: going back to school, doing volunteer work, getting a job, putting my ravaged house back together, losing weight (I had gained over 100 pounds from my medication), and most importantly reconnecting with all the people I had lost in my life at the merciless hands of OCD. Inspired by this motivational plan, I summoned up all the courage I could muster, put into play all the cognitive behavior therapy I had learned, and said *a lot* of prayers to find the grace to go forward.

And that is just what happened – I went forward. One by one, I was able to accomplish every goal on my very full plate and essentially put my life back together. As I said, it did not happen overnight, but literally took years of hard work and determination to reassemble all the pieces of my ravaged existence. Today, I have a very happy, stable and productive life. I was able to accomplish every goal on my list, including going back to school and earning a Masters Degree in social work. But without a doubt, my best accomplishment so far has been that of putting my marriage and family back together.

The first GK surgery for OCD in the US was performed over 15 years ago in the 1990s. Since that time only a handful - roughly 60 people - have had this procedure. While GK for OCD is still experimental, it is anticipated/hoped that the data for this research will be made public in the not too distant future and subsequently approved by the FDA. That being said, if it is approved, it will still take quite some time, probably years, before GK will achieve the level of being readily available to all those who need or want it, with health insurance companies being made responsible to cover the cost. I had my surgery done at Butler Hospital in conjunction with Providence, RI Hospital, which has been the main venue for this surgery in the US. It is also being done in South America and Sweden. Besides OCD, Gamma Knife is now being used for Epilepsy, Parkinson's, Depression, and Brain Tumors.

Today there are so many more available treatments, therapies, clinical procedures, medications, and research being done in the field of OCD than there was when I was first knocked down by OCD almost 20 years ago.



While GK still remains experimental and difficult at best to get, it is a good thing that a scientific technology like GK does exist for those 10-15% who are treatment resistant to OCD. I look forward to the day when everyone who needs or wants GK will be able to receive it. I am optimistic that with the recent transition in our government, research and technology will go forward even faster and all chemical brain disorders will in our lifetime go the way of Polio. At the end of the day, my ultimate hope is that the words “mental illness” and “OCD” will someday be eradicated to the point of being a distant memory or merely just a footnote in future medical journals and DSMs.

YOUTH CORNER

Life will be OK!

by Kathleen Dunn

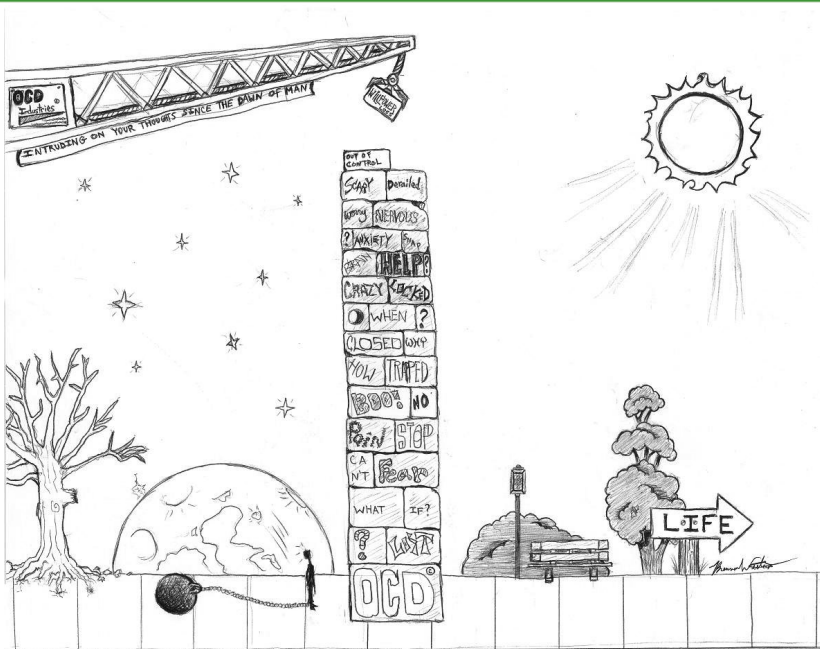
*Kathleen Dunn is the author of *The ABC's of OCD*, a book that provides a non-threatening method for families and children to understand and explain OCD in a new way. Please visit www.abccod.com for more information.*

My name is Kathleen. I am nine years old and I have Obsessive Compulsive Disorder. My mom figured out I have OCD when I was six. She knew what was happening since my older sister Bridget also has OCD. When I was six I had a lot of weird habits. Some of them I don't even like to talk about now. The main habit that I don't mind telling you about was that I would say 'I think' before everything I said! I mean everything. It was making me and my mom crazy and I was getting teased about it too. At first it seemed funny but then I couldn't stop saying it no matter what. I also did a lot of checking on things, like in the bathroom, and lights and doors. I would worry about all of these things all the time. I really became worried about everything then. I did not like how my mind would race and my OCD would make me do stuff I did not want to be doing or worrying about. Most nights I would have to sit with my mom on the couch and try to get my mind from racing about my worries.

My mom found a nice doctor that helps other kids with OCD and we started to meet at her office in town. She showed me ways to start to boss back my worries. We even named each 'worry' a funny name so that when I had them, I could say the funny name to take my mind off of it. After practicing this a lot, my worries would kind of go away.

Another thing I love to do to keep my mind off of my worries is write and draw and do art. When I was eight I wrote a book using each letter of the alphabet about my OCD. I really liked working on a book project and my mom said this might be able to help other kids with OCD. When I do my writing and art I don't worry about things so much. I keep so busy with it I don't have time to even think about my OCD. Almost every day after school I write and draw. I like crafts too! I keep my crafts near the kitchen so I can always work on something. The busier I am with my art projects the less I remember to worry!

Now that I am nine, my OCD has gotten much better. On a lot of days I don't even feel like I have OCD. I am very glad that I went to the OCD doctor to learn how to tell my habits to go away. Sometimes they are still there but the habits don't bother me as much because I know when I don't think about them they will not scare me. I like to say 'Life will be OK!'



Inside the Mind of a Phobic

By Brennan, from Northern California

Here is a drawing that I have done depicting the emotional response and impact of someone that has an anxiety disorder, specifically with OCD. I made it in response to my own OCD symptoms and wish to show those in the anxiety/treatment realm how one with this dreadful disorder can feel at times.

THE THERAPY COMMUNITY

Living with Someone Who Has OCD: Guidelines for Family Members

By Barbara Livingston Van Noppen, Ph.D. and Michele Tortora Pato, MD

Dr. Van Noppen is an Associate Professor in the Department of Psychiatry and Human Behavior and an Assistant Chair of Education at the Keck School of Medicine, University of Southern California. She is internationally recognized for her expertise in treating families with OCD, and she currently serves on the Scientific Advisory Board for the Obsessive Compulsive Foundation. Dr. Pato has been involved in the research and treatment of OCD for over 20 years. She is currently the Della Martin Chair in Psychiatry and Associate Dean for Academic Scholarship at the Keck School of Medicine, University of Southern California.

In an effort to strengthen relationships between individuals with OCD and their family members and to promote understanding and cooperation within households, we have developed the following list of useful guidelines. These guidelines are meant as tools for family members to be tailored for individual situations and are sometimes more powerfully employed with the help of a therapist experienced in working with OCD.

1 RECOGNIZE SIGNALS

The first guideline stresses that family members learn to recognize the “warning signals” of OCD. Sometimes people with OCD are thinking things you don’t know about as part of the OCD, so watch for behavior changes. It is important to not dismiss significant behavioral changes as “just their personality.” Remember that these changes can be gradual but overall different from how the person has generally behaved in the past.

Signals to watch for include, but are not limited to:

- Large blocks of unexplained time that the person is spending alone (in the bathroom, getting dressed, doing homework, etc.).
- Doing things again and again (repetitive behaviors).
- Constant questioning of self-judgment; excessive need for reassurance.
- Simple tasks taking longer than usual.
- Perpetual tardiness.
- Increased concern for minor things and details.
- Severe and extreme emotional reactions to small things.
- Inability to sleep properly.
- Staying up late to get things done.
- Significant change in eating habits.
- Daily life becomes a struggle.
- Avoidance.
- Increased irritability and indecisiveness.

People with OCD usually report that their symptoms get worse the more they are criticized or blamed, so it is essential that you learn to view these features as signals of OCD and not as personality traits. This way, you can join the person with OCD to combat the symptoms rather than become alienated from him.

THE THERAPY COMMUNITY

(Family Guidelines, continued)

2 MODIFY EXPECTATIONS

People with OCD consistently report that change of any kind – even positive change – is experienced as stressful. It is often during these times that OC symptoms tend to flare up; however, you can help to moderate stress by modifying your expectations during these times of transition. Family conflict only fuels the fire and promotes symptom escalation. Instead of sending a frustrating “Just snap out of it!” message, a statement such as: “No wonder your symptoms are worse – look at the changes you are going through,” is validating, supportive, and encouraging.

4 REMEMBER THAT PEOPLE GET BETTER AT DIFFERENT RATES

There is a wide variation in the severity of OC symptoms between individuals. Remember to measure progress according to the individual's own level of functioning, not to that of others. You should encourage the person to push him/herself and to function at the highest level possible; yet, if the pressure to function “perfectly” is greater than a person's actual ability, it creates more stress which leads to more symptoms. Just as there is a wide variation between individuals regarding the severity of their OC symptoms, there is also wide variation in how rapidly individuals respond to treatment. Be patient. Slow, gradual improvement may be better in the end if relapses are to be prevented.

3 AVOID DAY-TO-DAY COMPARISONS

You might hear your loved one say he feels like he is “back at the start” during symptomatic times. Or, you might be making the mistake of comparing your family member's progress (or lack thereof) with how he functioned before developing OCD. It is important to look at **overall** changes since treatment began. Day-to-day comparisons are misleading because they don't represent the bigger picture. When you see “slips,” a gentle reminder of “tomorrow is another day to try” can combat the self destructive labeling of “failure,” “imperfect,” or “out of control,” which could result in a worsening of symptoms. You can make a difference with reminders of how much progress has been made since the worst episode and since the beginning treatment. Encourage the use of questionnaires as an objective measure of progress that both you and your loved one can refer back to (for example, the Yale Brown Obsessive Compulsive Scale).

5 RECOGNIZE “SMALL” IMPROVEMENTS

People with OCD often complain that family members don't understand what it takes to accomplish something such as cutting down a shower by five minutes or resisting asking for reassurance one more time. While these gains may seem insignificant to family members, it is a very big step for your loved one. Acknowledgement of these seemingly small accomplishments is a powerful tool that encourages them to keep trying. This lets them know that their hard work to get better is being recognized and can be a powerful motivator.

6 CREATE A SUPPORTIVE ENVIRONMENT

The more you can avoid personal criticism, the better – remember that it is the **OCD** that gets on everyone's nerves. Try to learn as much about OCD as you can. Your family member still needs your encouragement and your acceptance as a person, but remember that acceptance and support does not mean ignoring the compulsive behavior. Do your best to not participate in the compulsions. In an even tone of voice explain that the compulsions are symptoms of OCD and that you will not assist in carrying them out because you want them to resist as well. Gang up on the OCD, and not on each other!

7 SET LIMITS, BUT BE SENSITIVE TO MOOD (REFER TO #14)

With the goal of working together to decrease compulsions, family members may find that they have to be firm about:

- Prior agreements regarding assisting with compulsions;
- How much time is spent discussing OCD;
- How much reassurance is given; or
- How much the compulsions infringe upon others' lives.

It is commonly reported by individuals with OCD that mood dictates the degree to which they can divert obsessions and resist compulsions. Likewise, family members have commented that they can tell when someone with OCD is "having a bad day." Those are the times when family may need to "back off," unless there is potential for a life-threatening or violent situation. On "good days" individuals should be encouraged to resist compulsions as much as possible. Limit setting works best when these expectations are discussed ahead of time and not in the middle of a conflict

10 SUPPORT TAKING MEDICATION AS PRESCRIBED

Be sure to not undermine the medication instructions that have been prescribed. All medications have side effects that range in severity. Ask your family member if you could periodically attend their appointments with the prescribing physician. In this way you can ask questions, learn about side effects, and report any behavioral changes that you notice.

8 KEEP COMMUNICATION CLEAR AND SIMPLE

Avoid lengthy explanations. This is often easier said than done, because most people with OCD constantly ask those around them for reassurance: "Are you sure I locked the door?" or "Did I really clean well enough?" You have probably found that the more you try to prove that the individual need not worry, the more he disproves you. Even the most sophisticated explanations won't work. There is always that lingering "What if?" Tolerating this uncertainty is an exposure for the individual with OCD and it may be tough. Recognize this and let the conversation go.

9 SEPARATE TIME IS IMPORTANT

Family members often have the natural tendency to feel like they should protect the individual with OCD by being with him all the time. This can be destructive because family members need their private time, as do people with OCD. Give them the message that they can be left alone and can care for themselves. Also, OCD cannot run everybody's life; you have other responsibilities besides "babysitting."

11 IT HAS BECOME ALL ABOUT THE OCD!

We have worked with families who have come into treatment and reported that their household conversations are mostly about OCD, whether it is about asking and providing reassurance to the family member with OCD or talking about the desperation and anxiety that the illness causes. When these family members are in treatment they are given the challenge of engaging in conversations that are "symptom free," an experience that they report feels liberating. We have found that it is often difficult for family members to stop engaging in conversations around the anxiety because it has become a habit and such a central part of their life. Setting some limits on talking about OCD and the various worries is an important part of establishing a more normative routine. It also makes a statement that OCD is not allowed to run the household.

THE THERAPY COMMUNITY

12 KEEP YOUR FAMILY ROUTINE “NORMAL”

Often, families ask how to undo all of the effects of months or years of going along with OC symptoms. For example, to “keep the peace” a husband allowed his wife’s contamination fear to prohibit their children from inviting any friends into the house. An initial attempt to avoid conflict by giving in just grows; however, obsessions and compulsions must be contained. It is important that children have friends in their home or that family members use any sink or sit on any chair, etc. Through negotiation and limit setting, family life and routines can be preserved. Remember, it is in the individual’s best interest to tolerate the exposure to their fears and to be reminded of others’ needs. As they begin to regain function, their wish to be able to do more increases.

13 BE AWARE OF FAMILY ACCOMMODATION BEHAVIORS (REFER TO #14)

First, there must be an agreement between all parties that it is in everyone’s best interest for family members to not participate in rituals (also known as family accommodation behaviors). However, in this effort to help your loved one reduce compulsive behavior, you may be easily perceived as being mean or rejecting even though you are trying to be helpful. It may seem obvious that family members and individuals with OCD are working toward the common goal of symptom reduction, but the ways in which people do this varies. Attending a family educational support group for OCD or seeing a family therapist with expertise in OCD often facilitates family communication.

“Without Risk,” by Ron D. Kingsley, Ph.D. Dr. Kingsley is a clinical and school psychologist as well as an artist and musician who grew up with ADHD and obsessive and compulsive issues.

14 CONSIDER USING A FAMILY CONTRACT

The primary objective of a family contract is to get family members and individuals with OCD to work **together** to develop realistic plans for managing OC symptoms in behavioral terms. Creating goals as a team reduces conflict, preserves the household, and provides a platform for families to begin to “take back” the household in situations where most routines and activities have been dictated by an individual’s OCD. By improving communication and developing a greater understanding of each other’s perspective, it is easier for the individual to have family members help them to reduce OC symptoms instead of enable. It is **essential** that all goals are clearly defined, understood, and agreed upon by any family members involved with carrying out the tasks in the contract. Families who decide to enforce rules without discussing it with the person with OCD first find that their plans tend to backfire. Some families are able to develop a contract by themselves, while most need some professional guidance and instruction. Be sure to reach out for professional assistance if you think that you could benefit from it.



ERP: Not Your Mother's Therapy

By Jennifer Alosso, BA

Jen Alosso is currently a doctoral student in the clinical psychology program at the Massachusetts School of Professional Psychology. She also works as a residential counselor at the Obsessive Compulsive Disorder Institute at McLean Hospital, and is a volunteer at the national office of the OC Foundation.

There are all sorts of things we associate with the word therapy: couches and dream analysis; mindfulness and relaxation; having a trusted witness to your deepest, darkest secrets. Therapy does for the mind what a massage does for the body, right?

We've seen television characters use therapy to figure out their questions about life. Our friends claim, "I'll have to see my therapist, and extra time this week" when they are particularly stressed or have been through some rough patches. Let's face it – we've all seen people we thought could probably use a little therapy. Therapy makes us feel good. Maybe it's because we learn new things about ourselves each time we go. Maybe it's the only place we get the support we need to get through our lives. Maybe it's the one hour per week we can speak full sentences without interruptions and distractions. We just know that we like the way we feel when we go.

Now let's put the word "behavior" in front of therapy. It's therapy with a twist. The therapy you didn't hear about from Mom. Behavior therapy might have the same goals as the therapy we're used to, but goes about it in a completely different way. We're still playing on the same team, but we're batting in a different ballpark.

For the past six years, I have worked as a residential counselor at the Obsessive Compulsive Disorder Institute at McLean Hospital, where I have learned about behavior therapy from some of the most talented treaters and determined patients in the world of OCD. Behavior therapy for obsessive compulsive disorder comes alive through Exposure and Response Prevention (ERP), in which the person fighting OCD is exposed to what triggers their anxiety and does not engage in the rituals that would immediately lower that anxiety. It sounds simple, but is much easier said than done. ERP requires that a person allow him or herself to be anxious while habituation (letting anxiety go down by itself) happens, to stay in a situation that may initially seem unbearable, and to not do anything about it. It's like having a mosquito bite on your hand, an itch within your reach, but you resist scratching and let yourself be itchy, only worse.

A lot of my time at the OCD Institute is spent coaching patients through exposure and response prevention exercises as prescribed by their behavior therapists. Coaching ERP is not something I do for people to feel good. I do it so people can feel *better*. I have yet to hear someone use the word "good" when they are in the midst of having their anxiety triggered. Touching toilets without washing afterwards is far from glamorous and is very distressing in the moment. I do my best to help people stay with what is making them anxious and not engage in any rituals. I help people stay focused on the task at hand so they can experience the greatest amount of habituation and get the most bang for their buck. It can be difficult to encourage people to do stressful things. It seems wrong to help someone be anxious when they're obviously looking for quite the opposite, but I am on the side *against* OCD!

Many people have lingering anxiety after completing an ERP task, and some just try to stay focused on what is next on the agenda. The most exciting thing is that most people have a sense of accomplishment. Any time rituals are resisted and habituation occurs should be considered a battle won in the war against OCD. Over time, the anxiety-provoking triggers just won't have the same effect. Reminding people about these accomplishments is one of the biggest perks of my job. I have been fortunate enough to watch hundreds of people become free from their OCD. I am in the business of helping people get better. Getting better from OCD means more quality time with family and friends, less trouble at work and in school, and more hours out of every day feeling "good."

(continued on p. 14)

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(ERP: Not Your Mother's Therapy, continued)

How can I become involved in helping those with OCD?

Obsessive compulsive disorder can be a difficult thing for family and friends to understand. The first step is to educate yourself about OCD. There are lots of great books about OCD in general and there are also books designed for parents, family members and friends. Talk with your loved one about what you have learned about the disorder and the treatments that are available. If treatment is sought, you may be an integral part in the process of getting better. Family and friends are often pulled into OCD rituals and may need to learn how best to handle those situations in the future.

If you are a professional looking to treat OCD, there are many different options available to you. A therapist of any kind is required to be licensed in the state in which they are practicing, and there are different levels of schooling that coincide with each license:

- **Medical Degree (MD)** – Psychiatrists are most often referred to for a client in need of medication. However, some may also be knowledgeable about cognitive behavioral therapy (CBT). In rare instances, some have been known to do home visits for clients in need. Psychiatrists are generally involved with research that involves a more biological basis and medication.
- **Doctoral Degree (PhD, PsyD, EdD)** – Psychologists create and carry out CBT treatment plans for clients with OCD. Psychologists often conduct research to further our understanding of OCD and how it is best treated.
- **Masters Degree (LICSW, LMHC, MA, MS)** – Social workers, mental health counselors and other masters level clinicians also create and carry out CBT treatment plans for clients with OCD. Some treaters with a Masters Degree are also involved with research.
- **Bachelors Degree (BA, BS)** – A bachelors degree does not allow you to provide behavior therapy for people with OCD, however opportunities are available to learn about OCD treatment through volunteer work, being a research assistant or being mentored by a licensed OCD specialist.

In addition to schooling, training specific to OCD and the OC Spectrum Disorders should also be obtained. The OCF's Behavior Therapy Institute (BTI) is an intensive 3-day workshop that was developed so that there are more mental health professionals who are qualified to treat OCD. The BTI is a great way to learn about the treatment of OCD, as well as getting to know other professionals that share the same interests.

Treatment for obsessive compulsive disorder is not easy and seems to go against our idea of what therapy is, but it is a rewarding experience for people suffering from OCD, their loved ones, and those of us lucky enough to help people get better.

2nd 2009 Behavior Therapy Institute (BTI)

Date Announced – Mark Your Calendars!

June 26, 27 & 28 in North Chicago, Illinois

The Behavior Therapy Institute is an In-Depth 3-Day Training Program
in State-of-the-Art Cognitive Behavioral Therapy for OCD

- Experienced OCD Faculty
- CE Credits Available
- Low Registration Fee

Space is limited to the first 30 registrants for each training!

For more information regarding the Institute, or to view our BTI Handbook and BTI Registration Forms:

Visit the OC Foundation website at www.ocfoundation.org or contact Michael Spigler at (617) 973-5801 or mospigler@ocfoundation.org



This program is sponsored by the Obsessive Compulsive Foundation (OCF), Inc. OCF maintains responsibility for this program and its content. This program is approved by the National Association of Social Workers (Provider #886509959, Exp. 2/28/2010) for 21 continuing education contact hours. This program has been approved by the National Board for Certified Counselors. Course meets the qualifications for 21 hours of continuing education credit for MFCCs and LCSWs as required by the California Board of Behavioral Sciences (Provider #PCE 4422, Exp. 12/31/2010). Application has been made to the American Psychological Association.

OCF Institutional Members

We are proud to announce that many of the intensive OCD treatment programs around the country have applied to become Institutional Members of the OCF. The OCF's Institutional Members are all programs that offer more than traditional outpatient therapy for those who need higher levels of care. Historically, we have run comprehensive interviews in the newsletter as a way of updating the OCD community about intensive treatment resources. Going forward, we will be posting briefer updates from each of our Institutional Members as needed in the newsletter.

Extensive descriptions of these programs are currently available on our website under the "Intensive Treatment Programs" tab. On this webpage you will see each program's contact information and a link to their website. Underneath each program name there will also be a "Download Program Description" button. These program descriptions are comparable to the newsletter-run interviews; however, on the website all of the programs have answered the same 15 questions describing their services so that programs can be more easily compared to each other.

Please see the announcements below for recent program updates.

TEXAS

Anxiety and Depression Treatment Center of Houston – A Program Update

The clinicians that developed and directed the (now former) OCD Treatment Program at The Menninger Clinic are excited to announce the opening of their new OCD residential program in Houston. The Houston OCD residential program is founded on evidence-based cognitive-behavioral principles for the treatment of obsessive compulsive disorder and related conditions. This program is offering a continuum of services including a specialty residential treatment program, intensive

outpatient program, diagnostic and treatment consultations, and individual cognitive-behavioral therapy. The Houston OCD program is currently accepting patients. Please visit their home page for additional information: www.HoustonOCDprogram.com or call (832) 298-7075.

WISCONSIN

OCD Center at Rogers Memorial Hospital Celebrates Ten Year Anniversary

The OCD Center at Rogers Memorial Hospital in Oconomowoc, Wisconsin, marks a milestone anniversary in 2009 by celebrating ten years of service to the OCD community. "There is no doubt that without the support of the OCD community, including the Obsessive Compulsive Foundation, we wouldn't be here," said the clinical director of Rogers Memorial's Obsessive Compulsive Disorder Center, Bradley C. Riemann, Ph.D.

The program grew out of a need experienced by the patients of Rogers Memorial's partial hospitalization program, which launched approximately two years before the OCD Center. Rogers Memorial's partial program offers 12-hours of treatment per week, and a typical stay involves four to five weeks of treatment. "We were able to treat most of the people we were seeing in the partial program," said Riemann, "but there was a subset of patients in that program that just needed more. We felt they could benefit from a more intensive experience. They were working hard, but they just weren't getting over the hump, so we wanted to 'up the dosage' of the therapy."

At that time, there was only one residential OCD treatment center in existence — the Obsessive Compulsive Disorder Institute at McLean Hospital. "The first thing we asked was, 'Does McLean believe there is a need for another program?'" said Riemann. McLean was immediately supportive of the idea. They said that the demand

for their services was great and that another program, especially one in the Midwest, would be a great asset to the OCD community. McLean and the OCF were both valued partners in the planning of Rogers Memorial's center. In early 1999 Rogers Memorial Hospital opened the nation's second residential obsessive compulsive disorder treatment program.

In 2008, the center moved into a much larger, newer facility. "The new building has been an incredible boost for this program. The move, along with the development of a training site for masters-level and Ph.D. candidates from around the Midwest, has helped take our program to another level," explained Riemann. In addition, Rogers Memorial has put a lot of time and money into developing a very structured cognitive-behavioral therapy training program across many of its service lines, including its eating disorders and child and adolescent-focused programs.

Building on ten years of treatment data, the Obsessive Compulsive Disorder Center is continuing to grow as an important center for clinical research on OCD treatment. "We always have multiple research projects going on at a time, many of which are looking at treatment outcomes, how to be more effective, more affordable," Riemann said. The OCD Center is collaborating with some of the national leaders in OCD treatment in research, and developing a consortium tasked with evaluating the enormous data set that the Center has collected over the years.

Through the continued support of like-minded organizations and the passion and support of the members and staff of the Obsessive Compulsive Foundation, the OCD Center plans to remain part of the OCD treatment community for a long time to come.

For more information about the OCD Center at Rogers Memorial Hospital, please visit www.rogershospital.org or call (800) 767-4411, Ext. 1347.

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New Horizons in OCD Research and the Potential Importance of Glutamate: Can We Develop Treatments That Work Better and Faster?

By Michael H. Bloch, MD, Vladimir Coric, MD, and Christopher Pittenger, MD, Ph.D.

Michael Bloch, MD, is a Fellow in the Solmit Integrated Program in Child and Adult Psychiatry at Yale University and the Assistant Director of the Yale OCD Research Clinic. Vladimir Coric, MD, is a Senior Research Scientist and Past Director of the Yale OCD Research Clinic. He is also an Associate Clinical Professor of Psychiatry at Yale University and a member of the OCF Scientific Advisory Board. Christopher Pittenger, MD, Ph.D., is an Assistant Professor of Psychiatry and Director of the Yale OCD Research Clinic. He is also an Attending Psychiatrist at the Connecticut Mental Health Center and an Associate at Yale-New Haven Hospital.

First-line treatments for obsessive compulsive disorder (OCD) – cognitive behavior therapy, drug therapy with selective serotonin reuptake inhibitors (SSRIs), or both – are quite effective for many patients. However, approximately one third of patients do not experience a significant reduction in symptoms from these treatments, or from established second-line interventions. Even in patients who do respond, symptom reduction usually occurs only over the course of two to three months, and response is often not complete. The development of treatments that work better and faster is a major goal of ongoing research.

Glutamate in OCD

Existing medications for OCD target two neurotransmitters (brain chemicals): serotonin and dopamine. However, there has been substantial interest over the last eight years in the potential involvement of another neurotransmitter, glutamate, in OCD. Glutamate is the most abundant excitatory neurotransmitter in the brain; it is critical to the communication of nerve cells with one another in practically every circuit in the nervous system. An abnormally high level of glutamate can lead to neuron damage, and glutamate-modulating therapies (medications aimed at affecting or normalizing the actions of glutamate in the brain) have been explored in medical conditions such as “Lou Gehrig’s Disease” (ALS) and in stroke.

Evidence from several sources suggests that abnormal levels of glutamate may contribute to OCD. Investigators at the Ruhr University in Germany examined the cerebrospinal fluid (CSF) of patients with OCD who were not on any medication. They found that individuals with OCD had higher levels of glutamate in the CSF than psychiatrically healthy controls. Since the CSF bathes the brain, this suggests that the brain is exposed to high levels of glutamate in patients with OCD. A similar increase of glutamate in the brain has been seen using another technique, magnetic resonance spectroscopy (MRS), by investigators at Wayne State University, and elsewhere.

The presence of abnormally high levels of glutamate in the brains of individuals with OCD does not prove that it contributes to the disease – problems with glutamate could be a consequence of the illness, rather than a cause. However, recent genetic findings lend support to the idea that glutamate imbalance may be an important causal factor in at least some cases of OCD. Two independent groups, from the University of Toronto and the University of Chicago, published evidence in 2006 that a protein that carries glutamate in the brain is linked to OCD in some cases; more recent studies from groups at the Massachusetts General Hospital and Johns Hopkins University have found the same thing. Although it is not yet clear whether these genetic linkages correspond to a functional problem with this protein, problems with these glutamate transporters can increase the amount of glutamate found outside neurons, which might explain the increased glutamate seen in the brain, and possibly lead to OCD symptoms.

Recent findings in mice further support the idea that changes in glutamate in the brain can produce behaviors that resemble OCD. Researchers at Duke University have described a mouse that is anxious and grooms itself compulsively. They genetically altered the mouse, so that it is missing the SAPAP3 gene. The SAPAP3 gene is a critical piece in structure of the glutamate receptor. The anxiety and compulsive grooming behavior of these mice decreased when they were given an OCD medication – a selective serotonin reuptake inhibitor (SSRI). A few doses of an SSRI did not decrease compulsive symptoms; the medication has to be given over a long period of time to have an effect – the same pattern seen with patients taking SSRIs to treat their OCD.

Although it remains unclear whether this gene (SAPAP3) is involved in OCD, the one genetic study performed to date in humans with OCD, from researchers at Duke and Johns Hopkins, showed preliminary evidence of a relationship to grooming disorders such as Trichotillomania but no links to OCD. Regardless, further work in this and related animal models will increase our understanding of how changes in the brain glutamate, and how neurons respond to it, can lead to compulsive behavior patterns.

Glutamate-targeting Medications

Is it possible then that medications that affect glutamate in the brain will benefit patients whose OCD does not respond to existing therapies? This hope has guided research in our clinic over the past several years, and early results, from our group and elsewhere, are promising – although the evidence for such drugs is not yet conclusive.

Fortunately, a number of medications that affect glutamate levels are already FDA approved for other medical conditions and are therefore readily available for research and clinical use. One such medication is riluzole (Rilutek®), which has been marketed since 1996 for Lou Gehrig's disease (ALS). Riluzole affects glutamate levels in several ways. In an initial open-label study in 2005 and a case series in 2008, we found that approximately half of the severely ill, treatment-refractory patients who have not responded to other treatments improved significantly when riluzole was added to their SSRI. Researchers at the National Institute of Mental Health have found similar results using riluzole in children with OCD. Controlled, double-blind studies (the best way to test the effectiveness of a medication) for riluzole in adult and pediatric OCD have already begun.

A second drug that is already available and affects how neurons respond to glutamate is memantine (Namenda®). Several case reports and two recent open-label case series suggest that the addition of memantine to standard medication therapy can benefit both children and adults with OCD. As in the case of riluzole, these studies are uncontrolled and need to be replicated in larger, placebo-controlled studies.

There is also some limited evidence suggesting that a third medication - N-acetylcysteine or NAC - also has benefit in the treatment of OCD. NAC is available without a prescription. It is an antioxidant and is used in cases of acetaminophen (Tylenol®) overdose to protect the liver from damage. However, animal studies by researchers at the Medical University of South Carolina have found that NAC can affect levels of brain glutamate as well. We worked with a patient with OCD who improved significantly after we added NAC to her existing medications. Unpublished clinical experience, from our group and elsewhere, further suggests that the agent may be of benefit in at least some patients with OCD. Well-controlled studies have shown benefit from NAC in a variety of other disorders of compulsive and impulsive behaviors including pathological gambling, Trichotillomania, and drug craving. Because it is inexpensive, has no significant side effects, and is available over-the-counter, this drug is a potentially attractive therapeutic option, though the evidence for benefit in OCD remains extremely thin.

Glutamate in Depression and the Possibility of a Rapidly-acting Anti-obsessional Drug

Abnormal glutamate levels may also play an important role in major depressive disorder. All of the medications discussed above (riluzole, memantine, and N-acetylcysteine) have been investigated in depression by researchers at Yale, the National Institutes of Health, and elsewhere. Indeed, an important question for future research is how the glutamate problems in these two disorders, which often occur together, differ from one another.

Glutamate is a neurotransmitter – a chemical that communicates from one nerve cell to another. A neuron can respond to glutamate when it binds to a specific kind of protein, a receptor (a receiver of a brain chemical message, like your cell phone receiving a phone call). So alterations in glutamate affect nerve cells by changing the activation of these receptors, and targeting the receptors with medications can change how the neurons respond to glutamate. There are several receptors for glutamate; a particularly important one is called the NMDA receptor. Drugs that affect these NMDA receptors have recently been found to produce a remarkably rapid antidepressant response. This contrasts starkly with the delayed response typically seen with SSRIs in both depression and OCD. This observation was first made by researchers at Yale, who reported in 1998 that depressed patients receiving a single dose of the NMDA-targeting drug ketamine became rapidly better, and stayed better for up to a week. Ketamine can produce a short “high,” lasting 1 or 2 hours. However, the improvements of mood were greatest at 24 hours and lasted in some subjects for as long as seven days, making it clear that they were not just

RESEARCH NEWS

(New Horizons, continued)

a result of this high. This striking and unexpected effect was reproduced in a double-blind study at the National Institutes of Health in 2006.

Memantine also affects NMDA receptors, but its effect is much weaker than that of ketamine. Unfortunately, a controlled study of memantine in depression from the National Institute of Mental Health did not show benefit. Newer medications that act on this NMDA receptor are under development.

Ketamine is by no means the answer for major depression. The antidepressant effects of ketamine usually wear off by a week or two. Furthermore, ketamine's addictive and abuse potential and the fact that it needs to be administered intravenously limit its long-term use. Potentially unpleasant psychological symptoms, such as anxiety, sadness, disorientation, flashbacks, and hallucinations can sometimes emerge during ketamine administration and also limit its potential for widespread use. However, a limited trial of ketamine may be useful to help a patient break out of a particularly severe or treatment-refractory depression. In addition, the rapid antidepressant effect of ketamine opens a window into an entirely new way of thinking about how to treat depression. A better understanding of how this drug works in the brain could lead to the development of new drugs that do not have ketamine's drawbacks, but do have its advantages - in particular, a more rapid effect than any standard antidepressants.

These observations raise exciting new possibilities for the field of OCD research. If glutamate contributes to both depression and OCD, and if ketamine can produce a rapid antidepressant effect, would this medication, or similar drugs that affect glutamate or the NMDA glutamate receptor, also be effective treatments for OCD? Depression frequently occurs along with OCD - could drugs that affect the NMDA receptor, like ketamine, be of benefit to both? Most excitingly, the antidepressant effects of ketamine are remarkably rapid - much more so than traditional medication or psychotherapy. It has long been possible to rapidly treat severe depression using ECT; but ECT is not effective in the treatment of OCD, and no rapid treatments have been available. Perhaps this unfortunate limitation will change.

In sum, increasing evidence indicates that abnormal levels of the neurotransmitter glutamate contribute to OCD and may be a fruitful target for new therapies. Ketamine's unexpected, rapid antidepressant effect suggests that similar anti-obsessional effects are a real possibility, since the disorders frequently occur together and problems with glutamate appear to be associated with both. No investigations of ketamine in OCD have been published to date, but developing new clinical treatments like this based on our advancing understanding of OCD at the molecular, cellular, and systems level has the potential to usher in a new era of therapeutics that work better and faster than those we have today.

Research Digest

*Selected and abstracted by Maggie Baudhuin, M.L.S. and John Greist, M.D.
Obsessive Compulsive Information Center; Madison Institute of Medicine, Inc.*

"Natural" treatments for various diseases, disorders, and ailments have been a topic of interest for centuries. Even though almost all of the attempts in the past to cure or treat disorders with vitamins, herbs, minerals, and other nutritional or dietary supplements have been unsuccessful, people continue to hope that through research and study we will be able to find "natural" cures and treatments for a number of disorders, including OCD, that will be safer, more tolerable, cheaper, and possibly more effective than current treatment options.

Since there is so much public interest in nutritional and dietary therapies in general, it is not surprising that both the OC Foundation and the Obsessive Compulsive Information Center receive hundreds of calls each year from individuals who want to know if there are any dietary, nutritional or other "natural" treatment approaches that have been shown to help OCD.

In the Fall 2007 OCD Newsletter Research Digest, we reviewed a pilot study of exercise added to ongoing serotonin reuptake inhibitors and/or cognitive-behavior therapy, both treatments of proven benefit in OCD. Before exercise started, the average Y-BOCS score was 22.9. After 12 weeks of exercise it had decreased 7.7 points to an average of 15.2, a worthwhile gain. Mood

and fitness also improved and the gains persisted for at least 6 months (R.A. Brown et al. *Journal of Nervous and Mental Disease*, 195:514-520, 2007).

Today people often ask about St. John's wort and the omega-3 fatty acids, two dietary supplements that have been studied extensively for treatment of depression and other mood disorders. With so much popular press on these two agents, and the fact that prescription medications for depressive disorders and anxiety disorders often overlap, it is only natural to ask if these substances might be useful in the treatment of OCD.

In this Research Digest, we present two recent articles that review the studies of dietary supplements for OCD and other anxiety disorders. We also reference the controlled studies of St. John's wort and omega-3 fatty acids for OCD.

Readers should understand that very little information about nutritional supplements for OCD is available. Results of the very few controlled research studies that have been published have been generally negative, with little support for effectiveness of these products for OCD or other anxiety disorders. However, some believe that further research is needed in order to reach firm negative conclusions on this topic.

Finally, we feel it is important to once again remind readers that cognitive-behavior therapy (CBT) is another "natural" treatment with well-proven efficacy, lasting benefit, and excellent tolerability. It would be unwise to try unproven "natural" treatments until and unless treatments of proven benefit including CBT and serotonin reuptake inhibitors have not been helpful.

Natural remedies for anxiety disorders: potential use and clinical applications

Depression and Anxiety, 26(3):259-265, 2009, G. Kinrys, E. Coleman and E. Rothstein

This review covers studies that have been published on various nutritional supplements for anxiety and anxiety disorders. The authors looked for studies of St. John's wort, kava, passionflower, inositol, valerian root, melatonin, omega-3 fatty acids, and S-adenosyl-L-methionine (SAME). They found no studies of melatonin or SAME for any type of anxiety or anxiety disorder. Only St. John's wort, inositol, and omega-3 fatty acids have been studied in individuals with OCD. Several of these supplements have been tried in patients with other types of anxiety and anxiety disorders, including generalized anxiety disorder, panic disorder, and social anxiety disorder.

In their review of the literature, the authors found only a small number of studies of dietary supplements for anxiety, and for the most part, these studies had very few study participants. Their main conclusion was that although interest in natural treatment approaches for anxiety is growing, very few studies exist. Based on their review, the authors conclude that there is no evidence to support the use of natural remedies as first-line treatments of anxiety. There may be a place for some of these products in treating anxiety disorders, but this awaits demonstration in future research. They found evidence to suggest that passionflower might help generalized anxiety disorder and inositol might be effective for some cases of OCD and panic disorder. However, these findings need confirmation by larger, placebo-controlled trials. They also point out that since so few controlled studies have been conducted, any study results should be viewed with caution.

Omega-3 fatty acids as treatments for mental illness: which disorder and which fatty acid?

Lipids in Health and Disease, 6(1):1-19, 2007, B.M. Ross, J. Seguin and L.E. Sieswerda

The authors review the double-blind, placebo-controlled studies of omega-3 fatty acids in the treatment of various psychiatric disorders, including attention deficit disorders, schizophrenia, personality disorders, depression, bipolar disorder, and anxiety disorders. At the time of this investigation, the authors found only two placebo-controlled trials of the omega-3s for anxiety. This included a study from 2004 by Fux and colleagues (see below) of fatty acids for OCD and a study from 2006 that looked at fatty acids for anxiety associated with substance abuse. The authors conclude that although there is some evidence to indicate that omega-3 fatty acids might alleviate certain types of anxiety, the study of fatty acids for anxiety disorders is a "field in its infancy." For the OCD study by Fux, these authors comment that "the limitations of this study leave open the question of whether omega-3 fatty acids have any efficacy in OCD."

For the broader topic of omega-3 fatty acids for mental illness, the authors comment that although most studies were well-designed, many included only a small numbers of participants. The most promising areas for beneficial effects of

(continued on p. 20)

RESEARCH NEWS

(Research Digest, continued)

omega-3 fatty acids are the mood disorders, including depression and bipolar disorder. There is little support for their use in the treatment of schizophrenia or ADHD. Omega-3 fatty acids were generally well tolerated by study participants, with mild gastrointestinal effects being the most commonly reported complaints. The authors conclude that, based on current research, it is not possible to recommend omega-3 fatty acids, as mono- or augmentation therapy for any mental illness, but that there is justification for further study of fatty acids in the treatment of attention deficit, anxiety and mood disorders.

A placebo-controlled cross-over trial of adjunctive EPA in OCD

Journal of Psychiatric Research, 38(3):323-325, 2004, M. Fux, J. Benjamin and B. Nemets

This study from 2004 is the only placebo-controlled trial of omega-3 fatty acids for OCD

The purpose of this study was to determine if eicosapentaenoic acid (EPA), a component of omega-3-fatty acids found in fish oils, could lead to further improvement in patients who show a partial response to a selective serotonin reuptake inhibitor (SSRI). Eleven patients with OCD currently taking an SSRI and showing no further improvement for a period of at least two months were randomly assigned to either 6 weeks of EPA (2 grams per day) followed by 6 weeks of placebo, or 6 weeks of placebo followed by 6 weeks of EPA. At the end of the study period, EPA supplementation was not shown to be more effective than placebo. This study does not support the use of omega-3 fatty acids (EPA or fish oils) as adjunctive treatment for OCD, although the authors point out that it is possible that the dose of EPA used in this study was too low. The authors also comment that it remains to be determined if EPA as monotherapy might be helpful for some individuals with OCD.

St. John's wort versus placebo in obsessive-compulsive disorder: results from a double-blind study

International Clinical Psychopharmacology, 20(6):299-304, 2005, K.A. Kobak, L.V.H.

Taylor, A. Bystritsky, C.J. Kohlenberg, J.H. Greist et al.

** This study from 2005 is the only placebo-controlled trial of St. John's wort for OCD**

In this double-blind, placebo-controlled study of St. John's wort for OCD, 60 patients were randomly assigned to either St. John's wort or placebo for a period of 12 weeks. Patients receiving St. John's wort were started on 300 mg twice a day for two weeks, with the option of dose increases to as much as 1800 mg per day. At the end of the study period, no significant differences were found between St. John's wort and *placebo* although numerically, *placebo* was fractionally more beneficial than St. John's wort. Although an earlier open trial (Taylor and Kobak, Journal of Clinical Psychiatry, August 2000) reported significant improvement in 5 of 12 OCD patients given St. John's wort, the results of this controlled study do not support effectiveness of St. John's wort for OCD.



Did you know...

The OCF maintains an online database that lists hundreds of OCD support groups that meet across the country. People can access this database 24 hours a day, 7 days a week, at www.ocfoundation.org/quick_search_groups.html to find the local support they need.

If you participate in an OCD support group, please ask the group leader to call us at (617) 973-5801 or email us at info@ocfoundation.org to speak with someone about listing your group in our database. Your listing might help someone connect with the resources that they need!

Research Participants Sought

Does your child or teenager have Obsessive-Compulsive Disorder?

We are conducting a research study to examine how cognitive-behavioral therapy delivered via videophone works in reducing Obsessive-Compulsive Disorder (OCD) symptoms in children and adolescents. Past research has found that CBT is helpful for as many as 85% of children with OCD. However, many people do not have access to CBT – therefore, videophone-administered CBT may be a way to make treatment more convenient and affordable (less travel costs) and less time-consuming.

Your child must be between the ages of 7-17 and have problematic OCD symptoms to be able to participate in this study. If he/she is eligible to participate in this study, he/she will either receive videophone-CBT right away, or after a 4-week waiting period. This study will involve 14 90-minute sessions of videophone-CBT (twice a week for the first 4 sessions) and 5 psychiatric evaluations of varying lengths.

Study treatment and evaluations will be provided at no charge.

If you are interested or have questions, please call Dr. Eric Storch at (727) 767-8230 or email him at estorch@health.usf.edu.

Screening tools for early detection of anxiety disorders

Are you the parent of a 6-8 year old who has been diagnosed with OCD? If so, your child may be eligible to participate in a research study at the Infant Cognition Lab at UMass Boston. We are investigating the visual and cognitive processes of children with and without OCD as well as children at risk for OCD.

If you decide to take part in this study, your child will watch short cartoons on a computer screen while we monitor what your child pays attention to. Afterwards, we ask that you fill out a few questionnaires. The entire study will only take about 45-60 minutes and we are offering \$50 and a small gift for your child as a thank you for your time.

Our study uses the advanced technology of the Tobii T120 eye tracker which is a perfectly safe and innovative type of equipment that monitors and analyzes exactly where your child is looking. No cumbersome equipment necessary. The child simply sits and watches a few fun videos; just like watching television. Meanwhile, the eye tracker is able to follow every eye movement and we can get a better understanding of what your child pays attention to. Eye tracking systems have been commonly used in infant and clinical research for many years, and the technology is not invasive. The equipment uses harmless near-infrared light; similar to what surrounds us everyday.

For more information about this research study, please contact Uchenna Eneh at the Infant Cognition Lab at (617) 287-6363 or (617) 287-4820. You can also send us an email at icl@umb.edu.

Online Scrupulosity Research Study

Does scrupulosity interfere with your life?

If so, and you are 18 years of age or older, have been diagnosed with OCD, and have access to the internet, you are eligible to participate in an anonymous research study.

The study will require you to spend about 20 minutes interacting with an investigational website, and answering questions about your problems with scrupulosity. No information will be recorded that would permit you to be identified.

To participate in this study, use your computer's browser to go to: www.btassessment.com.

Lee Baer, Ph.D.
William E. Minichiello, Ed.D.
Jedidiah Siev, M.A.

Sibling Relationships and OCD: Study deadline extended to April 30th

Anxiety is a Family Affair!

Anxiety disorders are among the most common troubles of children and as many as 8-12% of children are affected. As those with an anxious child know well, childhood anxiety affects everyone in the family. How about siblings? Sibling relationships are the longest in a person's lifetime, and siblings share very special bonds. There is some evidence that sibling relationships are both challenged and supported by the presence of anxiety and that there are many psychological benefits of having a sibling. But in general, siblings have largely been overlooked by research, which focuses instead mostly on parent-child relationships.

Can you help?

Researchers at Williams College Department of Psychology are seeking participants for an interesting survey on sibling relationships and well-being in families in which one child or teen has obsessive compulsive disorder (OCD). Your participation will help advance our

RESEARCH NEWS

(Research Participants Sought, continued)

understanding of how and why siblings are important.

The surveys are for a parent and two siblings: A 30-minute parent survey and a 20-30 minute survey for each of the siblings. Each person would do the survey individually and all surveys are anonymous and confidential.

In appreciation, we will send each family a \$10 Target gift card, OR we will make a \$10 donation to the OCF (Obsessive Compulsive Foundation). Once the study is complete, it would also be our pleasure to send you a summary of the results.

Am I eligible to participate?

Yes, if your child with the OCD diagnosis is between the ages of 10-18 and has at least one sibling who is also between the ages of 10 and 18. The sibling can be a whole-, half-, or step- sibling with whom the child with OCD has lived for at least one year.

I would like to participate.

How do I start?

Families can do the surveys either online at our secure website OR by mail at your earliest convenience, up until April 30th 2009.

Online option:

The parent should simply go to the following link to learn more about the study and to get started: <https://www.psychdata.com/s.asp?SID=127911>.

Mail in option:

Just email us at Ryan.J.Jacoby@williams.edu with your address, and we will send you the surveys with a self-addressed stamped envelope to send them back to us.

For more information, contact: Dr. Laurie Heatherington, Department of Psychology, Williams College at (413) 597-2442, Laurie.heatherington@williams.edu or Ryan Jacoby at (617) 775-5146, Ryan.J.Jacoby@williams.edu.

Open-Label Exploratory Investigation of D-Cycloserine Augmentation to Cognitive Behavioral Therapy with Exposure and Response Prevention for Adults and Adolescents Diagnosed with Obsessive Compulsive Disorder - A Feasibility Study

Principal Investigators: Moira Rynn, M.D.; Blair Simpson, M.D., Ph.D.
 NYSPI IRB Protocol: #5828
 Diagnostic Groups: Obsessive Compulsive Disorder (OCD)
 Age Range: 12-65 (inclusive)
 Gender: Male and Female
 Language Requirements: English-speaking only

Inclusion Criteria:

- Able to understand and follow study procedures
- Adolescents and adults ages of 12-65 who are in good physical health
- All sexually active participants of childbearing potential who are using a medically acceptable form of birth control
- If receiving SRI medication, participants should already be on it for at least 12 weeks
- If receiving other psychotropic medication, participants should already be on it for at least 4 weeks

Exclusion Criteria:

- Medical conditions that would conflict with participation
- Psychiatric disorders or symptoms that would conflict with participation
- Receiving psychotherapy
- Females who are pregnant or nursing, or who plan to become pregnant

Brief Summary of Study Procedures:

The purpose of this research study is to see if a medication called D-Cycloserine (DCS) is safe and helpful to enhance the outcome of cognitive behavioral therapy with exposure and response prevention (E/RP therapy) for adolescents and adults with obsessive compulsive disorder (OCD). The study will last up to 7 weeks, and will consist of a screening period of up to two weeks and a treatment period of up to 5 weeks that consists of twice weekly 60-minute E/RP sessions. Patients may receive up to 50 mg of DCS after some of the E/RP sessions.

Study Recruitment Ending Date: Ongoing

Contact Information:

Telephone: (212) 543-0266

New York State Psychiatric Institute (NYSPI) at 1051 Riverside Drive, New York, NY 10032

If you would like to advertise your research study in this newsletter or on the OCF website, please send the text of your ad, as well as a copy of your IRB approval notice, to editor@ocfoundation.org. The subject should read: Research Participants Sought.

FROM THE AFFILIATES

OCF Affiliates: Representing the OCF on a Local Level

By Elaine Davis, Ph.D., Vice President of the OCF of Western Pennsylvania

If you are reading this newsletter, you are probably familiar with the Obsessive Compulsive Foundation. The OCF is based in Boston, Massachusetts and runs the organization on a national level. You may not be aware that there are currently nine local groups called Affiliates which work within the framework of the national agenda to bring similar programs and services to people on a local level. Both the national and regional organizations work together for the same mission: to help people struggling with OCD, the people who support them on a personal level, and the professionals who work in this field.

Programming on the national level includes the Annual OCF Conference, Behavior Therapy Institutes (BTIs), and public awareness campaigns. The OCF also produces this quarterly newsletter, funds research into the causes and treatment of OCD, maintains national OCD treatment provider and support group databases, and participates in advocacy for people struggling with OCD. The paid staff of the national office is small to maximize the money directed toward these programs. The national office relies heavily on this dedicated staff and teams of volunteers to accomplish their work. Your membership dues are a key part of funding these programs and services.

The regional Affiliates work to bring similar services and programs to their local area. Their work is on a smaller scale than the national programs, but their dedication is no less intense. Most of these groups provide all these services via a volunteer force who devote their free time to help support the OCD community in their region. The leadership of these groups attempts to discern the most pressing needs of their area and tailors programs to address these concerns. These efforts may include producing local newsletters, providing educational opportunities via conferences or seminars, taking active roles in providing support groups, and/or working towards educating school personnel and the general public about OCD. All of the groups are dedicated to helping individuals find effective treatment by directing them to mental health professionals in their area who are part of the OCF treatment provider database.

But there is a more subtle aspect to these local groups: they provide an opportunity for their members to truly get involved in the OCF. Giving back can be intensely rewarding. It also helps to ensure that the Foundation is directing its efforts to the actual concerns of the people it is dedicated to serving. While you may not have the means to participate in the national programs, the affiliates can help bring a little of this support to your area. Participating in these programs can go a long way in the road to leading a more fulfilling life.

It is important to note that you do not **join** these local groups. Members of the OCF living or practicing within defined zip codes automatically become members of their local Affiliate. There are no separate dues for any of the Affiliates. A portion of your national membership fee is provided to these groups to help defray their operating costs and their programming. Regional affiliates are asked to help recruit new members who may not have heard of the OCF and to help reach out to people when their membership comes up for renewal. This is why you might also occasionally receive a membership renewal "reminder letter" from a regional affiliate if you happen to belong to one. This only serves as a backup system to ensure that members are not lost due to administrative errors or simply to give a friendly reminder if you have forgotten to send your renewal into the national office. Membership is still ultimately through the national Foundation.

You should be aware that you may also receive notifications with a request for donations to the local group or other local fundraising efforts. The funds collected are used to provide additional quality programming in the local area. These appeals are not a duplicate of those sent by the national OCF office. Donations can be given to either or hopefully both groups and will serve different efforts.

OCF affiliates are in place to serve your needs and to assist you at a local level, so feel free to tell us which services are the most beneficial to you. Give us your suggestions on how to reach out to the community or raise funds for additional programming. If you have skills which could help us to more effectively get the word out about OCD, please contact us. We welcome your help. You may even be given the opportunity to serve on a local board of directors. How cool is that?

If you do not live in an area currently served by a local OCF Affiliate and are interested in starting a group, please contact the OCF Program Director, Michael Spigler. He can guide you through the process of setting up an affiliate and can provide additional information on the structure and expectations of the responsibilities of these organizations.

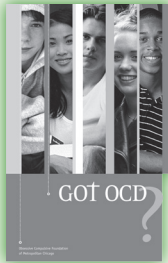
FROM THE AFFILIATES

Affiliate Updates

ILLINOIS

OCD Chicago to Give Out Free Copies of Teen OCD Guide

OCD Chicago has announced a giveaway of the last remaining copies of their highly acclaimed and effective "Got OCD?", a guide for teens with OCD. The guide is scheduled to be updated later this year. For now, free copies of "Got OCD?" will be sent to requestors on a first come, first served basis. This popular guide reassures teens that Obsessive Compulsive Disorder is a common and treatable neurobiological disorder.



Copies may be ordered from:

OCD Chicago
2300 Lincoln Park West
Chicago, IL 60614
Phone: (773) 880-1635
Email: info@ocdchicago.org
Website: www.ocdchicago.org

MASSACHUSETTS

OCF of Greater Boston's Les Grodberg Memorial Lecture Series

The OCF of Greater Boston (OCF/GB), in conjunction with McLean Hospital, presents a lecture series featuring distinguished speakers in the field of OCD and related disorders. Each presentation takes place from 7:00 – 8:00pm and is held in the De Marneffe Cafeteria Building, Room 132 at McLean Hospital in Belmont, MA 02478. Below is their upcoming schedule:

- May 5, 2009 The Role of Guilt in OCD
Leslie Shapiro, LICSW
OCD Institute, McLean Hospital
- June 2, 2009 Medication Q & A
Michael Jenike, MD
OCD Institute, McLean Hospital

NOTE: Please check www.ocfboston.org for information on schedule changes or cancellations.

The OCF/GB affiliate is pleased to announce that it will be sponsoring a new professionally-led parent support group directly before each monthly lecture. This group will run from 6:00 – 7:00pm in the De Marneffe Cafeteria Building, Room 116 at McLean Hospital. Babysitting will be provided.

Following each speaker presentation there are also several free self-help groups open to the public. For more information on these support groups please contact Denise Egan Stack, the OCF/GB President, at (617) 855-2252. These groups will begin at 8:00pm and run until approximately 9:30pm in rooms 114 and 132. The identity of participants and content of group discussion must remain confidential. Furthermore, if desired, you may remain anonymous. We remind participants to be open and supportive to the views of all those who take part in the support groups.

OCF of Greater Boston Announces 2nd Annual Bike Ride and Fundraiser for OCD

When: Sunday Aug 30th, 2009*
Time: 10:30 AM
Where: Concord Middle School
Sanborn Building
835 Old Marlboro Road
Concord, MA 01742

Ride Length: 40 miles

100% of the pledges you obtain will go directly to the Obsessive Compulsive Foundation to continue the critical research needed to help treat this condition. Volunteers are very much needed, so even if you don't ride your help will be just as important!

To learn more and to sign up for the ride, please visit: <http://bike.meetup.com/207/calendar/9464143>

*Rain Date will be Sunday September 13th.

PENNSYLVANIA

OCF of Western PA (OCF/WPA) Announces its Spring Conference

OCF/WPA will host its conference, entitled "Effective Treatment of Obsessive Compulsive Disorder," on May 8, 2009. The Keynote Address will be given by Alec Pollard, Ph.D., Director of the Anxiety Disorders Center at the St. Louis Behavioral Medicine Institute.

Mental health professionals will gain an understanding of the principles of Cognitive Behavior Therapy (CBT) and Exposure and Response Prevention (ERP) and discuss the advances in the treatment of OCD. An overview of the medications commonly used in the treatment of OCD and the benefits of incorporating the family into the therapeutic process will also be addressed.

This course is also open to all members of the community interested in this topic. The knowledge gained will allow patients to more effectively participate in the development of their treatment plans.

Online registration and additional information is available at www.ocfwpa.org.

5 hours of Continuing Education Credit is available to qualified Psychologists, Social Workers, Family/Marriage Therapists and Counselors.

This will be the final offering in our seminar series for this spring. Our seminars will resume in the fall of 2009.