

## FROM THE FOUNDATION

### Why The International OCD Foundation?



Left to right (Front Row) Dr. Jeff Szymanski, Executive Director, IOCDF; Dr. Thröstur Björgvinsson, Scientific Advisory Board, IOCDF; Dr. Zeping Xiao, President, Shanghai Mental Health Center; Dr. Edmund Neuhas; Dr. Szu-Hui Lee; and Dr. Xu Yong, Director of Training and Education, Shanghai Mental Health Center

At the Annual Conference in Minneapolis, MN, we formally announced that the Obsessive Compulsive Foundation had become the International OCD Foundation. There were two primary reasons for this. First, it was important to underscore that “Disorder” was in the title of the organization. One of the obstacles individuals with OCD face is that the struggles they encounter often get confused with the personality traits “obsessive” and “compulsive”. In other words, people with OCD are assumed to just have a personality quirk and that they can stop doing the compulsive behavior when they want to. It isn’t made clear that this is in fact an anxiety disorder and that what drives people with OCD is a constant and debilitating fear that if they don’t engage in a compulsive behavior something catastrophic might happen. It is not just a preference as is seen with people who are “obsessive” or “compulsive”. As a little more background, when the OCF formed there was already an OCD Foundation! In this case, OCD stands for the Oldest College Daily – a Yale University newspaper. When this newspaper developed a philanthropic component to help raise money from alumni, they ultimately became the OCD Foundation. So the name was already taken!

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## FROM THE FOUNDATION

## Letter From The President



Dear Friends,

If you, like I, are feeling a bit stuck with the winter blahs...think San Diego! It is not too soon to begin thinking about and planning your trip to this year's conference in beautiful Southern California. We are so excited to be heading back to the West Coast this summer, and there is no place more spectacular than

San Diego. We are currently accepting presentation proposals, and we expect that, as in previous years, we will have an amazing agenda of presentations, workshops, support groups, and other activities. We hope you will be able to be there.

We are also in the process of accepting research grant proposals. Our Scientific Advisory Board Committee will begin reviewing proposals in March, and we are sure that we will have an array of top-notch proposals to choose from. We are limited to how many proposals we can fund only by how much we receive in research donations, so if you have not yet made your donation to the Research Fund, it is not too late!

On another front, it is my great pleasure to welcome our newest board member to the IOCDF, Susan Dailey. Susan is a mom to a 9-year-old daughter, and is the owner of a small business and an entrepreneur. Two years ago, her home was rocked by the arrival of sudden onset OCD in her daughter. As a result, she plunged head first into exploring the correct treatment plan, and became very involved in advocacy for pediatric patients. After discovering that well trained Exposure and Response Prevention (ERP) therapists were not available in her local area, she began a fundraising program to train therapists across the Southeast in how to do ERP with kids. She has been responsible for funding 15 providers

to attend Behavior Therapy Training Institute (BTTI) trainings. She is now actively working on fundraising and advocacy for those suffering from Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) OCD. As a result of that advocacy and involvement with the IOCDF, Susan was very pleased to join the board in November.

Susan says "joining the Board at IOCDF is a great honor for me. Finding ways to help those that suffer from OCD find appropriate and effective treatment is a passion in my life. We learned so much at the conference we attended when my daughter first became ill. We both made wonderful friends all over the country, and found the right treatment plan as a result of our attendance. Now, being able to give back just a little is very exciting. All of the board, staff, and volunteers at IOCDF are so inspiring and committed to helping further OCD research, treatment and education. I look forward to a productive first year."

In fact, just this week we received an email about a therapist who received one of Susan's scholarships to attend a BTTI, and was able to quickly intervene with a rapid onset pediatric OCD patient and get the child the help they needed. She credited the BTTI for instructing her about recognizing possible PANDAS, and about how to respond quickly to rapid onset symptoms. It is just these kinds of stories that help us to know that the BTTI's are helping so many patients get the help that they so desperately need. In this case, Susan's dedication was a part of that! We are so excited to be working with her and know she will bring with her boundless energy and loads of creative ideas. Please join me in welcoming her to the IOCDF!

*Diane Davey*

President, IOCDF Board of Directors

## OCD Newsletter

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The International OCD Foundation (IOCDF) 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.

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## DISCLAIMER:

IOCDF 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.

## FROM THE FOUNDATION

## Why The International OCD Foundation? (Continued from front page)

The second reason we adopted the new name was to emphasize the international directions we have already begun to take. As many of you know, the Genetics Collaborative is a group of genetics investigators from North America, South America, Europe and Africa. The Collaborative currently has more than 50 members and has been in operation since the Foundation's Annual Conference in 2002. The goal is to allow investigators specializing in genetics to collaborate with one another and to share their findings and DNA samples. The hope is that this will speed up our understanding of the role genetics play in the development of OCD. In addition, we have had an increase in inquiries from countries all over the world via mail and email. The inquiries have ranged from individuals looking for services in their own country to requests for guidance on how to set up a foundation like ours in their country. As a result, in 2011 we will be contacting OCD foundations around the world to help coordinate efforts. These efforts could range from collaborating on OCD Awareness Week, to translating psychoeducation about OCD into different languages, to helping others around the world find the

limited resources available for the treatment of OCD.

Finally, many of our Scientific Advisory Board (SAB) members have been very active around the world for many years helping to educate and train mental health providers in other countries. A recent example of this was a trip that was recently taken to Shanghai, China to train 100 mental health professionals in the use of Cognitive Behavior Therapy (CBT) for treating OCD. As far as we know, this training – held in October, 2010 – was the first CBT training for OCD in all of China. The faculty involved in the Shanghai training included IOCDF Executive Director, Jeff Szymanski, PhD, and IOCDF SAB member Thröstur Björgvinsson, PhD (additionally, Dr. Szu-Hui Lee was a third trainer, while Dr. Ed Neuhaus served as the course director). The Shanghai Mental Health Center generously sponsored all aspects of the training (no IOCDF funds were used), and it was a tremendous success.

We hope to continue to reach out to all individuals suffering from OCD and will continue to update you on our progress nationally and internationally as we go forward.

INTERNATIONAL  
**OCD**  
 FOUNDATION

# Annual Conference 2011

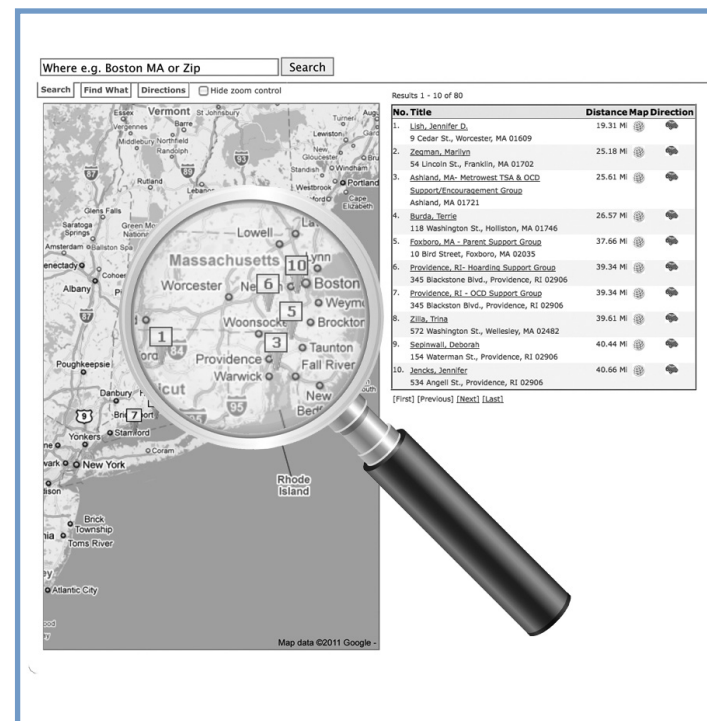
July 29-31 - Sheraton San Diego Hotel and Marina




More info at: [www.ocfoundation.org/Conference.aspx](http://www.ocfoundation.org/Conference.aspx)

## FROM THE FOUNDATION

## Treatment Provider Database - New-and-Improved and Ready to Launch!



This February, we will be unveiling the new and extensively updated Treatment Provider Database on the IOCDF website. This will help website users search for treatment providers that specialize in OCD and OC Related Disorders in their area.

Following up on the Support Group Database we launched in September 2010, the Treatment Provider Database will mirror the Support Group Database's design and function. The new search engine will feature a Google search browser that generates an interactive map when one searches for treatment providers in their area. In addition to searching by location, users will also be able to search for treatment providers based on the populations they serve (children, adolescents, and adults), their payment options (whether they are self-pay only, offer Medicare, sliding fees, etc.), their treatment strategies (CBT, ERP, Group Therapy, etc.), and specialty areas (Perfectionism, Hoarding, BDD, etc.).

Most provider listings in the new database will also feature a biography of the treatment provider, including a description of his or her training, credentialing, and experience in treating OCD and/or OC Related Disorders. In addition, each treatment provider was asked to provide a description of his or her services and current practice. This will be especially beneficial as you will be able to get a personal sense of what a

treatment provider offers and their specific background and history, hopefully making it easier to decide whether or not this is the right treatment provider for you. Finally, users will be able to search by whether or not a provider is a Behavior Therapy Institute (BTTI) graduate or faculty member. The BTTI is offered for professionals by the IOCDF and is an in-depth 3-day training program in state-of-the-art cognitive behavior therapy for OCD and related disorders.

We have received much positive feedback in regards to the improvements we have made to our Support Group Database, and we hope to provide the same ease of the searching and breadth of information with the new Treatment Provider Database.

If you are a treatment provider that is currently listed in our old Treatment Provider Database, please contact us (if you have not already done so) to confirm that your professional membership is up-to-date so that we can ensure you are included in the new database when we switch over in February. If you are a treatment provider that is not currently listed in the Treatment Provider Database, please go to our website at [www.ocfoundation.org/treatment\\_provider\\_submission\\_landing.aspx](http://www.ocfoundation.org/treatment_provider_submission_landing.aspx) for the steps to complete in order to become listed and start receiving referrals. If you have any questions or concerns about the new Treatment Provider and Support Group Databases, please feel free to call the IOCDF office at (617) 973-5801.

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twitter.com/IOCDF

## FROM THE FOUNDATION

## Are We Moving Closer to a Consensus on PANDAS?

Following the IOCDF Annual Conference in July of this past year, another conference was held. This conference was held at the National Institute of Health (NIH) and was sponsored by Yale University, the IOCDF, and a private sponsor with the goal of addressing the ongoing debates and controversies surrounding Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus, or PANDAS. Researchers, clinicians, immunologists, microbiologists, neurologists, psychiatrists and pediatricians gathered to discuss the evidence and come to some resolutions about future directions regarding PANDAS. On August 13, 2010, National Institute of Mental Health (NIMH) Director Thomas Insel, MD, wrote a blog about his thoughts of the PANDAS conference. A copy of his blog is available on our website at: [www.ocfoundation.org/childOCD.aspx](http://www.ocfoundation.org/childOCD.aspx). A formal report on this conference is coming out soon and we will be sure to post this on our website as well.

In November, 2010, IOCDF Scientific Advisory Board Chairman, Michael Jenike, MD and IOCDF Executive Director, Jeff Szymanski, PhD, attended a follow-up meeting with Dr. Insel, Dr. Susan Swedo (who has been instrumental in the identification and much of the research investigating PANDAS) and several other leaders within NIMH. The group heard how young children had been robbed of much of their childhood by PANDAS. They also heard how devastating this disorder is, and also how frustrating and demoralizing it is for parents to find the help they need for their children.

Parents suffer as they watch their high functioning child become symptomatic "overnight", only to be punted back and forth between medical professionals and mental health professionals who seemed to agree on very little. With persistence and perseverance, eventually some parents are able to find effective treatments for their children as they continue to find their way around the chaotic world of PANDAS (see page 6 of this newsletter for a parent's personal account). The goal of both the conference and this follow-up meeting was to help stimulate research on PANDAS and to help bring together the diverse group of professionals working with these children in order to identify the most efficacious and safe treatment for them.

Converging evidence presented at both the IOCDF and NIMH meetings indicate that a number of medical illnesses may be causing severe, sudden onset OCD in young children. According to these researchers, the study of PANDAS provides a unique window into the relationship between the immune system and the brain, especially an area of the brain called the basal ganglia. On his blog, Thomas Insel asks "Do infectious agents influence the development of autism, anxiety, or mood disorders? This remains a frontier area for NIMH research." Here at the IOCDF, we hope to see research in the immediate future that will answer this question and provide children with sudden onset OCD the most effective treatment options.

At the IOCDF, we continue to work on launching our new pediatric OCD website coming in the Spring of 2011. On that new site we will greatly expand our education about PANDAS. In the meantime, a "fact sheet" on PANDAS is currently available at: [www.ocfoundation.org/childOCD.aspx](http://www.ocfoundation.org/childOCD.aspx).



## FROM THE FRONT LINES

## A PANDAS Journey by Victoria Blavat

On September 26, 2008 my world forever changed. It was supposed to be a day filled with fun and laughter being that it was my son, Mark's, 5th birthday. But at about 5pm on that day, chaos broke loose. Mark went into hysterics when he became convinced another child at the party touched his food. Even though no one touched it, there was no way to change Mark's mind. He ran around screaming, eyes bulging, had no reasoning. We pulled him into his room, but he would run out and drop onto the floor crying. My husband and I stood there in disbelief, unsure of what to do. This wasn't like any tantrum we had ever seen before. It was different. It was a full-fledged meltdown. The boy we knew and loved was not there. We debated calling an ambulance, but we eventually somehow calmed Mark down on our own. Now our son wanted to be invisible to everyone. He bent down and kind of waddled around, asking us if anyone could see him. This was not a joke, he was serious. We managed to finish the party by accommodating everything Mark wanted done as to try to save the day and the party.

The days following brought on more confusion. We realized our now 5 year old was running to the bathroom every few minutes to wash his hands. He washed them to the point of bleeding. Mark spoke of dirt and germs. He walked around with closed fists and refused to hold hands. His little sister, Ella, was now considered contaminated. Mark couldn't as much as look at Ella. If she passed him, he spit out his food. If he even thought we touched her, he screamed. Our son appeared to suddenly have OCD. We convinced ourselves that it would go as fast as it came. There were things that one may consider life changes occurring and that must be the reason for all of this. But the real reason was a shock to us all.

It was time for Mark's 5 year well child check. We were running late since Mark didn't want to leave the house and refused to put his shoes on. The only way to get him out the door was to hold him down, force his shoes on, and carry our 5 year old to the car. Once there, he wouldn't let anyone touch him and spat at the nurse and doctor. We explained what had been happening and a strep test was done to rule out a disorder the doctor once read about. The rapid test was negative. We were told to give Mark two more weeks to get better on his own, and then we would have to see a psychiatrist. How can this happen? How can a "normal" 4 year old turn into a 5 year old that needs a psychiatrist in a matter of two weeks? It just didn't make sense.

Three days later we received a phone call from a nurse from the doctor's office. They ran a strep culture as well while we were there and it came back positive. Mark did, in fact, have strep. I was actually excited since there was a reason for all of this. I didn't know what it meant exactly, but there was a reason. Mark did not have a red throat, fever, nothing. We were told Mark might have this thing called PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal). We were given antibiotics for the strep and sent on a long journey to figure out what was going on with our son.

It has now been over two years later since that fateful day. We have seen pediatricians, neurologists, psychiatrists, psychologists, etc. Mark has a diagnosis of PANDAS and has now experienced three strep-triggered exacerbations, even after tonsil and adenoid removal. Mark has also had setbacks with viruses and allergies. We found out the hard way that NONE of our three children get symptoms of strep when they are infected. Luckily, Mark is the only one who shows symptoms of PANDAS. With every one of Mark's PANDAS exacerbations, the symptoms, severity, and the duration has varied, but OCD was always the main symptom. I have seen my little boy convince himself he needed to spin down the hall if he passed his sister's room; push his chair in over and over until just right; ask me to repeat things back in a specific way or answer questions that I knew darn well he knew the answer to. I've had to follow rigid routines that Mark put into place, not wavering at all from them; I've watched a 5 year old prepare his own meals since no one else could touch his food and fill a piece of paper up with the number 4 written over and over since 4 was "his number".

But there was much more than OCD, too. At some point, Mark became agoraphobic, had physical rages, wouldn't eat any food AT ALL, and even had two hallucinations. Simple touches hurt him, he was overly sensitive to hot and cold temperatures and wet his bed nightly even though he hadn't done so since he was potty trained at 2 years old. Mark had his childhood innocence stolen from him and was given a life of doubt, worry, anxiety and fear.

You would think along the way, we would have found support and teams of doctors trying to help our young son, but unfortunately that was not the case. We've met doctors that have literally laughed in our faces in front of our child, had the nerve to tell us PANDAS didn't exist, that perhaps my son was "just bipolar" or "just had OCD", that we were trying to find an easy way out. We saw doctors that should have no right to see suffering children.

Early on, PANDAS parents learn to develop a thick skin. We have no choice but to be strong and fight for our children. We are their voices in a world where many just want to sweep them under a rug and forget they ever existed. My family has fought doctors and PANDAS all the way. Eventually, we got Mark back with the help of antibiotics, steroids, and a whole bunch of time and patience...maybe even a parental nervous breakdown along the way. But I now have a 7 year old that smiles, plays with his little sister, and has no symptoms to speak of. He excels at school, has made friends, and is overall...happy. My son has recovered from PANDAS. I wouldn't say he is cured, but rather in remission. I pray every day he remains that way and all those families still suffering will find peace and happiness. One sad part is amongst all this elation and triumph, I know there is a microbe sneaking around in the public, at the park, in the grocery store, in Mark's school and all over the place that can take it all away. I know in a heartbeat we can be thrown into the chaos again.

## ORGANIZED CHAOS

## The Monster in my Head by Kellie Quinn

My mom once told me this story about walking into the bathroom and seeing me organizing her tampons. I sat on the cracked yellow tiles of our bathroom floor sorting the paper covered sticks, completely absorbed by the task. I was three years old. I was born like this, a perfectionist. Cursed to always make sure everything was just right, to need everything to feel exact. My blocks sat beneath a wooden cabinet in my family's dining room, the edges perfectly aligned with the corners of the smooth brown wood. In elementary school my pencil eraser bore holes in my homework assignments as I tried to ensure that every letter felt right after I had imprinted it in dark grey graphite on the white paper.

As a child I avoided sidewalk cracks just like every other kid. But I wasn't afraid for the health of my mother's back. I was concerned about the pit in my stomach that would grow into a black cave if I stepped on a crack. "Don't step on a crack or you'll fall and break your mother's back." More like "don't step on a crack because then you'll have to step on it with the other foot in the exact same way, and don't do it wrong because then you'll be lost in a maze of trying to even out both sides of your body."

Over time I began to avoid a lot of actions like this. Running on the treadmill became a nightmare as soon as I bumped an arm against the side of the machine. Taking the Advil my mom brought me to relieve a headache made me agonize about the what ifs of taking a whole bottle. I didn't want to, but I couldn't get the idea of it out of my head.

When I washed dishes I would dread finding a steak knife in the sink the way a criminal fears a knock on the door accompanied by a shout of "police open up." Our steak knives were so old the dull silver blade that was once a serrated edge could have been mistaken for a butter knife. It didn't matter-the idea of handling a knife sent a storm of gruesome images through my head.

*What if I took this knife and stabbed myself? What if I ran into the living room and stabbed my mom? What if I actually did kill someone? Do I want to kill someone? Get out of my head get out of my head get out of my head get out of my head.*

I felt like a criminal, except I had not committed a crime. I was petrified that there was a monster inside me, a psychopath, a horrible human being just waiting to get out.

At school I felt no better. I would get anxious sitting in class because I would get distracted trying to perfect my penmanship. I can remember sitting crouched over in my seat hiding my notes because I kept rewriting words. I would glance around the room making sure no one noticed my compulsion. Posters on the wall would stare down at me accusingly, the friendly faces of presidents judging me with their eyes. "Freak," they said. "Crazy." Minutes would tick by, but I would be writing the same sentence while the teacher continued to tick off important points. I'd miss them. There was no end in sight. The letter or word could sit right with me like a perfectly balanced scale, or it could make my skin crawl as if a spider ran across my hand.

Teachers and fellow classmates complimented my neat handwriting. They didn't see that my hands were tortured into the practice by a brain that had skidded out of control.

When I got stressed, when driving, sometimes for no reason at all the anxiety crept up my back to gently squeeze my neck and cut my breath short. What if accidentally hit someone when I'm driving? What if I took the whole bottle of Advil sitting on the kitchen counter? What if when I grow up I'm a child molester, or rapist, or murderer?

My sophomore year of college my obsessions became unbearable. I found myself sitting in my school's Mental Health Services bearing my soul to a psychologist named Viviana. Her cherub face was a stark contrast to the unfriendly walls of the facility. Walls lined with posters warned me about STDs and the swine flu, as if I didn't have enough anxiety already. I imagined I was sick with some physical ailment like this instead. Something palpable. Something I could explain. Something a doctor could fix with a script for penicillin.

I told her that I couldn't handle the thoughts anymore, they were taking up too much space and time. They were controlling me. I couldn't break free of them and they wouldn't leave me alone. I told her I was afraid. Afraid of myself, of what I could do, of the possibility that I could want to hurt myself or others.

"Kellie" she said, pausing to glance at her notes before looking at me kindly, "It sounds to me like you have OCD. These intrusive thoughts that take over you and cause you anxiety. It fits." She told me not to worry, that there was nothing wrong with me, that I actually had a serotonin imbalance in my brain that caused me to have all these thoughts that invaded my consciousness and then suctioned on so that I could not for the life of me get rid of them. The walls that had been closing in on me minutes before started to inch away.

A combination of Cognitive Behavioral Therapy and Zoloft was the treatment path I took. Combined, they would relieve my anxiety and actually reduce the obsessions that had nailed themselves to the walls of my brain. Bloody heads bloody heads guns guns guns get out of my head get out of my head get out of my head. At first the thoughts took over my day. But slowly, like waiting for the last of the honey to squeeze out of the bottle, the nails that held the obsessions began to loosen.

Cognitive Behavioral therapy is the hardest thing I've ever had to do. It forced me to immerse myself in my obsessions so that my brain would become desensitized and my anxiety would decrease. I was training my brain to battle against the OCD.

My therapist also suggested I name my OCD. To call it something so that it is separate from who I am. She called it spam, like you receive in your email. I always thought of it as a monster. It would sneak up on me and send tremors of fear through my body. The thoughts were not me, they were part of the monster. This name sticks.

After two months in therapy I had decreased my obsessions by half. After four months I was almost obsession free. I had the power again.

Sometimes I'm scared that I'll relapse. The monster is on vacation, but at some point it might want to come home and terrorize me. This time though, I'll know how to fight.

## FROM THE FRONT LINES

## “Machine Man” Gives OCD A Voice Through Mainstream Media

By Kellie Madison

Two years ago, a very close friend of mine confessed to having OCD. Like most people, I thought I had at least a general understanding of Obsessive Compulsive Disorder. I was wrong.

It turned out that what I knew about it was built on the usual stereotypes that center around the ‘obsessive’ part of OCD. Some of us obsess about TV shows, our mothers obsess about cleaning, our friends obsess over ex boyfriends and girlfriends. The acronym has morphed into an adjective and I sometimes hear my peers saying things like “I’m OCD about being on time” or “Have you seen her closet? She’s so OCD.” But after hearing about how much my friend has suffered and how drastically the disorder impacts his life, I realized that a greater piece of the OCD story was still missing to me.

So, I set out to learn the truth about OCD. The real version. The more I researched, the more I realized how ignorant I truly was. There were aspects of the disorder that I had absolutely no idea people were struggling with. And I logically concluded that, if I didn’t know about these things, there must be millions of other people who don’t know.

As a filmmaker, I felt compelled to do something about it. And the best way I know how to bring the truth about OCD to light is through the powerful medium of film.

Why is it crucial to give a voice to OCD through film? Because in this modern age, OCD is still considered to be a closeted disorder and that’s unacceptable.

We’ve witnessed an amazing transformation for ‘mental health’ in the great American discourse of our time. Just a generation ago it was a hush-hush topic with words like “depression” and “anxiety” reserved solely for the medical realm. Today, Zoloft and Prozac have become readily recognized names and accounts of mental illness quickly climb the bestseller list. Undoubtedly, mental health and its associated terms have become part of our every-day language.

Yes, we have the words for it now. We also have the TV shows, the magazines, the songs, the celebrities, the books, and the websites. The OCD community has benefited tremendously from this sudden surge in mental health awareness and it’s almost as if OCD is simply out in the open.

Almost, but not quite.

The fact is, OCD patients have not enjoyed the public embrace that depressed or even bipolar communities have in recent years. Somehow, amidst a decade of self-empowerment and social revolution, people with OCD have danced around the periphery of dinner table conversations. Why is it that people can tell friends and family about a struggle with depression, but not obsession?

And while we’re asking questions, why is it that some people have to “come out” about their OCD? Why is it that in this day of Dr. Oz and Dr. Phil, and every primetime medical drama that ever was or will be, we choose to use the words “come out” when we can say, “shared” or “opened up”?

Perhaps in the hype and excitement of our great

American mental health makeover, we failed to notice that OCD, unlike the more easily digested depression or anxiety, was not given the red carpet treatment into the collective American psyche.

It can be argued that mainstream media, singlehandedly, made mental illness OK over the last 10 years. A healthy dose of Oprah coupled with a Radiohead album was enough to tell anyone in the late 90’s that hey, a lot of people suffer from mental illness, get used to it. And we did.

Some might argue it wasn’t the right time to start a civic dialogue about OCD. Others have said that the nuances of OCD are too severe and not palatable to a culture that likes to have their disorders neatly packaged into a 30-second-Pfizer commercial.

“Now, it’s time to give OCD a voice. It’s time to tell the real story in a way that gives full attention and full authenticity to the disorder.”

## FROM THE FRONT LINES

I, however, think that OCD was simply never given a mainstream media vehicle through which the public could explore it. Mainstream media, as misleading as it can be, can also be a potent tool for enlightenment of the masses.

Indeed, it wasn’t until “Rain Man” and “Children of a Lesser God” that the autistic and hearing impaired communities were given a voice. Before that, films like “One Flew Over the Cuckoo’s Nest,” albeit a dramatized depiction, gave audiences a peek into mental health facilities.

Now, it’s time to give OCD a voice. It’s time to tell the real story in a way that gives full attention and full authenticity to the disorder. Film allows you to affect people’s emotions, encourage people to see things differently, educate and evoke newfound empathy for others - all while entertaining them.

So, I embarked on the journey of writing “Machine Man,” a screenplay about a man suffering with OCD. The story received a great deal of input and support from leaders in the field of OCD, including expert and radio news anchor, Jeff Bell, author of *Rewind, Replay, Repeat*.

As Bell says, “One of the things I found most impressive about “Machine Man” was how it was able to provide context for the compulsions that are visible to an audience. What’s so often missing in a depiction is what is prompting those compulsions, what is going on inside the head ... and one of the things that I so appreciate about the script for “Machine Man” is that it ultimately leaves the audience with a sense of hope.”

Along the way, the project and its cause have gained a small following, which has now blossomed into a fully interactive community at [www.MachineManTheMovie.com](http://www.MachineManTheMovie.com). It was all confirmation that getting OCD in the public eye was long overdue.

This is the right time for OCD to enter the public dialogue. It’s time we let people hear the authentic voice of OCD and effectively take this condition out of the closet – strip away the shame and the embarrassment.

I realize it’s a great undertaking, but I’m not alone in my efforts. The community that has formed around “Machine Man,” or Team Machine as the effort has been affectionately named, has been incredibly supportive and interactive. It was by way of the community’s open arms that “Machine Man” turned into not only just a film waiting to happen, but a grassroots, multi-media movement. A movement aimed at the one goal of giving a voice to those that have been silent for too long.

This is exactly why I thought it was vital to have the characters in “Machine Man” actually say the words “Obsessive Compulsive Disorder.” In so many films of our generation, we have been made aware of the mechanics and emotions of mental illness, but filmmakers are still apprehensive to actually name the disorders they depict. A strange phenomenon, this reflects our society’s eagerness to accept mental illness but its persistence in keeping mental health confined to its appropriate corner. It’s my feeling that this is not just the right time for a major film about OCD – it’s the right time for a major film that dares to name the illness out loud.

I know from personal experience that audiences respond to honest stories. And that’s exactly what I intend to do: tell the real story about what it’s like to suffer from OCD- just the raw truth, minus the shame and secrecy. These people deserve to have a voice and I feel privileged to be someone who wants to give them that.

If things go well, this may actually turn into OCD’s coming out party. Or should I rephrase that- let’s make “Machine Man” OCD’s red carpet appearance.

**MACHINE MAN THE MOVIE**

SUPPORT NOW

HOME VIDEO ABOUT THE FILM THE EXPERTS UNDERSTANDING OCD NEWS

**FILM SYNOPSIS**

A typical day behind the wheel of a car for most people quickly turns into chaos and distress for thirty-something BEN LYLE. Driving to meet his best friend, MIRA, at a local coffee shop, Ben is distracted for a split second when his cell phone falls to the floor and his car darts into something. A rattled Ben, thinking he may have his someone, gets out of the car to check on his victim, only to find there's no one there.

Something is plaguing Ben's mind, causing him to have inexplicable, irrational fears. These fears lead him to have an overactive imagination, making him falsely believe that horrible things are occurring in his world. His fears and anxieties slowly begin to consume him and take over his life. The situation becomes even more problematic when it increasingly affects his relationship with the person he loves most - Mira.

It is soon revealed that Ben suffers from a very serious anxiety disorder known as OCD (Obsessive Compulsive Disorder). Ben's symptoms worsen when he learns of his father's passing, overwhelmed with guilt and remorse for something catastrophic he did to his father as a child, Ben soon spirals out of control when he discovers that he will no longer have the opportunity to properly reconcile the tragic event.

Ben's growing anxiety creates a huge obstacle in fulfilling what his heart has been telling him for quite some time - that he is in love with Mira and wants to be more than friends. As his internal conflict escalates, he fights it with everything he's got.

He must struggle to get his mind under control simply to appear normal to the girl he loves.

Just when it seems like he may be losing the battle, Ben is forced to come face to face with one of the biggest, most daunting fears in his life. He has to reach inside of himself and find courage he never knew existed. An unexpected turn of events leads Ben to the greatest discovery in his life so far... hope.

image from <http://www.machineanthemovie.com>

## FROM THE FRONT LINES

**My Journey With OCD By Joan McGrath**

As part of the IOCDF's OCD Awareness Week this past October, Joan McGrath participated in one of the "OCD Stories" events that happened around the country. Here is the story she shared with the members and guests of the Hudson Valley OCD Support Group, of which Joan is a long-time member.

When Chris Vertullo asked me if I would be willing to give a presentation tonight sharing my history of living with OCD and Generalized Anxiety Disorder, and to include what I have found to be most helpful in coping, I was willing. Learning from each other's experiences is one of the most effective methods of self-help and managing a potentially debilitating disorder. OCD will never go away, but it can be managed. When you learn to manage it, you also benefit from renewed confidence and a feeling of self-empowerment.

My symptoms blossomed when I was 19 years of age. They first manifested in being very precise about paper work. I was working in New York City as a secretary. Scanning through a "Shipping Journal" that looked like the classified ad section of a very large newspaper and typing out a report detailing iron ore shipments was not exactly my strong point. Scanning did not fulfill my need for "certainty", and thus, this job became a nightmare. And then there was filing; did I put the paper in the right place?

There was a time when I couldn't handle my own checkbook because I was too busy checking and re-checking the numbers. I had problems worrying if I had turned the stove off, the lights out, and locked the door.

Driving a car suddenly became a big problem. My mind was racing with thoughts, all negative, but I didn't know why. In fact, I thought the thoughts were telling me the truth and that there was some substance to them. As a result, I tortured myself about whether or not I hit someone with the car. I even quit driving for a while.

But then scrupulosity became part of my life and I could not deal with it. Many people say: "What is scrupulosity?" The book *The Doubting Disease – Help for Scrupulosity and Religious Compulsions* by Joseph Ciarrocchi reveals that studies have shown scrupulosity as the fifth most common form of OCD. The scrupulous mind works by dramatically overreacting to perceived failures. When religion is involved, the scrupulous mind sees something wrong where there is nothing wrong. The scrupulous person judges some behavior as immoral that his or her faith community would see as blameless in comparison.

Sufferers of scrupulosity around the world share their own versions of nightmarish thoughts. They have persistent, irrational, unwanted beliefs and thoughts about doing the wrong thing, saying the wrong thing, not being devout or moral enough, not saying their prayers properly, repeating and repeating prayers, etc., despite all evidence to the contrary.

But, Dr. Ciarrocchi's book was published in 1995 and the time I am writing about was 1964 when I was 28 years old: that is a 31 year difference. Up to this point, I thought most of my thinking was somewhat normal; I was just a perfectionist. But with my scrupulosity problem, the irrational way I was thinking really came to light.

I didn't know what to do. I knew something was really wrong with me. I had accepted that something was wrong. I went to a psychiatrist, who proved to be very helpful, but at the time, there was no diagnosis for OCD, there was no tried-and-true method of treatment like Cognitive Behavioral Therapy and Exposure and Response Prevention therapy, and there was no such medication as an SSRI. There was no explanation of why my mind would not and could not manage the symptoms I was experiencing.

My psychiatrist tried every pill he could to reduce my anxiety and stress. We talked and I listened and tried very hard to follow his advice. He did help me, but only for a while. Time went on and I became so depressed that he told my husband he had no other choice but to recommend that I be hospitalized. At this time, I was 33 with two toddlers. I was hospitalized in 1969 for 6 months. While hospitalized, I received electric shock treatment and insulin therapy.

In the hospital, I attended support groups and found out that other people had mental problems, too. Everybody's problem was different, but at least I was no longer alone. From the treatments I had received, I was not depressed and my anxiety and stress were manageable. I felt a renewed vigor to understand and fight. I consider this time to be the turning point in my life. Now would begin the second step: Education.

Upon being released from the hospital, I went back to my doctor and to church to talk to a priest. The priest told me to go to confession only once a year and to not even think about "sin". I listened and obeyed that advice. The priest was my authority, and that gave me the confidence

## FROM THE FRONT LINES

I needed. I knew my thinking was irrational. From that point on, my experience of faith has served as a source of peace and strength, as it should.

In 1971, through networking, I joined a support group, "Recovery Inc.", whose mission was to make available a self-help method to improve mental health. At a Recovery meeting people volunteer to give an example of a situation they had to deal with and then how they used the Recovery tools to deal with it. As an example, one could get upset and anxious about preparing for the holidays. At the Recovery meeting, the first step would be to describe the event, including your temperamental reaction. In the second step you would describe your symptoms and discomfort. The third step would explain how you managed this situation. For example:

Think about it- if you say to yourself your imagination is on fire, you are seeing the symptom for what it is. It's

- **Fearful anticipation is worse than any reality**
- **Everything is a triviality compared to my mental health**
- **My negative thoughts and feelings come from a nervous imbalance**
- **Fears must be confronted and patterns of behavior reversed**
- **Imagination on Fire**
- **Have the will to bear discomfort and comfort will come**

imagination. And that is accepting the fact that your symptoms are caused by an overactive imagination, and this ultimately reduces your emotional response, clarifies the reality, and helps change your attitude toward nervous symptoms and fears. It also serves to take the symptom and nip it in the bud, avoiding what

can become a vicious cycle.

There are weekly meetings in community-based settings throughout the United States and many other countries. You can find more information about Recovery International on the web, including locations of meetings: [www.LowSelfHelpSystems.org](http://www.LowSelfHelpSystems.org).

In 1998, while watching TV, a program came on about OCD and driving. I was totally amazed. They were talking about OCD, they were talking about ME, and I finally had a name for my illness. It only took 34 years. They also mentioned the OC Foundation (now the International OCD Foundation), which I joined. Shortly after that, I became aware of a local affiliate of the IOCDF, founded in New York in 1996 by Christina Vertullo and Dr. John George. Dr. Christine Young has since joined the group. I became a member in 1998 and I was finally able to share with people who suffer from the same affliction.

In the support group I am currently attending, we usually discuss a particular issue, or we might have a guest lecturer. Dr. George gave a talk at one of our OCD meetings, which he repeats every so often when the need arises, entitled "Our OCD Toolbelt". After his presentation, we discuss it amongst the group. Another topic which has been very helpful is "Fighting OCD: What Works for Me", which includes coping and treatment strategies utilized by fellow group members. When you have reached a crossroad, you have a choice. You can take the OCD road, which leads to more symptoms, or you can choose to follow the road of "averageness" and apply all you have learned about this disorder.

The family also plays an important role in the success of an OCD patient achieving his or her goals. I have always had the loving support of my husband. Without his help over all these years, I don't know how I would have reached the peace of acceptance and management that I now have.

There are many ways of helping yourself. There are books on every symptom of OCD, support groups, IOCDF Conferences, spirituality, meditation, exercise, journaling, etc. You have to take charge of your mental health, but be sure that you are staying self-led rather than symptom led.

## THERAPY COMMUNITY

**Clinician's Corner**

by Bruce Mansbridge, PhD Director, The Austin Center for the Treatment of OCD

With this issue we introduce a new feature called Clinician's Corner, which will present cognitive and behavioral strategies that have proved useful in therapy.

I love doing ERP (Exposure and Response Prevention) therapy, which is the behavioral part of CBT (Cognitive Behavioral Therapy), because it works, reliably, dependably, and totally naturally. It will – dare I say always? – work, assuming the person with OCD actually does the ERP. Most of my energy is devoted to motivating people to do the ERP, which I recognize and appreciate is the very opposite of what they want to do, what comforts them, what relaxes them, what “feels right.” But the medicine won't work if you won't swallow it. In these columns I will be presenting some cognitive strategies that I hope you will find will help motivate you to do your ERP.

Cognitive strategies often differ from behavioral ones in that they can prove useful over a lifetime; there's no reason not to keep using them if you find them helpful. Here's a cognitive strategy many people have found helpful in being able to better tolerate difficult exposures.

**THE ROOMMATE**

Imagine that you have a roommate that you can't stand. (For males, please change the gender.) You can't kick her out, because her name is on the lease, but she's driving you nuts. You can hope, however, that she might decide that she wants to move out. You happen to know that she hates Bob Dylan. And let's say that you don't like Bob Dylan very much yourself, but you start playing his music all the time. You're willing to tolerate some discomfort, because you know it's causing her twenty times as much agony. The roommate here is OCD, and you want OCD to move out.

Ordinarily after drinking a glass of milk, most people would rinse out the glass and put it in the dishwasher. Totally normal behavior, hardly OCD-neatnik. Now I suggest that when you finish a glass of milk, you don't even rinse it out but set it on the counter – to dry – overnight. Even people without OCD cringe when I suggest that. That's just wrong! So of course it causes you some discomfort – perhaps a lot if you

have neatness OCD. But you realize that it's the OCD in you, the evil roommate, that's having the hissy fit, so you can tolerate the discomfort of the exposure in order to drive the roommate out. If you're obsessively fussy about having everything perfect, you might try literally leaving a used coffee cup or milk glass out, unrinsed, to dry. The more the idea of doing that creeps you out, the more therapeutic it probably is.

Many ERP exercises can be made more tolerable using this roommate model: Not washing your hands, for example. Yuk, it feels so gross not to wash my hands after I <fill in the blank>. “OK, if you don't like it, why don't you just move out?” you say to OCD, assigning the discomfort to OCD. OCD's the one who's unhappy about the situation. You're willing to tolerate the discomfort, because you know that it's driving OCD out.

Unlike cognitive strategies for OCD, behavioral strategies often don't make sense to keep doing forever. For weeks after knee surgery, for example, your physical therapist may want you to lift weights with your leg. This is abnormal behavior, and when therapy is over, you will stop doing it. In the same way, we usually recommend “exposures” (and ritual prevention, of course) as therapy for OCD. These are often strange behaviors that you may well stop doing when they have served their therapeutic purpose.

Here's a behavioral strategy to help you get control of your perfectionism. The ultimate goal is for you to be able to choose your level of quality or accuracy appropriate to the situation and not let perfectionism run you.

**TYPOS**

Do you knowingly send out emails that have typos in them? I don't. If I notice one, I almost always go back and correct it. I guess I'm a bit of a perfectionist. I like to think I take pride in doing a good job. There's nothing wrong with having high standards. But like anything else, OCD can take hold of a seemingly good idea and take it to painfully extreme lengths, and that's when perfectionism becomes a problem.

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First, we should recognize that not all emails are alike. You might be writing your brother; or the head of your department; or 300 important people. The consequences of sending out an email with multiple typographical errors would likely be very different.

Also, not all typos are alike. When you type, do you put one or two spaces after a period? Either is correct. (Back in the days of typewriters, putting in two spaces was generally taught, while printers have always used one space.) The smallest typo I can think of is occasionally putting in two spaces if you usually use one, and vice versa. There, I just did it. Did you notice? Being consistent would not constitute a typo, since both are correct; but being inconsistent would be “wrong” in anyone's book. Chances are, most readers would not even notice the difference in spacing.

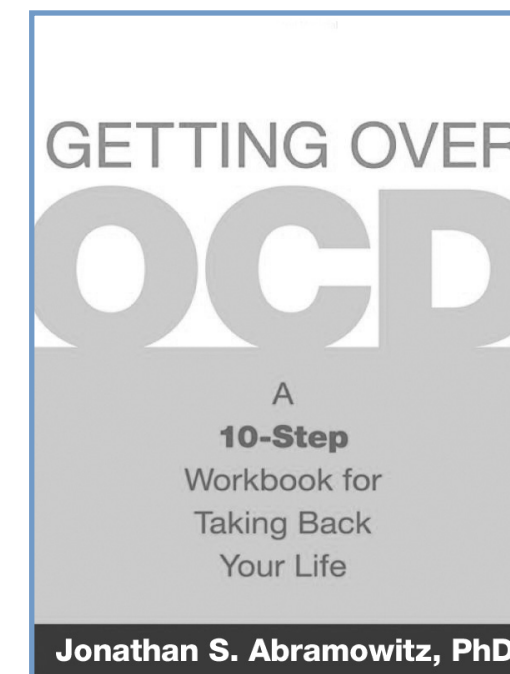
The next most “serious” typo, in my opinion, would be putting two spaces between two words in the middle of a sentence. Did you notice that one? A more serious typo might be leaving out the space between two words. Most people would notice that but not think too much of it. (It's more noticeable in a newsletter than in an email to a friend.) Next up the ladder might be mistyping the word “the” as “het” or “teh.” Again, people would probably notice it but know exactly what you meant, and it wouldn't slow them down at all or cause them much concern. Now we can start getting creative, putting in typos like that one, and maybe that one, and in fact, lots of little ones. One I would not be willing to do is type “your” when I mean “you're.” There's a huge difference between carelessness and illiteracy, and it's more than I could bear to have someone think I was that illiterate.

So a policy I might recommend to a perfectionist is to put typos into all emails. If the email is going to a VIP, make the typos tiny, like the extra space after a period. If it's going to a close friend or relative, knockj yourslef out! Even though your perfectionism may not be a problem at all for you when it comes to emails, adopting this policy will strengthen the same mental muscles that you will be using for tolerating imperfections (resisting perfectionist urges) in areas that may matter a great deal to you. And when your perfectionism is under control, you can stop deliberately putting in typos.

**Book Review: Getting Over OCD: A 10-Step Workbook for Taking Back Your Life**

By Jonathan Abramowitz, PhD

Reviewed by: Brad Riemann, Ph.D.



*Getting Over OCD: A 10-Step Workbook for Taking Back Your Life* is a self-help workbook written for individuals with obsessive-compulsive disorder (OCD) and the author is Dr. Jonathan S. Abramowitz, PhD. Dr. Abramowitz is a Professor of Psychology and Director of the Anxiety and Stress Disorders Clinic at the University of North Carolina at Chapel Hill. He is an award winning, highly acclaimed researcher and respected therapist. This workbook is part of The Guilford Self-Help Workbook Series. It contains 307 pages and its price is listed at \$19.95.

This extremely well-written workbook guides the reader through the necessary steps to overcome OCD. *Getting Over OCD* is divided into three parts. Part One is entitled “Getting to Know Your Enemy” and includes the first three steps or chapters of the program. Step One educates the reader on what is and is not OCD, uses varied examples to illustrate what it is like to have OCD, and includes a detailed description of types of obsessions and compulsions. OCD subtypes are also reviewed. Potential causes of OCD as well as an introduction to Cognitive

## THERAPY COMMUNITY

Behavioral Therapy (CBT) and medication options are also included. Abramowitz uses side boxes to summarize and emphasize key points throughout his workbook. Step Two begins a more detailed approach to analyzing one's OCD symptoms. Easy-to-follow self-assessment worksheets are used to aid the reader in this important step. Discussion centers on triggers and feared consequences of obsessional thoughts, analyzing avoidance behavior, and compulsive rituals. The latter portion has a very well done section on the sometimes all too confusing concept of mental rituals. Step Three introduces the reader to how OCD "operates" and what its "battle plan" is. Abramowitz's idea here is you can't defeat an enemy unless you know how it operates and know where you can counterattack. This discussion centers on how intrusive thoughts become obsessions, including obsessional beliefs and attitudes, and how rituals keep the cycle of OCD going.

Part Two is entitled "Getting Ready" and includes the next two steps. Step Four begins a more detailed description of CBT and how it is applied to OCD that continues throughout the workbook. Abramowitz teaches the reader by continuing to build on basic concepts that he introduces. Here the reader learns more about exposure and response prevention, and the steps to build their own exposure hierarchy. Detailed examples of subtype-related exposure hierarchies are given including imaginal exposures. Step Five helps the reader assess their readiness and motivation for self-help treatment. Topics in this step include a self-analysis of the negative consequences of having OCD, the pros and cons of treatment, proper goal setting, and the use of a "treatment buddy".

In Part Three of *Getting Over OCD*, entitled "Your Treatment Program", Abramowitz uses his vast knowledge of the subject and years of clinical experience to gently but firmly take the reader by the hand and lead them into battle against their OCD. He continues to build on the basic concepts of CBT by providing more details along the way. Step Six trains readers to "attack" OCD through the use of cognitive therapy strategies. "Battle Plans" are used to instruct readers in exactly what they need to do

to apply cognitive restructuring strategies such as the Continuum Technique, Pie-Chart Technique, Life-Saving Wager Technique, Double Standard Technique, and Cost-Benefit Analysis Technique.

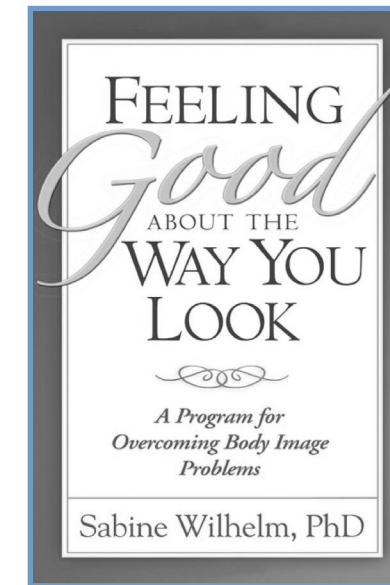
Step Seven targets in more detail the OCD from an exposure standpoint. The role of avoidance behavior, as well as the keys to making exposure exercises effective, are discussed. Abramowitz also provides useful "Treatment Buddy Tips" throughout this step and the remainder of the workbook. Step Eight details the use of imaginal exposure in overcoming OCD. Discussion centers on how situational and imaginal exposure can be used together, examples of when and how imaginal exposure can be applied, and setting up imaginal exposure practices. Step Nine details the use of ritual prevention to defeat compulsions. Ritual monitoring forms are introduced, as well as response prevention strategies. A discussion regarding family accommodation and its damaging effects on OCD treatment is also provided. Step Ten outlines practical ways to return to normalized behavior, measuring progress, and relapse prevention tips. Abramowitz discusses "living the CBT lifestyle" and how to end treatment.

Overall, this is an outstanding resource for anyone attempting to overcome OCD. Abramowitz uses a battle mentality throughout the book to educate and motivate the reader. He has written a workbook that is meaningful, yet explains complex topics in an easy-to-understand manner. Abramowitz has also sprinkled in just the right amount of humor in just the right places throughout his book. Everything someone needs to learn to overcome OCD is provided in this workbook. Nothing is missing. It is extremely comprehensive but not to the point of overwhelming the reader.

This workbook could also be easily used by therapists as a roadmap to direct care with their OCD patients. It is essentially a treatment plan manual that can be individualized to meet any OCD patient's needs. I also believe it would be a valuable read for graduate students attempting to learn more about OCD. All of the basics are provided in this workbook and taught by one of the leading experts in the field.

## THERAPY COMMUNITY

**Feeling Good About The Way You Look**  
**By Sabine Wilhelm, Ph.D.**  
**Reviewed by: Brad Riemann, Ph.D.**



*Feeling Good About The Way You Look* is a self-help treatment manual written for individuals suffering from a wide-range of body image-related issues including body dysmorphic disorder (BDD). The author of the book, Dr. Sabine Wilhelm, is the founder and director of the BDD Clinic and Research Unit at Massachusetts General Hospital, and is an Associate Professor of Psychology in the Department of Psychiatry at Harvard Medical School.

The manual is divided into eleven easy-to-follow chapters, an appendix, and a resource section. Chapter one provides detailed case vignettes that help the reader gain an understanding of the wide variety of body image concerns that one could have. In addition, Wilhelm makes the distinction between perception (one's body image) and reality (one's actual appearance) and states that the gap between these two concepts is where the problem lies. Chapter two provides the reader an understanding of why they may be having body image concerns. Wilhelm reviews media influences, family and cultural contexts, peer influences, personality traits, and brain functioning as all possible factors in the development of body image issues. Chapter three helps readers assess their readiness for treatment and introduces techniques (e.g., cost analysis) to

increase motivation to change. Chapter four includes a very thorough self-assessment protocol. Readers are trained to identify appearance-related thoughts, situations avoided because of body image concerns, body image-related rituals that one may perform, and long-term goals an individual has for their program.

Chapters five through eight provide detailed step-by-step, concrete strategies to overcome appearance-related distress. Numerous worksheets, questionnaires, and monitoring forms are provided. Specifically, chapters five and eight address the cognitive, or thought piece, of body image concerns including the use of Thought Records and Core Belief Worksheets. Chapters six and seven instruct readers in the application of the behavioral strategy of Exposure and Response Prevention. Included in these chapters are Exposure Worksheets, Trigger Situation Worksheets, and Self-Monitoring Forms for Appearance Rituals. Chapter nine provides very helpful tips related to relapse prevention (e.g., Relapse Prevention Planning Worksheet), while chapter ten presents a discussion regarding the potential use of medications to aid in the treatment of body image concerns. Chapter eleven is a review of ways to help a family member or friend with BDD or other related conditions. This chapter includes topics such as "Learning About the Problem", "Being Supportive", "Seeking Emergency Care", and "There is Hope". The manual concludes with an appendix describing BDD's relationship with other disorders (e.g., eating disorders, obsessive-compulsive disorder) and a very detailed listing of resources including treatment clinics, websites, and books Wilhelm feels would be helpful to readers.

Overall, I believe this is an outstanding resource for anyone dealing with body image related concerns. Wilhelm provides research-supported step-by-step advice as to how to reduce mild to completely incapacitating body image concerns. The manual is well-written and organized. Wilhelm displays a great ability to explain extremely complex concepts in an easy-to-understand manner. I believe this one-of-a-kind manual will also prove beneficial to loved ones and therapists not familiar with treating these issues.



## THERAPY COMMUNITY

## Institutional Member Updates

## KANSAS

Kansas City Center for Anxiety Treatment (KCCAT)  
 KU Medical Center Anxiety Research Program  
 10540 Marty Street  
 Overland Park, KS 66212

**(913) 649-8820**

It is with great excitement we share news of KCCAT's recent move and latest developments! While we didn't move far (across the street!), our brand new building triples our space and provides a variety of amenities that enhance our treatment, research, and training mission. One example is our Core CBT/Support Specialist Service that assists patients and families in addressing other diagnoses or issues that may co-occur and interfere with OCD treatment and their goals for ongoing management. This reduced-cost service is provided by Staff Psychologist Dr. Caroline Danda. Additionally, a new Support Group for Friends & Family of OCD Sufferers was developed by popular request and recognition of this area of need.

## ILLINOIS

Alexian Brothers Behavioral Health Hospital  
 1650 Moon Lake Boulevard  
 Hoffman Estates, IL 60169

**(847) 755-8566**

The Center for Anxiety & Obsessive Compulsive Disorders (OCD) at Alexian Brothers Behavioral Health Hospital is pleased to offer an Intensive Outpatient Program (IOP) with evening hours. The program offers support for anxiety disorders in the form of check-in and check-out groups, CBT psychoeducation groups, and 1.5-2 hours of individual exposure time on each programming day. It is intended for adults ages 18 years and up, as well as adolescents evaluated for appropriateness on a case-by-case basis.

This program is ideally suited for individuals who are working during the day or otherwise unable to attend

the afternoon IOP program, but are in need of a higher level of care than traditional outpatient treatment.

Program Hours:

Monday, Tuesday, & Thursday Evenings- 6:30pm to 9:30pm

Saturday Mornings- 9:00am to Noon

For more information, please call (847) 755-8566.

## CALIFORNIA

Cognitive Behavior Therapy Center for OCD & Anxiety  
 990 A Street, Suite 401  
 San Rafael, CA 94901-3000

**(415) 456-2463**

**www.cbtmarin.com**

The CBT Center offers new services for sufferers, parents, significant others and professionals.

Drs. Paul R. Munford and Arna M. Munford at the Cognitive Behavior Therapy Center for OCD & Anxiety developed an outreach program that uses free podcasts on our website to address the concerns of OCD sufferers, their families, significant others, and mental health professionals. The first podcast of the series is addressed to OCD sufferers who are reluctant or refuse to undergo Exposure and Response Prevention (ERP) because they fear that their anxiety would be unbearable. To reduce their apprehension we have produced a podcast that describes how we use exposure exercises that generate only mild to moderate levels of distress. The podcast is whimsical in the form of a fable entitled "The Lady Who Learned to Love Rats". Upcoming podcasts will be "The Irony of Doing the Opposite" and "Help for Families and Significant Others". PDF files of these podcasts will also be available.

## RESEARCH NEWS

### Are online support groups for hoarding helpful? Considering D.I.T.C.H. (Delivery of Internet Treatment for Compulsive Hoarding)

By Jordana Muroff, LICSW, PhD

Dr. Jordana Muroff and collaborators Dr. Gail Steketee, Dr. Randy Frost, and Dr. Joseph Himle would like to thank the International OCD Foundation (IOCDF) for the 2007-2008 Research Award that supported this research project. Additionally, they are sincerely grateful to the online group leader Paula Kotakis, participants of the H-C Group, and the research assistants. For more information on online support groups for hoarding please see [www.ocfdoundation.org/hoarding/self\\_help.aspx](http://www.ocfdoundation.org/hoarding/self_help.aspx) and [health.groups.yahoo.com/group/H-C](http://health.groups.yahoo.com/group/H-C)

In 1998, several innovative people organized and began to moderate an online peer-led self-help support group for people with hoarding and clutter problems, inspired by a strong desire to connect with others to reach their common goal. This online community has grown tremendously over the years, including 100+ members and a waitlist of similar length. Members have access to resources, tips, and tools to help them work on their dehoarding/decluttering and report action steps and/or progress at least once monthly. While many people attest to its helpfulness, the online support group leaders desired a better understanding of how effective their group intervention was in helping people manage their hoarding and reach their goals. A joint investigation between the group leaders and researchers was started, fondly termed D.I.T.C.H. (Delivery of Internet Treatment for Compulsive Hoarding) (Muroff, Steketee, Frost, & Himle, 2010).

#### The Problem

Hoarding includes too much clutter in the home or workplace such that the areas cannot be used fully for their intended purpose (e.g., possessions are piled on the kitchen counters and stove so that it cannot be used for cooking), resulting from strong urges to keep, and great difficulty in discarding, things (Frost & Hartl, 1996; Mataix-Cols et al., 2010). Some people with hoarding buy, collect, or acquire things excessively. Affecting about 1 in 20 people (Samuels et al., 2008), hoarding symptoms cause much stress as well as strained relationships and employment problems. In some cases, the clutter

creates a safety hazard for the individual, family, and community, violates health codes, and/or leads to other problems such as evictions. Some view their own hoarding behaviors as being a problem while others do not recognize it as such, showing poorer insight and lower motivation to change.

As hoarding sufferers themselves, the group leaders understood the complexities of this problem, the great need to distribute helpful information and reduce the considerable loneliness that those with hoarding experience. They developed this online Yahoo-based support group by working with hoarding experts and having an eye toward research.

#### Background Research

Early research suggests that hoarding is challenging to treat and less responsive to medicine and therapy that has been shown to be effective for other obsessive compulsive disorder (OCD) symptoms. A specialized form of cognitive behavioral therapy (CBT) for hoarding was developed by Drs. Gail Steketee and Randy Frost and colleagues (Steketee & Frost, 2007), and has shown promising results (Tolin et al., 2007; Steketee et al., 2010). However, few people have access to therapists well-trained in this treatment. Evidence suggests that an internet-based self-help support group for hoarding may be helpful. The internet has become an important source of health information for a growing number of people, with anxiety problems being among the most common health conditions for which people seek information online (Taylor, 1999). Web-based programs for other mental health problems related to hoarding have shown good results (e.g., depression, social anxiety) (Andersson, 2006; Carlbring et al., 2006). Self-help CBT strategies with little or no therapist involvement also have been shown to be helpful in treating OCD and hoarding (Fritzler, Hecker, & Losee, 1997; Mataix-Cols & Marks, 2006; Pekareva-Kochergina and Frost, 2009). An internet-based support group may be particularly useful given the home-based nature of hoarding, the resulting

## RESEARCH NEWS

shame, desire for confidentiality, and the need for accessible and affordable interventions for this complex problem. Such a group may also increase motivation and reduce isolation associated with hoarding. The current study was the first to test the effectiveness of an internet CBT-based self-help group for hoarding.

### Intervention

The group includes a formal application process and requires that each member post action activities, goals, and/or progress at least once monthly (referred to as action stage reporting). Such activities may include sorting, discarding, going to the store without buying anything, maintaining organized or cleared areas, applying specific CBT tools, etc. Members may request a “breather” (a temporary departure from the list approved by the list managers with the ability to return when ready). If a member does not post monthly and does not request a breather then they are removed from the group. Members may also access information about the nature and treatment of hoarding, worksheets to help them address problematic beliefs, and referral lists. They also communicate directly with one another, discussing hoarding related topics, sharing successful strategies, resources, and photos, and helping each other problem-solve specific situations.

### Evaluation

Members of the online support group and those on the waitlist were invited via email to participate in anonymous web-based surveys. A total of 5 surveys were offered over the span of about one year, about every 3 months. Each survey included questions about hoarding behavior and related problems, mood, other mental and physical health problems, and social connections. For example, the Saving Inventory – Revised (Frost, Steketee, & Grisham, 2004), Clutter Image Rating Scale (Frost, Steketee, Tolin, & Renaud, 2008), and Clinical Global Impression scale (Global Improvement item; Guy, 1976) were included. Research participation was completely voluntary, did not affect participants’

access to the group, and was unknown to the group leaders. Each participant was offered a gift card for each survey that they completed.

Research participants were mostly female, white, middle-aged, and well-educated with about half being employed and/or married. This is consistent with the characteristics of the group members and those on the waitlist. Researchers divided the participating members into 2 groups: those who had recently joined the group and those who were long-term members. Recent members were defined as those who had become members any time between 3 months before the surveys started and 15 months later when the final survey was given. Long-term members were those who had been members for longer than 3 months before the surveys began. By separating the membership groups, the researchers aimed to examine the effects of recently joining the group versus being in the group for a long time, with the expectation that those who had already been in the group for a while would have had improvement before this study started. This was actually shown to be true. At the start of the study, long-term members reported less hoarding problems than those who had recently become members or were on the waitlist.

Researchers compared recent and long-term members and those who were on the waitlist for a 6 month period. Recent members showed greater improvement in hoarding symptoms and less clutter over the 6 months than those who were on the waitlist. Those on the waitlist showed little improvement. When examining the full study period (15 months), both recent and long-term members showed further improvement. Researchers could not compare members to those on the waitlist because all those on the waitlist were invited into the group by that point. These results suggest that participating in the online CBT-based support group led to many benefits, especially for those participating for longer periods. Finally, participants who were less active (made fewer postings) in the group had significantly greater hoarding problems than those who posted more, suggesting that greater involvement in the group was helpful. [For more detailed results please see Muroff et al., 2010.]

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### Conclusions

This is the first study to test whether an online CBT-based support group intervention helps those with hoarding better manage their symptoms. Results suggest that this is a promising intervention that can reach large numbers of people across the US and abroad. While the web-based support group results are more modest than individual and group in-person hoarding treatment (Muroff et al., 2009; Steketee et al., 2010; Tolin, Frost, & Steketee, 2007), it was still shown to be helpful sans more intense CBT interventions, therapist-assisted home visits, or even minimal therapist support. This study adds to the growing evidence that specialized CBT-based methods for hoarding are effective and may be delivered individually, in groups, and online, with varying levels of therapist involvement, and through self-help strategies. It also shows that people with hoarding problems are skilled at using computers and navigating the web, allowing them to access online treatment. Additionally, as shown by this study and other studies by Dr. David Tolin and colleagues, people with hoarding seem comfortable completing online surveys. Furthermore, this study also points to the very strong interest among people with hoarding problems in web-based interventions, given the overwhelming interest in this group for over a decade shown by large numbers of members and a long waiting list. Such methods may extend access to treatments that are supported by research findings (e.g., cognitive behavioral methods for hoarding) and reduce costs associated with such treatments. Moreover, online interventions may extend access to peer support, group interventions, and clinicians who are well-trained to treat this challenging problem, as well as facilitate home-based practice. Some may combine web-based and office-based treatments while others may only seek online assistance. It is very important to continue developing and researching online interventions given their rising demand and popularity.

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## RESEARCH NEWS

## Participants Sought

## NEW YORK

**Neural Correlates of Emotional Response Inhibition in Obsessive-Compulsive Disorder**

The Mount Sinai Center of Excellence for OCD and Related Disorders is recruiting participants 18 years of age or older with a diagnosis of Obsessive-Compulsive Disorder for a functional magnetic resonance imaging (fMRI) study.

Participation in this study requires one three-hour visit to the Mount Sinai Medical Center for a clinical evaluation and a separate 60-minute MRI scan, which patients will receive at no charge.

Inclusion criteria for the study include:

- Age 18 years or older
- Current DSM-IV diagnosis of Obsessive-Compulsive Disorder

Exclusion criteria for the study include:

- Severe medical or neurological illness;
- Presence of any type of metal in the body that cannot be removed (e.g., braces);
- Claustrophobia or anxiety that precludes being in the scanner for one hour;
- Visual disturbance of sufficient severity as to impair performance while in the scanner without glasses.

You will receive \$170 for your participation in this study.

For further information, please contact Elisabeth Cordell at (212) 659-8823 or email [centerforOCD@gmail.com](mailto:centerforOCD@gmail.com)

## NEW YORK

**Understanding Obsessive Compulsive Personality Features**

Is perfectionism causing problems for you?

Do others complain about your rigidity?

Do you worry too much about order and details?

Do you find it difficult to relax and enjoy free time?

Are you constantly trying to control things?

Do you plan out every minute of your day?

Researchers at Columbia University Medical Center/ NYSPI in Manhattan are seeking participants (age 18-60) in the NY metro area with several of these features for a study designed to learn more about the obsessive compulsive personality style and ways of thinking, and how these features affect life functioning. Participants will receive a confidential evaluation at no cost and payment upon completion of an interview, questionnaires, and computer tasks.

For more information about the study, contact Jordan at (212) 543-5938.

To learn more about our research center, visit [www.columbia-ocd.org](http://www.columbia-ocd.org)

## RHODE ISLAND &amp; NEW YORK

CHILDREN WITH BODY IMAGE CONCERNS: Body Dysmorphic Disorder (BDD) Research Study for Adolescents and Children

- Are you an adolescent or child who dislikes the way any part(s) of your body (for example, your skin, hair, nose, eyes) look?
- Do you think about your appearance for more than one hour per day?
- Do you engage in any behaviors intended to check on, hide, or fix your appearance (for example, mirror checking, comparing yourself to others, excessive grooming, skin picking, or clothes changing)?
- Do you avoid any places, people or activities because of your appearance concerns (for example, do you avoid bright lights, mirrors, dating, or parties)?
- Do you have problems with your school, family, or relationships because of your appearance concerns?
- Do your appearance-related thoughts or behaviors cause you a lot of anxiety, sadness, or shame?

If you answered yes to any of these questions you may qualify for a no-cost evaluation and to take part in a 12 week medication research study for children and adolescents (16 years old and younger) being conducted at the Montefiore Medical Center/Albert Einstein College of Medicine in New York City and the Rhode Island Hospital/Alpert Medical School of Brown

## RESEARCH NEWS

University in Providence, RI. The goal of the study is to find out if Fluoxetine is an effective treatment for pediatric body dysmorphic disorder. All eligible children and adolescents who enroll in the study will be placed on either Fluoxetine or a placebo. All study participants will be offered 12 weeks of treatment following the study at no cost to them.

After a brief telephone screening (parental approval will be obtained before speaking with the child), interested participants have an interview with a research study doctor. During the interview, they will receive a psychiatric and medical evaluation to find out if they are able to participate in the study. Depending on the outcome, they may or may not be enrolled.

If enrolled, there will be a physical examination at the beginning and end of the study. Lab tests, including blood and urine tests and an electrocardiogram (a test used to measure heartbeat irregularities) will be done at the beginning and end of the study. After the initial screening, all following evaluations will include recording vital signs/weight, side-effects and completing rating scales.

This study is being directed by Drs. Eric Hollander and Katharine Phillips who are internationally known for their expertise on the treatment of BDD.

Participants will be paid for their time and study medication will be provided at no cost.

If you are interested in participating in this study, live within 1-1.5 hours driving distance of New York City and would like further information, please contact:

Casara Ferretti  
The Compulsive, Impulsive, and Autism Spectrum Disorders Program  
Montefiore Medical Center University Hospital for The Albert Einstein College of Medicine  
Bronx, NY 10467-2490  
Phone: (718) 696-3036  
Email: [cferrett@montefiore.org](mailto:cferrett@montefiore.org)

If you are interested in participating in this study, live within 1-1.5 hours driving distance of Providence, RI, and would like further information, please contact:

Martha Niemiec  
The Body Dysmorphic Disorder Program  
Rhode Island Hospital, Coro Center West  
One Hoppin St.  
Providence, RI 02903  
Phone: (401) 444-1644, Email: [bdd@lifespan.org](mailto:bdd@lifespan.org)

## PENNSYLVANIA &amp; NEW YORK

## Maximizing Treatment Outcome in OCD

This study compares the effectiveness of two proven treatment strategies for OCD patients who are currently on a serotonin reuptake inhibitor medication (SRI, i.e., clomipramine, fluoxetine, fluvoxamine, paroxetine, sertraline, citalopram, or escitalopram) but still have residual symptoms. Participants remain on their current medication and receive either cognitive-behavioral therapy (CBT) consisting of exposure and ritual prevention or an additional medication (risperidone).

The goal of the study is to compare risperidone against cognitive-behavioral therapy as add-on treatments, each of which has been found effective in prior studies. All treatment is at no charge. Note: Patients who do not improve after 8.5 weeks of treatment will be offered at no-cost the treatment they did not initially receive (either the therapy or the add-on medication).

To schedule a confidential screening, contact: New York Metropolitan area: Dr. James Bender Jr. (212) 543-5462 or Liane Hunter (212) 543-5380; Philadelphia: Center for the Treatment and Study of Anxiety (215) 746-3327

## CALIFORNIA

## Neural Correlates of Compulsive Hoarding

Researchers at The University of California, San Francisco are conducting a study to learn more about people with severe hoarding behaviors and their family members.

Participation involves:

5-10 hours of patient time, over 2 to 3 visits;  
Payment up to \$200

Inclusion criteria:

18 years old or older; Have severe compulsive hoarding symptoms; Have at least one blood degree relative available to participate

Exclusion criteria:

Diagnosis of the following: Schizophrenia, Mental Retardation, Known Dementia or any acute condition known to effect executive functioning; No living blood relatives

## RESEARCH NEWS

We are also recruiting individuals with non-hoarding OCD and their blood relatives. If you would like to learn more about this study, please contact Shiva Fekri at (415) 476 - 7732. We look forward to hearing from you!

**ONLINE**

How much do you care? Self-compassion in Obsessive Compulsive Disorder

Help us as we examine the relationships between self-compassion and values in OCD.

<http://www.surveymonkey.com/s/2ZVJVNC>

Help us as we examine the relationships between self-compassion, mood, and response styles in OCD.

<http://www.surveymonkey.com/s/PYHKNM2>

Enter either link into your web browser to do the survey. If you are over 18 years of age and have Obsessive Compulsive Disorder, you may participate. Participation is completely anonymous. Your information will never be sold or shared and is only for research purposes.

**ONLINE**

Online Survey of Obsessions and Compulsions.

We are looking for individuals to fill out two short online questionnaires regarding their OCD symptoms. Doing so should take approximately 10 to 25 minutes of your time and you have the chance to win a Visa Gift card.

If you are between the ages of 18-89, have been diagnosed with OCD, and are interested in helping researchers at Eastern Virginia Medical School better understand how these two questionnaires can identify and assess OCD symptoms, please go to: <http://OCD.questionpro.com>

If you have questions, please contact the researchers: Amber Walser, M.A., at [amberlea5@gmail.com](mailto:amberlea5@gmail.com) or (305) 304-4196 or Richard W. Handel, Ph.D., at [handelrw@evms.edu](mailto:handelrw@evms.edu) or (757) 446-5888.

Advertising approved by the Eastern Virginia Medical School IRB. IRB #10-06-WC-0134

## FROM THE AFFILIATES

**NEW JERSEY****OCD New Jersey (www.ocdnj.org)**

OCD New Jersey would like to announce the following upcoming event:

On Monday, March 14, 2011, Anthony Pinto, Ph.D. will be presenting at the OCD New Jersey quarterly education/meeting. His topic is entitled, "Understanding Obsessive Compulsive Personality Disorder and Its Impact on Obsessive Compulsive Disorder." This quarterly meeting will be held at Robert Wood Johnson Hospital in New Brunswick, NJ

Dr. Pinto is a Research Scientist in the Anxiety Disorders Clinic of the New York State Psychiatric Institute and Assistant Professor of Clinical Psychology (in Psychiatry), Columbia University College of Physicians and Surgeons. His research has focused particularly in elucidating the relationship of OCPD to Obsessive Compulsive Disorder (OCD).

In addition, we had a table set up at the Middlesex County Psychologist Association Brunch on December 12. The topic was on alternative theoretical approaches to the treatment of OCD.

For more information on this event and OCDNJ, please go to our web site at [www.OCDNJ.org](http://www.OCDNJ.org), or contact our president, Ina Spero, at (732) 828-0099.

**Announcing our two newest affiliates****ARKANSAS****OCD Northwest Arkansas**

So far, we are a small but enthusiastic group. We need volunteers who are interested in helping us get the word out to the community and developing and publicizing a website. Northwest Arkansas has a limited number of practitioners who treat OCD and related disorders. We will be reaching out to local practitioners to encourage and support efforts to further their education in the assessment and treatment of OC related conditions.

Currently, there are no support groups in the area, which means that we need volunteers who are willing to participate in developing and/or leading support groups. Lastly, we need help organizing a quarterly lecture series and fundraising efforts. If you are interested in volunteering or making a financial donation to support our efforts, please contact Suzanne Meunier at (479) 200-1922 or [ocdArkansas@ocfoundation.org](mailto:ocdArkansas@ocfoundation.org).

(From the Affiliates Continued on back cover)

**2011 Research Awards Request For Proposals****Submission Period:**

**January 3, 2011 — February 28, 2011 at 5PM**

The International OCD Foundation is committed to finding and promoting effective treatment for everyone. To further this mission, the Foundation is interested in funding research into the brain, its chemistry, structure and functioning; basic neurobiology; the genetics of OCD; its epidemiology; and all aspects of OCD and the OC Spectrum Disorders that will lead to prevention and treatment advances.

The Foundation has been awarding research grants since 1994. Since then, it has funded millions of dollars in OCD research.

For application guidelines and submission information, go to [www.ocfoundation.net/grants](http://www.ocfoundation.net/grants)

If you have additional questions, please contact Barbara Rosemberg at [brosemberg@partners.org](mailto:brosemberg@partners.org)

## FROM THE AFFILIATES



### TEXAS

A kickoff conference, held in Austin, TX October 16, 2010, in conjunction with OCD Awareness Week, was a huge success with 77 attendees.

Elizabeth McIngvale, IOCDF Spokesperson, gave the keynote address, "Life With OCD: From Sufferer to Advocate". Bruce Mansbridge, PhD, Director of the Austin Center for the Treatment OCD, gave an "OCD 101" lecture. Several special support and networking break-out sessions gave participants opportunities to share experiences and make new friends.

In her welcome and opening remarks, Irene Tobis, President of OCD TEXAS, said that starting an affiliate was scary, but that the small group of volunteers had decided to "feel the fear and do it anyway" and they had already learned that to make it happen they had to let go of perfection.

OCD TEXAS's mission is to bring together OCD sufferers, their families and friends, and treatment providers across Texas to:

- Raise awareness and provide education and information about OCD and related disorders to sufferers, their loved ones, treatment providers, and the public;

- Assist individuals afflicted with OCD to identify, seek, and gain access to appropriate support and affordable treatment; and
- Improve quality and availability of treatment and support for individuals with OCD.

Officers are:

Irene Tobis, President

Bobbi Duncan, VP & Member Support

Saharah ShROUT, Secretary

Robert Norris, Treasurer

Loren Haas, Outreach

OCD TEXAS also plans to hold quarterly conferences. The next conference, with the theme "OCD Treatment in Texas" will be in Dallas on February 19. Contact Peggy McMahon, PhD, Dallas Meeting Coordinator, at [meeting-Dallas@ocdtexas.org](mailto:meeting-Dallas@ocdtexas.org) to help. The following meeting will be in Houston.

The IOCDF currently has only 139 members in Texas. OCD TEXAS hopes to increase membership and participation substantially.

To opt-in for email announcements, send an email to: [membersupport@ocdtexas.org](mailto:membersupport@ocdtexas.org).

For more information, please go to our website: [public.ocdtexas.org](http://public.ocdtexas.org)



Irene Tobis, President  
OCD Texas