

FROM THE FOUNDATION

Increased Emphasis on OCD in Kids and Teens Initiatives at the Foundation



Home page on www.OCDinKids.org

A conservative estimate is that as many as 1 in 200 kids and teens have OCD. This means four or five kids with OCD are likely to be enrolled in any average-sized elementary school. In a medium to large high school, there could be 20 students struggling with the challenges caused by OCD. In the spring of 2011, I did an interview for the Teens Kids News show. The first thing the interviewer asked was: "So kids and teens can really have OCD? I've never heard of that!" We clearly have our work cut out for us!

The innovative "OCD in the Classroom" kit – developed by the Foundation over a decade ago – is aimed at educating school personnel about OCD so that they could more readily recognize it and help children get proper care. This kit has been used for the past decade by our affiliates and has been an incredibly successful program in disseminating information about OCD in kids. Our recent, informal online survey about OCD in schools showed that 95% of kids report that their OCD symptoms affect their school performance with lowered grades (60%), school day absences (44%) and trouble with teachers (41%) leading the list. Additionally,

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FROM THE FOUNDATION

Letter From The President



Dear Friends,

I hope you all enjoyed the holiday season and are off to a good beginning in 2012! I want to thank all of you who contributed to our year-end and research campaigns. Your support, as always, is what keeps us going, and it is so appreciated.

It is very exciting to announce to you two new members of our Board of Directors. Paul Mueller and Shannon Shy both joined the board this past November, and we feel very lucky to have them involved in our organization. Paul is currently the Chief Operating Officer of Roger's Memorial Hospital in Oconomowoc, WI. With a Bachelor's and a Master's degree in Social Services from the University of Wisconsin/Milwaukee, Paul has over 25 years experience in the administration and management of behavioral health services. Paul has a passion for treating children and adults with mental illnesses, and we know his broad expertise will be invaluable to us as we continue to grow our organization both domestically and internationally.

Shannon is a retired Marine Lieutenant Colonel who currently works as a senior civilian attorney with the Department of the Navy. Shannon is the author of *"It'll be Okay": How I Kept Obsessive-Compulsive Disorder (OCD) from Ruining My Life*. A poignant speaker about the devastating effects of OCD, Shannon offers a message of hope to our many constituents. His personal investment, as well as his many obvious strengths, will be a huge asset to our board.

It is so rewarding to see the changes in the IOCDF over the past four years during my tenure as President. I will be stepping down as president in March of this

year, and this role will be one that I will look back on as one of my most cherished accomplishments. Four years ago, we had recently moved the office to Boston, had an entirely new staff, and were just beginning to have a broader vision of the foundation as an international presence for people with OCD and their loved ones. Now, four years later, I am so proud of our board of directors and national office staff and what we have accomplished. As a team, we have grown a small, grassroots organization into the place to find information about OCD. We are offering more Behavior Therapy Training Institutes, have doubled the number of our affiliates, have expanded our web site and added two more companion sites, and have broadened our reach beyond the borders of our own country to many others. We are also raising more money for education and research. Our conference is widely recognized as a leading resource for OCD clinicians and researchers, as well as for patients and families. There is no organization with which I could be more pleased to be associated. I will remain on the board of directors, but look forward to "passing the baton" to the next president, who I am sure will continue to move forward with our very important mission with great success.

Of course I thank all of you who have offered me support and guidance throughout my two terms as President. It is all of you who inspire me to do my best work every day.

Wishing you all peace and happiness in the New Year.

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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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.

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FROM THE FOUNDATION

Fundraising Initiatives

I want to first take a moment to introduce myself. My name is Jeff Smith, and I am the International OCD Foundation's new Development Director. For 25 years, the IOCDF has helped people living with OCD, their families and friends. Since its beginning in Hartford, Connecticut, the Foundation has relied solely on the generosity of individuals who support its work through making a charitable donation. The combined generosity of its donors and members allows the IOCDF to remain committed to its mission and goals of:

- Educating the public and professionals about OCD in order to raise awareness and improve the quality of treatment provided;
- Supporting research into the cause of, and effective treatments for, OCD and related disorders;
- Improving access to resources for those with OCD and their families; and
- Advocating for the OCD community.

Below are the various ways in which YOU can contribute to the fundraising efforts of the IOCDF which and help us to fulfil our mission.

Annual Fund Appeal

In October of each year, the IOCDF conducts its Annual Fund Appeal (No Show Ball). The Annual Fund Appeal supports the work of the Foundation through the receipt of unrestricted donations. These annual fund gifts provide tremendous flexibility for the foundation to address needs and absorb the cost of existing and new initiatives without jeopardizing the commitment to its mission to help people living with OCD. And because annual fund dollars are available for immediate use, their effect is significantly realized. Annual fund contributions are the lifeblood of the IOCDF. Gifts to the annual fund, no matter the size, have a direct and lasting impact on everyone who has been helped by the IOCDF. When you give to the Annual Fund, you are supporting the programs that are critical to the IOCDF's mission, including:

- Behavioral Therapy Training Institutes- the IOCDF conducts nationwide trainings for therapists and clinicians on the most up to date and effective ways of treating their patients with OCD;
- Awareness and Advocacy Programs- like OCD Awareness Week;
- Web-based outreach- including the IOCDF website, hoarding, and pediatric websites; and
- Our comprehensive international Treatment Provider Database.

Research Appeal

A top priority of the Foundation is to promote research into the causes and treatment of OCD and related disorders. Each November, the IOCDF solicits donations that go directly to support qualified and worthwhile research projects. In 1994, the Foundation launched the Research

Grant Award Program. Each year, the program funds three to eight research projects of \$25,000 to \$50,000 per grant. Total grant awards range from \$70k to \$300k annually, and the Foundation has distributed a total of \$2.7 million dollars in research grant funding since the inception of the program. We all know how important research is in helping find the causes of OCD and related disorders and in helping to develop new and more effective treatments. Funding for these yearly research awards would not be possible without the generosity of Foundation donors, who designate a gift to the OCD Research Fund. **One hundred percent of contributions to the Research Fund are used to fund winning projects.**

Corporate Matching Gift

Many companies support the philanthropic interests of their employees by offering to match your gift either completely or by some multiple or percentage of your donation. If you have questions about how to do this, please contact us here at our office at **617-973-5801**. You can also directly contact the appropriate representative at your place of work (such as your Human Resources department) to find out if they match contributions to charities supported by their employees. A matching gift is a great way to make your generosity go even further!

Remember the IOCDF in Your Will

Most people know how important it is to have a will. And once you have provided for the people you love, we hope you will consider a bequest to the IOCDF. Bequests of any size can help ensure that the foundation will be here, serving the OCD community and your loved ones, for years to come.

Have you already named the IOCDF in your will? Let us know! Call us at **617- 973-5801** so we may include you in our Legacy Program.

There are many other ways to make a gift to IOCDF while providing you some tax benefits. Speak with your estate planner about Gifts of Appreciated Stock, Life Insurance, and Charitable Remainder Trusts.

There are many valuable ways in which you can support the IOCDF. We sincerely hope that if you have not yet made a gift to support the Foundation, you will consider doing so today. For your convenience, we have included a giving envelope in this newsletter. If you have already made a gift to the Foundation, we are extremely grateful for your help. However, if you find that you are in a position to make an additional gift, we ask that you consider helping the IOCDF by supporting our No Show Ball or Research Appeal.

Thank you again for your continued support of the IOCDF!



Jeff Smith
Development Director

FROM THE FOUNDATION

Increased Emphasis on OCD in Kids and Teens Initiatives at the Foundation

(Continued from front page)

almost a third of kids report bullying as a result of OCD symptoms. As a result, getting information out to the school system in light of these figures is imperative.

In fact, we are currently updating our OCD in the Classroom kit to be included on our recently launched OCDinKids.org website. Tremendous thanks go out to Drs. Evelyn Stewart, Aureen Wagner, Fred Penzel, Jeanne Fama, Eric Storch, Barbara Van Noppen and Tanya Murphy for writing all of the content for that site, as well as for their work updating the OCD in the Classroom kit. The new OCD in Kids website is broken down into five different sections: information for parents, kids, teens/young adults, school personnel and mental health professionals. Support groups, books, personal stories and other resources will continue to be added to this site in the coming years.

In 2010, we also launched a kids and teens specific “track” at our Annual Conference which features presentations and interactive workshops aimed at educating kids and teens about OCD. If you were at the conference this past year, you might have seen the kids running around the hotel during the “Can Harry Potter Cure OCD?” experiential activity run by Jennifer Wells from the Lindner Center, Ohio. We heard from several parents and conference goers how great it was to see the kids enjoying themselves so much at the conference. The kids and teens track is a complement to the extremely popular art therapy rooms. This year, the kids and teens art therapy rooms were run by Jenifer Waite-Wollenburg and Erin Headley from Rogers Memorial Hospital in Wisconsin and as always we heard what an amazing experience everyone had together.

Another pediatric OCD initiative that was launched this year was the promotion of awareness through the use of media. As a result we have had media stories about OCD in kids and teens in CNN.com, USA Today, Teens Kids News (aired around the country), Dallas Morning News, NBC San Diego, and two stories on PANDAS (Pediatric Neuropsychiatric Disorder Associated with Strep) in the LA Times and Wall Street Journal. Kids having an opportunity to tell their stories raises awareness of OCD in general, and also helps other kids and parents recognize that they are not alone.

Our most recent project has been to develop a pediatric-specific Behavior Therapy Training Institute (BTTI). As many of you know, our BTTI's are extremely successful and well-attended three day, intensive trainings for mental health professionals. These trainings have been run by Dr. Alec Pollard, who enlists OCD experts all around the country to help train professionals in effective assessment and treatment strategies for OCD. This new curriculum will be put together by Dr. Pollard, along with pediatric experts Dr. Eric Storch, Dr. Aureen Wagner, Dr. Martin Franklin and Dr. Evelyn Stewart. The first training should be available in early 2013. Please help spread the word to anyone you think might be interested.

As always, we are open to hearing feedback from the Foundation community about any of these programs as well as any other projects and programs we are working on. For those of you who are members and/or donors, thank you again for all of your support. None of this could be done without you.

Jeff Szymanski, PhD
Executive Director



ANNUAL CONFERENCE 2012

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- **Find support groups and treatment**

Who should attend?

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- **Professionals who provide therapy, support and information to those affected by OCD**
- **OCD Researchers**

More info at: www.ocfoundation.org

FROM THE FRONT LINES

A Life Interrupted – The Story of My Battle with Bullying and Obsessive Compulsive Disorder

by Sumi Mukherjee

Sumi is a 35-year old author from Plymouth, MN. He is also a professional public speaker focusing on impact of prolonged childhood bullying on mental health. For more information about Sumi please visit www.bullyingandocd.com.

As I write in this edition of the OCD Newsletter, I am ready to share my graphic, first person account with everyone around the world. My recently published book, “A Life Interrupted: The Story of My Battle With Bullying and Obsessive-Compulsive Disorder”, establishes a definitive connection between prolonged childhood bullying, Post Traumatic Stress Disorder and the development of one of the more taboo forms of OCD later in life. Moreover, my most crippling OCD symptoms would consist of mentally picturing images of bullies who had tormented me in the past. These images would soon become further attached with an unspeakable irrational fear - that they would force me to hurt or kill my loved ones if the images were not ‘neutralized.’ If you find these concepts difficult to understand at a first glance, you cannot imagine how perplexing they appeared to me as a terrified teen and young man.

The onset of my OCD occurred in May 1992 at the age of 16. For the first five years of my mental illness, my single greatest struggle and obstacle became simply telling someone what was going on. Instead I lived a secret life hiding in the shadows being afraid that I was losing my mind. My frightening condition kept me isolated from others and unable to pursue the normal drives of a healthy young man. Friendships were few and far in between, while dating remained out of the question. Before long, merely managing to function through an average day became the greatest challenge of all.

The first success that I can speak about finally came at the age of 21 in 1997, following the loss of my job at a hotel due to my incapacitating symptoms. At last I came out to my family about what was going on, and they were able to get me the therapy and medication that I needed to defeat OCD. But learning about the complex nature of OCD would be a process that would take me several more years to complete. First came a phase of tremendous relief at the realization that I wasn’t going crazy after all, and that I would not have to be institutionalized at a psychiatric hospital! Then second came a major bout of depression and self pity over the fact that I had been diagnosed with this form of OCD. However, I was at last able to change my pessimistic perspective, willingly engage in cognitive behavioral

therapy, and begin to make significant progress with my illness. During this time period, I was also able to look up and confront my very worst bully from childhood. This most fascinating, revealing encounter helped me to finally deal with the bullying and with my PTSD.

Tragically, nearly all of this progress would be sacrificed when I foolishly decided to go off my medications so that I could drink alcohol and party in my mid to late 20s. Having missed out on such fun thus far in my life, I was willing to risk everything just to feel as though I was normal like everyone else. As a consequence of these poorly thought-out actions, I suffered a devastating relapse and ended up in the intensive OCD treatment program at Rogers Memorial Hospital in Oconomowoc, Wisconsin in April 2005.

Amazingly, I was able to derive a lasting positive impact after spending only 16 days in Rogers’ inpatient treatment facility – a positive impact that has lasted throughout the past six years of my life. I attribute my lasting success to a specific change in my medication regimen made at the facility, as well as their tough approach to ERP (Exposure and Response Prevention) which I took to heart upon leaving the program. Though my success did not come until several months after I had left Rogers, the change in my meds and the knowledge I had gained would slowly show their purpose over time.

Today, I am thrilled to report that I have finally regained control over my once incapacitating mental illness! Though my ordeal has now reached this much better point, there are millions of other people out there who continue to struggle hard with OCD on a daily basis. I am here to tell fellow OCD sufferers that this does not have to be your long-term fate. Just as I took back control of my life, you too are capable of freeing yourself from the powerful clutches of this hideous disease.

It is my profound hope that OCD sufferers, their loved ones and mental health professionals are all able to learn and benefit from reading my new book. Along with sharing my personal story, I further lay out a proven formula which, along with the proper medication regimen, any patient can use to slowly overcome the crippling symptoms of Obsessive-Compulsive Disorder. For more information about me and my book, please visit my website at www.bullyingandocd.com.

FROM THE FRONTLINES

Finding my Way by Joe Alterman

Joe Alterman is a 23-year-old pianist originally from Atlanta, Georgia. He is currently living in New York City where he is earning his Master's Degree in Music from New York University and is also an adjunct faculty member. More information about Joe can be found at www.joealtermanmusic.com.

I used to cringe whenever I'd hear the words "obsessive", "compulsive," or "disorder"; my eyes would even twitch. I'd hear the words muttered, most often incorrectly (often in reference to a girl who likes to shop or a boy who is often thirsty) and I'd shake as those words reminded me of the tortuous hell in which I once lived and of the evil slave-master and his house in which I once dwelled. Just hearing the words "obsessive compulsive" would send me back 5 years to a time in which counting, organizing, cleaning, and fixing were king and ruled my time and my life.

I remember sitting in class during my freshman year of high school, and how in the middle of an important test my mind would instruct me, instead of focusing on the test, to count to 60, 80 times. Of course, I'd have to obey my mind, abandoning the test to satisfy my then-needs. I remember one of the hottest days of my life, at summer camp in North Georgia, walking through the woods by myself. In mid-walk and without any water, my mind forced me to retrace each step, multiple times, before I could continue on to my next step. What could have been a five minute walk turned into an hour and a half walk; I didn't even make it to the end of the trail. A counselor found me, dehydrated, mid-step, and he had to literally pull me away from my compulsions; I remember fighting him to let me stay and finish. I remembered how excited I used to be, once I finished my night's counting, lying there in bed and closing my eyes; finally, in my sleep, I'd have eight hours of freedom.

I remember finally getting treatment. Every medicine backfired. By the end of my go with one of the drugs, my eyes had been dilated for nearly a week and I'd lost the ability to climax sexually. I didn't care. I didn't even have the time to think about girls; my mind was always preoccupied with obsessions and compulsions. But then again, what 16 year old boy spends their time thinking about girls anyways?

Before I found solace in behavior therapy, the only place I found any sort of freedom was in music. I'm a pianist, and as I struggled and exhausted myself faking my way through social situations, I found that the only place I could be myself was at the piano. Also, while I was away from the piano I found that the music of people like Ahmad Jamal, Sonny Rollins, and Nat King Cole was like medicine to me; it calmed me down like nothing else could. Eventually, I reached

out to Sonny Rollins, a jazz legend, expressing to him via his guestbook on his website how his music had been helping me through a difficult time. He wrote back, and I'll never forget his response: "Dear Joe, Your comments were appreciated. We all have to use adversity as an opportunity to find a way. Keep a strong mind throughout this short existence. Your example gives us all hope, as all of us here in this life have to struggle."

What he wrote about having a strong mind really struck a chord with me, and with all the medicine failing me, I decided to beat OCD with behavior therapy. After many months of intense therapy - my doctor would come over many mornings and walk me through my daily routines, changing everything each time and challenging me to complete difficult and time-consuming tasks in a very quick and timely manner - I eventually beat OCD.

Sure, OCD is known to wax and wane, but through the behavior therapy treatment I have acquired the skills to control my own mind, so that when an urge does pop up, I can fight it back and reject it.

The main focus of my life since recovering has been my music. I just graduated from New York University with a music degree this past May. I have surprisingly had quite a lot of success in music, and I feel that I owe everything that I have accomplished to the things that I learned while dealing with OCD. Living with and dealing with OCD has given me the strength to fight through hard times, the knowledge of finding out the things that I truly love, the fire within to really explore those passions, and an overall greater appreciation for life in general. People often say to me that my music has a lot of feeling; that it sounds like an older man who's been through life. To me, everything that's happened in my music is related directly to everything that's happened to me, and my experience with OCD is the most powerful experience I've had. I don't think my music would have a soulful quality had I not had my OCD experience; having the experience with OCD gave me something to sing about.

In other words, I wouldn't be where I am today had I not suffered with OCD, and I'm very aware of this.

I no longer cringe when I hear the words "obsessive", "compulsive," or "disorder"; my eyes no longer twitch. Instead, I am reminded that I have been fortunate enough to have been given the chance at an opportunity to strengthen my mind and myself. It's extremely hard to see this as such while suffering, but after a few years of looking back on it, I've realized that OCD helped me, like Sonny Rollins said, "find a way."

FROM THE FRONTLINES

My Journey through Hell and Back: The Story of My Battle with OCD

By Jason McClary

Jason McClary is 35 and originally from Broomfield, Colorado. He currently resides in Brentwood, Tennessee with his wife and 2 cats.

It all started one brisk fall day in September of 1989. I was 12 years old. It was the end of class and I couldn't get my locker to open up. All of the other students had gone on to their other classes and I was left alone trying to get my locker to open. I went to my teacher and asked him if he could help me. He said "No problem." He came over and jokingly said "Let's make sure no one is looking", and opened the locker. I thanked him and went on to my next class. As I left the classroom I had this horrible feeling that I had just been "molested." This wasn't possible. I just needed my locker opened up. I tried to shake the feeling off, but couldn't. I went home and played the scene over and over again in my head. I was almost certain that nothing had happened, but couldn't be 100% sure. This was the beginning of my journey into the hell known as OCD.

Almost overnight I was horrified that I had AIDS and was spreading it everywhere I went. I knew I was contaminated. I started calling the national AIDS hotline numerous times a day telling them that I thought I had given someone AIDS because I sat on a toilet seat and then they did. I would tell them that I might have gotten some saliva on someone inadvertently and thought I had given them AIDS. They would reassure me that people couldn't get AIDS from toilet seats or saliva. I would feel better for a while and then I would get anxious again and start calling the hotline looking for reassurance. I didn't know that I was enabling OCD because I didn't know I had OCD.

I started to wash my hands until they bled. I didn't want anyone to get sick because of me. I refused to use my towels more than once. I tried my best not to touch people. If I was going to be around people, I would make sure to wash my hands to get rid of my contamination. The germ phobia lasted until I was about 13. Then the disease morphed.

I was helping my dad mow the lawn. It was a nice summer day and I was feeling pretty good. I was taking the lawn bag from the mower to empty it when my world went empty. The feeling I had was almost indescribable. I felt like my soul was lost and I didn't have a way to get it back. The thing that made me have this feeling was I questioned the existence of God. I had grown up always believing in God and that was all there was to it. Now I was questioning if God existed. I

went and asked my dad how I knew if there was a God or not and he told me that was a decision that every person had to make for themselves.

Now I had a whole new thing to worry about. I started to read my bible obsessively. If I didn't read my bible a certain way then I would send someone I knew to hell or something bad would happen to them. I would spend hours reading my bible at night. I started to have to read the sentences a certain number of times or something bad would happen to someone I loved. I didn't understand

what was wrong with me. I thought I was losing my mind. I couldn't tell anyone about these rituals I was performing because they would think I was crazy and lock me up.

Suddenly when I read my bible, I had to put it on my nightstand

table at just the right angle. If it was not at the right angle I would not be able to go to bed. I tried to fight this by lying in bed and trying to go to sleep without thinking about moving the bible, but the anxiety would be too much. I really thought I was going crazy. I didn't know what was wrong with me. I thought I might be better off not being in this world. Somehow I made it through and continued to function.

On top of everything else, I thought I was secretly trying to poison people whenever I would eat with them. One of the worst times of my life was when I was staying over at my great grandmother's house. It was a Saturday and we were making fried chicken. It was my favorite thing that she cooked. The smells that came out of the kitchen when she cooked were incredible. She asked me if I would like to help her and I jumped at the chance. I loved spending time with her and loved helping her cook. She gave me the chicken and flour and I shook the chicken in the bag. Out of the blue, I had this terrible feeling that I had just poisoned the food because I had touched it a certain way. I tried my best to keep it together, but came up with an excuse and went into the living room. I stood there shaking and in a panic. How could I be having these thoughts? Was I turning into a monster? I looked in the mirror and looked myself in the eyes and said "You are not trying to poison anyone!!!" I managed to pull myself together and continued to help with dinner. As we were sitting at dinner, my great grandmother and great uncle and I talked about how my life was. I told them everything was great and I was looking forward to going into high school. The whole time I was thinking that this was going to be the last meal I had with them because I had poisoned them. As we went to bed that night, I knew they would be dead in the morning. When I

"I didn't know that I was enabling OCD because I didn't know I had OCD."

FROM THE FRONTLINES

awoke to the smell of bacon, I was really relieved. While I felt good, it wouldn't last for long.

One morning when I was 16 I awoke to a horrible thought. What if I sexually abused a child? Where did this thought come from? It seemed like it appeared out of nowhere. I had never even thought about this before. I was now convinced I was a monster. I didn't know how I could go on with my life.

I was in high school at this time and needed to keep it together. I couldn't let anyone know about the thoughts that I was having. I hated having these thoughts. I didn't know where they were coming from. I was sure that I was some sort of deviant that needed to be put away for the safety of others. Normal people did not have the thoughts that I was having. I somehow managed to keep it together and act as if everything in my life was normal. One day I decided I needed to tell someone about the thoughts I was having so I thought I would tell my girlfriend. That didn't go over too well. She told me to just stop thinking those thoughts, so I tried. It didn't work.

When I went to college things seemed to calm down for me. The thoughts were there, but not as often. I finally thought I was free of all these terrible thoughts once and for all. Things were going great. I was getting good grades, being social and enjoying life. Then, my girlfriend broke up with me. I had a panic attack and the thoughts started coming back. I moved to Florida for a couple of years and then moved back to Colorado to start over.

Things went well in Colorado. I finished college, got married and had a good job. One day I was in the book store looking at books trying to figure out what was wrong with me when I found a book on OCD. I started reading it and it sounded just like me. I finally had a name for this disease and it was OCD.

I found a doctor who put me on medication and things started to get better. I thought medication would be the answer. Things were going great. I thought I had finally beaten the disease and all would be well.

However, my wife then got transferred to Chicago. I was pretty excited to move to Chicago. I was doing fine there until one day I was in a Target and was in the bathroom when my worst fears came true. I was stuck in a bathroom with a child, and I was alone. I immediately froze and made my way out of the bathroom. I made it out of the bathroom but was in a complete panic. My head was spinning and my hands were clammy. I immediately thought that I had tried to check him out at the urinal. I couldn't get that thought out of my head. I played the scene over and over again and couldn't be sure that I didn't try and check him out at the urinal. I didn't know what else to do so I got drunk and blacked out. The next day I called a doctor again.

I went to a therapist who didn't specialize in OCD, but did help me with some of my anxiety. I was starting to do really well. I was reading about OCD and getting better.

I was on a different medication and was in good shape. Then we moved to Nashville.

I wasn't looking forward to another move, but it was the right thing to do. I quit my job and we moved to Nashville. I did okay for a while, but I had too much time to sit and think. My thoughts started creeping back in and pretty soon they took over my life. I was at the lowest point of my life. I was ready to give up, but then I found a therapist who specialized in OCD using the International OCD Foundation's online treatment provider database.

My therapist saved my life. When I told her about the thoughts I was having, she said that she could help me. I have never had anyone tell me this before. She said it would be a lot of hard work, but I could get better. I have been seeing her for about two years and my life is completely different than it used to be. I have learned through cognitive behavior therapy (CBT) that I suffer from a chemical imbalance. My brain sends out faulty signals. I have learned how to resist doing rituals and compulsions. I have learned that OCD is not who I am - OCD is something that I have.

I still have thoughts and when I am stressed out my symptoms worsen, but I now have the tools necessary to wage war against OCD. I won't lie, sometimes it does get the best of me, but for the first time in my life I am having more good days than bad days.

If you have OCD, remember that it is nothing to be ashamed of. This disease doesn't reflect who you are, it is just a disease. Don't be afraid to get help. Therapy is nothing to be ashamed of. It is not easy and is a lot of hard work, but if you stick with it you can get better.

Keep up the fight!

**"I have learned
that OCD is not
who I am..."**

**OCD is something
that I have."**

ORGANIZED CHAOS

Ursula's Nasty Grip by Lisa Joseph



I can only hold up a façade for so long. The stress and sadness that is constantly surrounding me is beginning to pull me down to a point where I wonder if I'll be capable of standing back up. At the age of 15, I should not feel this way. No one at such a young age should feel this way. Life as a young teenager should be carefree, happy, and lived to the fullest. But mine? No, not mine. The depression and sadness I am constantly feeling surrounds me and refuses to let me go. Some may say I'm "dramatic." Oh, how I wish I could agree... when people like my family, friends, or strangers see me, they think I'm just a regular, normal, and happy teenager living life. On the contrary, I'm a drowning girl in a pool of darkness. A pool so dark and closed off, light is incapable of entering. Fear, depression, hatred, sadness, and pain... all words to describe the feelings I contain, and hide from the rest of the world. I write in order to get feelings out that I refuse to express to anyone else. I write in order to release. I write in order to somehow be able to get air and breathe, even if only for a moment. Support, GOOD friends, love surrounding me, all of which fail to exist in my life. I feel weights sitting upon my shoulders, keeping me down making it so it's almost impossible to stand back up. Strength brings happiness. Yet I always wonder if my strength will come forth and bring my former happiness back. Trust... you can't trust anyone, sometimes not even yourself. You don't know what's going to happen to

you, which could instantly change the course of your life. I need to burst, to scream, to let someone know how I constantly feel on the inside. The pains I take to my heart emotionally, every day, are feelings a person at my age should never have the unfortunate chance of feeling. Because that's all this is: Chance. Biologically received. Chance. I'm incapable of understanding how Ursula, my OCD, my disorder, my problem... could wrap itself around me so tightly and purposely hold me down. I dream. I hope. I believe that there is light at the end of the seemingly never-ending tunnel, and one day, I'll get there. At the age of 15, I am already damaged. My light switch is on and my light switch will never fully be off again. I wish, every day, that I could feel happiness again. That I could smile without a door secretly thrown in my face. That I could smile and laugh because I know my problems in life are minor details that make up who I am. Rather, my problems are issues which could probably scare anyone away. My anger. My fears. My depression. Even my thoughts... the list is endless, all of which tear me down. I'm 15 years old, but I don't believe my life truly began till I was 7 years old. 7 years old when I let OCD enter me and take control. But believe me bitch; the day will come when you won't have all of me. You'll have a part forever, and I've grown to except that, but I'm a tough one. Strength is happiness. A phrase I truly believe. And I promise you this: one day, I will feel that happiness again. But for now, study hall's over, and my façade is back.

**"And I promise you this:
one day, I will feel that
happiness again."**

ORGANIZED CHAOS

Somebody's Story

by J.A.B.

This is Somebody's story. Somebody's story is one to be read with an open and closed, paranoid and relaxed mind, yet cannot be read in any particular way. Don't thank me, but you're welcome; I know the nuisance of having to read and do things in an excessively particular way. Easily put, one doesn't need a neurotic disorder to think neurotically in today's fast-paced, high-pressure society where basically everyone suffers from Media Suffocation Syndrome (MSS), Teenage Angst Disorder (TAD), or the classic The-Economy-Might Kill Me-Osis (TEMKMO). All three disorders are now trending fashionably into our 21st century. But parents, teachers, and teens: what exactly is "abnormal"? Please consider the following letter written to an evidently troubled sixteen year old girl with a 4.0 average and a seemingly simple, normal lifestyle. Two years ago, the following letter, addressed to a girl by the name of No Name, was finally discovered by a team of psychological officials:

Dear No Name,

All of your note titles must be underlined nineteen times. If someone borrows your pen and does not understand your course material, you better not use it or you'll fail that final exam. Tilt your head nineteen times after reading a quote in a magazine...yes, even in public. Wait until a clock has the digit 'nine' on it before turning out your light, getting out of bed, or doing one of your rituals (don't worry, I've got some for you). By the way, set that clock at least nineteen minutes fast. Look in the mirror and tilt your head ninety-five times before walking away from it. Put your sleeves over your hands in public. For breakfast, slice a bagel into ten equally-sized pieces and put peanut butter and honey in the perfectly measured middle of your yellow plate. Yes, the plate must be yellow. Your bathroom mat's gotta be positioned perfectly parallel to the door frame and you must flick the lights on and off ninety-five times before you shut the door while looking backwards- Don't ask why. Before you take a series of sips of a drink, gargle "Somewhere Over The Rainbow". Then, and only then, may you drink, but only if you swallow nineteen times before taking a breath. Don't touch your dog without gloves, or anything around the house for that matter. Paint your nails pink before a test. Oh, and before I forget, don't throw ANYTHING out, even that candy wrapper... you never know when you'll need it.

Do all of these compulsions over nineteen times if you don't get them right the first time. The rest of your three-page list of compulsions and obsessions will be sent to you tomorrow. Trust me, you can count on it.

Your Faithful Defense Mechanism,
OCD

No Name became a master at hiding her predicament with OCD. It seemed as though nobody could have guessed that ninety-five percent of No Name's day was devoted to fulfilling the relentless and indisputable demands of OCD. 'No Name' only changed her name to 'Somebody' after finally reviewing this very letter with her stunned (and for a while, disbelieving) parents two years ago. Somebody's parents brought the extremely troublesome and perplexing letter to a qualified psychiatric team and they in turn diagnosed Somebody with severe Obsessive Compulsive Disorder.

Not everyone can easily determine why mental illness affects them. It's natured and nurtured and more common than you'd think. Somebody obviously came from a long line of over-reactors, enthusiasts, obsessive-thinkers, and secret perfectionists. God bless the people who have been witnesses to Somebody's infamous family dinner conversations. Nonetheless, for the sake of understanding Somebody's case, I must conclude that it's important for you to know where Somebody's obsessive-compulsive condition originated.

Psychologists might call OCD Somebody's "coping mechanism"...Somebody called it her seemingly mastered, yet paradoxically dysfunctional, escape route.

As an elementary school child, severe and recurrent bullying caused Somebody to believe that school was a degrading prison. By kindergarten she was already being publically humiliated and displaced (she could deal with being alone in the play-area but she will always remember being locked in a bathroom by her four-year old classmates). In the third grade, the bullying went from frightening to emotionally damaging (getting laughed at and having food fired at her after a 'show and tell' singing presentation was simply delightful). And by the fifth grade, she had to switch schools (the constant notes passed around the class about how 'ugly' and 'fat' she was started to get the best of her).

Kids get meaner in middle school. Being locked in lockers seemed like nothing but a strange, yet rather harmless, form of welcoming considering her middle-school track record. The eventual death threats, attempts to literally push her off ski chair lifts, stealing her puffer during severe asthma attacks, rants against her in the hallways, and the spreading of vicious unqualified rumors pertaining to her and a male teacher pushed her into a state of constant fear...and she soon realized she couldn't live in this foreboding, silent nightmare alone any more.

(Continued on page 12)

ORGANIZED CHAOS

Somebody's Story

(Continued from page 11)

So, Somebody learned to make friends with her new and ever-so-predictable buddy, Obsessive Compulsive Disorder. It started with obsessing over school work. Unless her notes were taken four times, they were inadequate. Assignments and tests could have a mark no less than one hundred percent and failure to achieve this goal meant that something horrible (such as a death of a family member) would happen.

Eventually, the compulsions and obsessions continued to pile up on each other until the ever insistent demands from OCD began to paralyze any semblance of function Somebody had. By now, Somebody was experiencing several triggered panic-attacks between the endless compulsions. Every breath was counted, every step was calculated, every precious relationship Somebody had was now falling by the wayside. To make matters worse, Somebody's treatment seemed to be going nowhere with therapists that seemed to neither understand nor have the effective capacity to treat her disorder. Somebody's longing for life was quickly evaporating.

By October, 2010, after almost a year of fighting a losing battle, Somebody's obsessions and compulsions, intensified bullying, a newly established eating disorder (a lovely by-product of OCD's demands), and endless panic-attacks left her with no choice but to practice home-schooling. Her parents, aggravated with the now proven incompetence of therapists who ignored their pleas to literally save their daughter from death, were now engaging any means to help save their daughter and booked Somebody into an intensive OCD treatment program over one-thousand miles away.

From the moment Somebody arrived at this new treatment program it became quickly apparent that the no-nonsense, highly-trained, well-researched psychologists would be the answer to desperate cries for help and would "help her get her life back". The doctor she was working with explained from the first day the origins and progression of OCD, graphed the different stages of anxiety, and introduced the concept of "exposure therapy". Right away, Somebody began to undertake a serious, focused battle against all that she had known for sixteen years. Not only was she supervised by a team of psychologists as she painfully resisted her compulsions, but she willingly did the opposite of whatever OCD demanded.

Somebody literally fought day and night against what she once thought brought her stability, predictability and comfort. She cried a great deal, laughed harder than she allowed herself to before, and endured unfathomable periods of exhaustion and rejuvenation that only those

who have endured a true fight against OCD can truly appreciate or testify to.

Somebody came into the intensive therapy program with a three-page, single spaced, 10-point font-typed list of crippling obsessions and compulsions.

Somebody left the intensive therapy program without any.

When Somebody got back from a month of treatment, she hugged her mother for the first time in years. She spent her first evening at home patting her dog, eating whatever uncooked food she could think of, saying her prayers in all the wrong order, and literally breathing again. She cried when, for the first time in five years, Somebody simply went up the stairs, washed her face, and turned out the light in less than five minutes.

Somebody may still battle with OCD, and even give into compulsions now and then...but OCD knows that Somebody did the unthinkable: she got her life back again. Somebody still faces the same girls she used to but has started to do motivational speaking in schools about the effects of bullying. Somebody maintains a 4.0 average (even without her pink nail polish). She acts and sings professionally and has finished her first all-original demo CD. She also works at her local hospital in a high school co-operative placement, helping care for sick patients and dreams of someday going into medicine.

Somebody can honestly say that she would not have been the strong, successful individual she is today if she didn't once receive that highly troublesome, perplexing letter from OCD.

You might know a person a lot like Somebody... or maybe you're looking at a letter addressed to you that is similar to the one that Somebody was faced with over two years ago.

Somebody believes that her personal name should not yet be referenced in her story, not because she's hiding from some sort of embarrassing shame or boasting with unquestionable pride, but because her name shouldn't be important to those who read about her very real experiences. After all, those who read about Somebody's story have their own name and their own journey to follow.

However, I thought you should know:

I am Somebody.

DONOR PROFILE: JOY KANT

Dare to Believe YOU can Make a Difference



In this newsletter, we are launching a new column: "Dare to Believe You Can Make a Difference." Each issue will profile a donor who has committed their time, skills and resources to the IOCDF. We thought it fitting to launch this new column by highlighting Joy Kant- a long time board member, past

president, and advocate for the OCD community. Joy's involvement with the International OCD Foundation began more than 10 years ago. Like many others, her first exposure to the IOCDF (then called the Obsessive Compulsive Foundation, or OCF) was when she stumbled across the IOCDF website as she searched for information about OCD.

Joy's son Jared was eleven years old, and like many kids his age he had left home excited about spending seven weeks at an overnight summer camp. Ten days later, Joy and Doug, her husband, received a distressing phone call from the camp psychologist who described their son's behavior and told them that he thought that Jared had Obsessive Compulsive Disorder. Joy and Doug were confused and deeply concerned for their son. Joy, who at the time was a teacher in one of the best schools in the country, had never heard of OCD. "From that moment on, our lives were forever changed."

Nine months into Jared's full-blown onset of OCD, Joy was searching the web and discovered the International OCD Foundation Website. It was there that she found much needed information and learned of the Annual Conference, run by the Foundation. Joy realized that the conference was in Boston that year and she and her husband took turns attending, as one of them had to be home with Jared. At the Boston conference, Joy met many people who shared her desire to learn more about OCD and others who were experiencing some of the pain that she and her family were experiencing. Thus began her decade-long relationship with the IOCDF.

Joy and her family wanted to give back to the Foundation - a place where they had received much needed information and help. As a result, Joy and Doug decided to host a fundraiser for the Foundation in their home. They invited family, friends and colleagues to join them for coffee and a talk with Dr. Michael Jenike. This was not only a way to fundraise much-needed support for the IOCDF; it was also a way for others to learn more about OCD. The fundraiser was a huge success and raised \$35,000 for OCD research projects.

Years later, as President of the board of directors (from 2004 - 2008), Joy and her husband helped established a scholarship fund for the Behavioral Therapy Training Institute, because they continued to hear about how so many individuals with OCD could not find qualified treatment providers trained in OCD in many areas of the country. The IOCDF's Behavioral Therapy Training Institute (BTTI) is a three-day intensive course on the diagnosis and treatment of OCD and related disorders designed by members of the Foundation's Scientific Advisory Board. The scholarship fund is used to help defray the costs of attending the training for many treatment providers unable to afford the expense of travel, food, lodging, and registration.

Joy and her family have made an enormous difference for the OCD community. We are fortunate to have the support of the Kant family and many others like them who are committed to the IOCDF mission. We simply could not do this work alone. If you or someone you know would like more information about how you can support the IOCDF, please call Jeff Smith, Development Director, at **617-973-5801**, or visit the IOCDF website at **www.ocfoundation.org**.

"The money really does make a difference...if you look back at how many treatment providers have attended a BTTI, one can just imagine how many more people have been helped by their training!"

THERAPY COMMUNITY

What High School Physics Can Tell Us About CBT Treatment For Hoarding

by Rachael Hatton, M.A. and Jim Hatton, Ph.D.

Rachael Hatton is a registered Marriage and Family Therapist Intern in a private practice setting in San Diego, CA. She can be reached at rachael.hatton@rhattontherapy.com.

Jim Hatton is a Marriage and Family Therapist and Family Coach in private practice in San Diego. He can be reached at jdhhatton@ucsd.edu.

Hoarding as an OCD symptom category has lately been a focus of increasing attention. Several books on the subject have recently been published, local coalitions of mental health and legal entities are forming hoarding task forces to help deal with the social impact of hoarding, and the DSM-V committee is considering moving hoarding to its own diagnostic category as a cousin of OCD rather than as a subset of it. Many would say that it's about time. Most hoarders live with their places quite cluttered, their living space significantly diminished by accumulated items, and their shame about the condition of their surroundings leading them to become socially isolated. Some of us refer to this as CHAOS (Can't Have Anyone Over Syndrome). Additionally, the piles of stuff can create health and safety hazards, and occupants go tripping through their homes along the pathways between the piles of things they intend to address one day. They might be said to be living in the land of the Someday Isles (or is it the Someday Aisles? or even the Someday I'll-s?). The frequent plan in the minds of hoarders is that there might, or even will be, a future use or plan for the items at hand, even though time passes with little or no action on those plans.

Our understanding of the difficulties faced by hoarders in recovery is currently in a growth phase, though it lags somewhat behind our understanding and treatment of many other parts of the OCD spectrum. We do know that some hoarders are faced with the problems of going out and acquiring too much (excessive acquisition), some have difficulties discarding things that have come into their lives through passive means (like the mail), and some deal with both issues. These are often complicated by problems with decision-making ("what if I make the wrong choice, and I need this after all?") and/or prioritizing ("I have to do this, but I have to do that first, and before I do that..."). Like people with other forms of OCD, they have difficulty tolerating uncertainty ("How do I know for sure that I won't need this?"), and they often have a harder time than average dealing with a sense of loss.

CBT for OCD

For other forms of OCD, our current best treatment includes the type of cognitive-behavioral therapy (CBT) known as Exposure and Response Prevention (ERP), and the SSRI-class of medications. The former is primarily designed to help sufferers develop a higher tolerance of uncertainty and anxiety by exposing them to the feared situation (e.g., contamination, seemingly risky situations, etc.) and having them prevent doing the safety maneuver (ritual) that would make them feel a temporary sense of relief. For many people, this process works quite well. The spike in anxiety after the exposure tends to go away by itself (without a ritual) after a few seconds to a few minutes, and with repetition the person's fears of that situation extinguish. Using this process with a series of exposure tasks, experienced from least anxiety producing to most, results in a significant reduction of OCD symptoms for many people.

Problems in using the ERP model in treating hoarding

In treating hoarders using ERP, the same model is often intended, but the implementation often ends up being less directed. All too frequently the efforts of the family, the community, the hoarder, and even the therapist become directed toward cleaning up the mess and discarding the belongings. Treatment can easily get sidetracked from the intention of building up tolerance to anxiety and to uncertainty in favor of not acquiring things or of simply discarding things. This sometimes ends up with a cleaner or more orderly living environment (since often the most dominant focus of social treatment is the reduction of harm and the creation of a safe living space), but often does not treat the mental health part of the hoarding problem itself. Although people hoard for many different reasons, and the problem is a complex one, one reason for this is straightforward: hoarding is not simply a problem of having too much stuff; it's really a problem of the way one thinks about stuff. To paraphrase George Carlin, our houses have become places where we keep our stuff while we go out and get...more stuff! Additionally, certain cognitive interventions (such as learning to prioritize or schedule) are necessary to supplement routine ERP for hoarding. We would like to present a model of thinking that would allow the efforts of exposure to be better directed than they often are.

THERAPY COMMUNITY

A short diversion: High School physics – kinetic vs. potential energy

Mr. Zetterholm, the High School physics teacher for one of us (Jim Hatton), might be proud to know that I still remember this part of my physics class after so many decades: back then, energy was divided into two sorts, kinetic energy and potential energy. Kinetic energy is the energy of action, or of use. An item falling from a shelf releases kinetic energy when it crashes to the floor (or perhaps more useful, the hammer delivers its kinetic energy when it strikes the head of the nail). On the other hand, potential energy is the energy of storage, or of future use. The item sitting on the shelf has potential energy, because it COULD be converted into kinetic energy if it is pushed off of the shelf. It always struck me that potential energy was an interesting concept, but not a very practical one (sorry, Mr. Zetterholm), because it requires one to put energy INTO the system in order to convert one form into the other (you have to make an effort to push the item off the shelf). The conversion of potential into kinetic energy requires paying a price in terms of energy input.

Kinetic vs. potential value

What might this have to do with hoarding treatment? Let's replace the notion of energy with the notion of value. An item can have kinetic value (we define this as the value of use) if it's being used in a relevant time frame. It can also have potential value (the value of storage, or of future use) if it is not being used presently but MIGHT be some day. Much of the hoarder's home is often filled with items that have potential value – IF one has time for that project, IF it can get to a good home, IF one can ever get around to repairing it... These things often do not have any kinetic value, and they sit there for long periods of time without any such value. As with energy, most of the time the potential value of these items can only be converted into kinetic value by putting energy INTO the system, by fixing it or attending to it or by donating it. One very common problem with hoarding is that people think they will have the time and energy to put into these items but rarely ever do!

Tolerating the loss of potential value

In order to use ERP to help hoarders build up the same kind of tolerance to their fears that those with other forms of OCD do, we might have to specifically target having sufferers of hoarding tolerate a loss of potential value, at least for people hoarding out of

low loss-tolerance. It wouldn't be helpful for them to experience loss of kinetic value by tossing out things they are actually using. Nor would it be AS useful (although it might be a required starting point) for them to put their energy into donating things, giving them away, or selling them on eBay as a way of lowering the potential value loss. This would be the equivalent of someone with contamination fears wiping down the dirty item first before touching it, if the response prevention is to not wash their hands afterward. Donating becomes simply a substitute ritual designed to lessen the impact of the exposure. Experiencing the loss of potential value, and learning to let that feeling of loss diminish over time, is a significant part of hoarding treatment. Loss of potential value might mean evaluating that an item might be useful someday or to someone, and then putting it in the trash anyway. It might mean putting something in the trash instead of into the recycling container (loss of potential benefit to the environment). It could also mean going to a store WITH money, looking for items they believe they will want or that someone else could use, and tolerating walking out of the store empty-handed. These should be the targets of our exposure therapy, at least for the group of hoarders having these concerns.

We should be thinking about the potential value of something vs. its kinetic value. So High School physics turns out to be useful in the hoarding field - who knew?



THERAPY COMMUNITY

Institutional Member Updates

Child & Adult OCD Treatment Program

University of South Florida

USF OCD Program

800 6th Street South

4th Floor North, Box 7523

St. Petersburg, FL, 33701

Phone: (727) 767-8230

E-mail: estorch@health.usf.edu

The Child & Adult OCD Treatment Program at USF, in conjunction with Dr. Dan Geller's program at the Massachusetts General Hospital in Boston, MA recently received a two-site grant from the NIMH to investigate the efficacy of d-cycloserine augmentation of cognitive-behavioral therapy in pediatric OCD. Recruitment for this free trial is ongoing and taking place in the Tampa Bay region and in Boston. You can contact Dr. Eric Storch at (727) 767-8230 for more information about the free trial taking place in the Tampa Bay region, and Dr. Dan Geller at (617) 726-5527 for more information about the free trial taking place in Boston.

Rogers Memorial Hospital

OCD Center and CBT Services

Rogers Memorial Hospital

34700 Valley Road

Oconomowoc, WI 53066

Phone: (800) 767-4411 (ext. 1347)

Email: bthomet@rogershospital.org

Rogers Memorial Hospital is happy to announce the ground breaking for the new Child and Adolescent Centers has occurred. Completion is expected in August of this year and the medical staff, behavioral specialists, social workers, experiential therapists, residential counselors and nursing staff eagerly await this stunning addition to our beautiful 50 acre campus. Please visit our website at www.rogershospital.org for information, including treatment outcomes for OCD and Depression in child and adolescents.

2012 Research Awards Request for Proposals

Submission Period:

January 2, 2012 - February 29, 2012 at 5pm EST

Promoting research into the causes and treatment of OCD and related disorders is a top priority of the International OCD Foundation. In 1994 the Foundation launched the Research Grant Award Program. Grants range from \$25,000-\$50,000 each and we have been able to fund between three to eight projects each year totaling between \$70,000 to over \$300,000 given out annually. The Foundation has distributed \$2.7 million dollars in research grant funding since the inception of the program.

Funding for these yearly research awards comes from contributions of the Foundation's members and friends with 100% of these contributions going directly toward funding the winning projects. Historically, we have solicited donations for a general research fund. This year we wanted to provide an option for more targeted giving. As a result, donors were asked if they wanted to keep their donation for the general research fund or to earmark it toward a specific area of interest that may affect them directly. When submitting a proposal keep in mind the following areas of research we have prioritized:

The options for restricting their research donations include:

- **OCD spectrum disorders**
(Body Dysmorphic Disorder, Trichotillomania, Skin Picking, Tics/Tourette's)
- **Hoarding**
- **Genetics**
- **Pediatric OCD**
- **PANDAS/PANS specific research**

For information about how to apply please go to: www.ocfoundation.org/Research.aspx

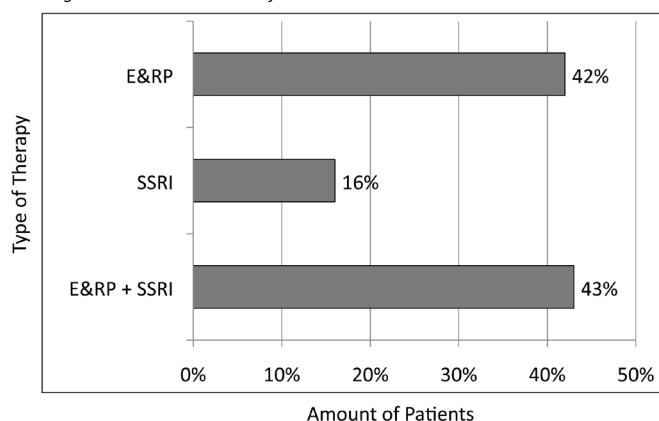
If you have additional questions, please contact Barbara Rosemberg at ocfresearch@ocfoundation.org

RESEARCH NEWS

BT Steps: Web-based Self-Help for OCD by Revere Greist

Despite the best efforts of physicians, therapists, advocacy groups like the IOCDF, and OCD sufferers themselves, evidence-based psychotherapy for OCD remains elusive for many of those with OCD. There's no question that many OCD sufferers want psychotherapy. In one study about preference of available OCD treatments, 42% of patients wanted cognitive behavior therapy (CBT), 43% a combination of CBT and SSRI medications, and only 16% wanted SSRIs alone (Figure 1).

Figure 1: OCD Treatment Preferences



Patel et al. JCP 2010;71:1434-1439.

However, OCD patients far outnumber well-qualified therapists, care can be expensive, and therapists' schedules and locations might not be convenient for patients. Computerized and web-based programs that teach patients CBT skills promise to expand access to care and can support physicians and therapists who choose to incorporate these programs into their practices. These programs can even be enough for some patients who use them without other help. Computerized CBT has a long history – the first programs were developed and studied in the 1980s – and a strong track record of success across a range of mood and anxiety disorders. One of the first computerized CBT programs, BT Steps, was developed for OCD. This article discusses the history of BT Steps and ongoing research intended to make computerized CBT for OCD more widely available.

Therapy...from a computer?!?!?

The idea of doing therapy with a computer might sound strange. In some cases, the relationship between patient and therapist is what defines the patient's experience with therapy and contributes to the

benefit the patient receives from therapy. This can be especially true with approaches like interpersonal and problem-solving therapies, two effective treatments for mood disorders that rely on the ability of the therapist to apply an open-ended approach. By contrast, CBT is structured and standardized and thus can be imitated by a computer program. This idea was not lost on pioneers in the field of computerized CBT, who developed programs addressing a range of mood and anxiety disorders, including depression, generalized anxiety disorder, social phobia, simple phobias, post-traumatic stress disorder, and OCD. These programs have been evaluated in many published clinical trials and shown to be as effective as face-to-face cognitive behavior therapy, especially when they are combined with some human support.

Calling BT Steps

First developed by Drs. Lee Baer, John Greist, and Isaac Marks in the mid-1990s, BT Steps was one of the earliest computerized CBT programs, and the first for OCD. BT Steps started life as a telephone-based program combined with a workbook patients would read. When instructed at various points in the text, patients would call a toll-free interactive voice response telephone system, much like the systems used by banks and airlines. The BT Steps telephone system connected callers to a computer program that collected information from patients and, based on their answers, provided patients with a customized self-management program.

The BT Steps approach followed the established pattern of CBT for OCD:

- Identifying triggers of obsessions and rituals,
- Exposure to these triggers, and
- Ritual prevention following exposure.

BT Steps offered a customized approach by allowing patients to choose from and personalize over 160 common triggers. Patients were also allowed to add their own unique triggers in addition to those suggested by the program. Selected triggers were shaped into personalized exposure goals, and patients reported their exposure experience to BT Steps and received specific feedback and recommendations after exposure sessions. Patients also completed periodic evaluations of OCD symptoms, tips on fine-

(Continued on page 18)

RESEARCH NEWS

BT Steps: Web-based Self-Help for OCD (continued from page 17)

tuning exposure, troubleshooting for difficult triggers, and could access coping strategies for dealing with discomfort during exposure sessions. While BT Steps did not personalize the therapy to the same extent that a human therapist might, the major components of CBT were tailored to patients' needs, and since BT Steps was computerized, patients could benefit from its convenience and consistency.

The telephone-based version of BT Steps was evaluated in a randomized controlled-trial that was published in the *Journal of Clinical Psychiatry*. Compared to study participants who received 12 hours of in-person therapy with expert cognitive behavior therapists, participants who were assigned to BT Steps did well. All patients who did BT Steps – including those who dropped out of the study early – experienced a 23% reduction in the severity of their OCD symptoms. Those who did at least one exposure and ritual prevention session had a 32% reduction in the severity of their symptoms – similar to the amount of improvement achieved by those study participants who received the in-person therapy. Both the BT Steps and the in-person therapy patients improved significantly more than the relaxation control, or placebo group. Both the patients who completed BT Steps and the in-person therapy patients averaged 3.4 hours less per day obsessing and doing rituals compared with only 0.6 hours less per day for the placebo group (Figures 2 & 3). In addition to strong clinical results, BT Steps received praise from the study participants, who found it easy to understand and use.

Back to the future

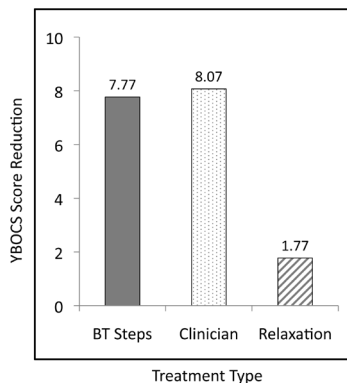
Despite the effectiveness of BT Steps, the researchers who developed it did not seek to distribute it commercially, so the program sat on the shelf. Fast forward to 2007, when Jazz Pharmaceuticals contacted Dr. Greist to see about licensing a version of BT Steps. Jazz understood that patients and physicians wanted access to CBT, but often could not find it. Jazz worked with Dr. Greist and Waypoint Health Innovations, a Madison, Wisconsin company that had licensed BT Steps from its developers, to create a web-based version of the program. This version has been used by more than 2,000 OCD patients since 2008, including those who took medication and those who did not.

Ongoing research

The clinical effectiveness of BT Steps and other computerized CBT programs is apparent, but there is still work to be done to improve the patient experience, better support clinicians as they integrate such programs into their practices, and study outcomes in different care settings.

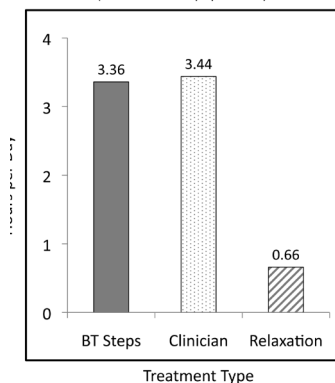
Waypoint is working with the Center for Psychological Consultation, a Madison, Wisconsin-based research organization, to pursue these opportunities. Waypoint has developed a new web-based version of BT Steps that will make the program easier to use for patients and clinicians and will start research on the new version in early 2012. The new version, as in previous versions, is interactive and personalized. For example, the new version delivers instruction and feedback through videos featuring Dr. Greist, a spokesperson, and actors who demonstrate various exposure scenarios, and an actual former OCD sufferer who is also a cognitive behavior therapist. It also allows for more customization of content and tasks to suit patients' specific needs. The content in the program has been streamlined to make it more accessible and engaging and to move patients more rapidly to the steps that provide relief from OCD symptoms. Continued focus on visual structure and design has also increased the "usability" of the most important components of the new version – for example, where patients select the trigger, setting, and timing for an upcoming exposure session, and where they later record the degree of success they achieved in a completed exposure session.

Figure 2: Symptom severity reduction (BT Steps and Clinician subjects who did at least 1 ERP session)



Greist et al. *J Clin Psychiat.* 2002;63:138-45.

Figure 3: Hours/day reduction in rituals and obsessions (Intent-to-treat population)



Greist et al. *J Clin Psychiat.* 2002;63:138-45.

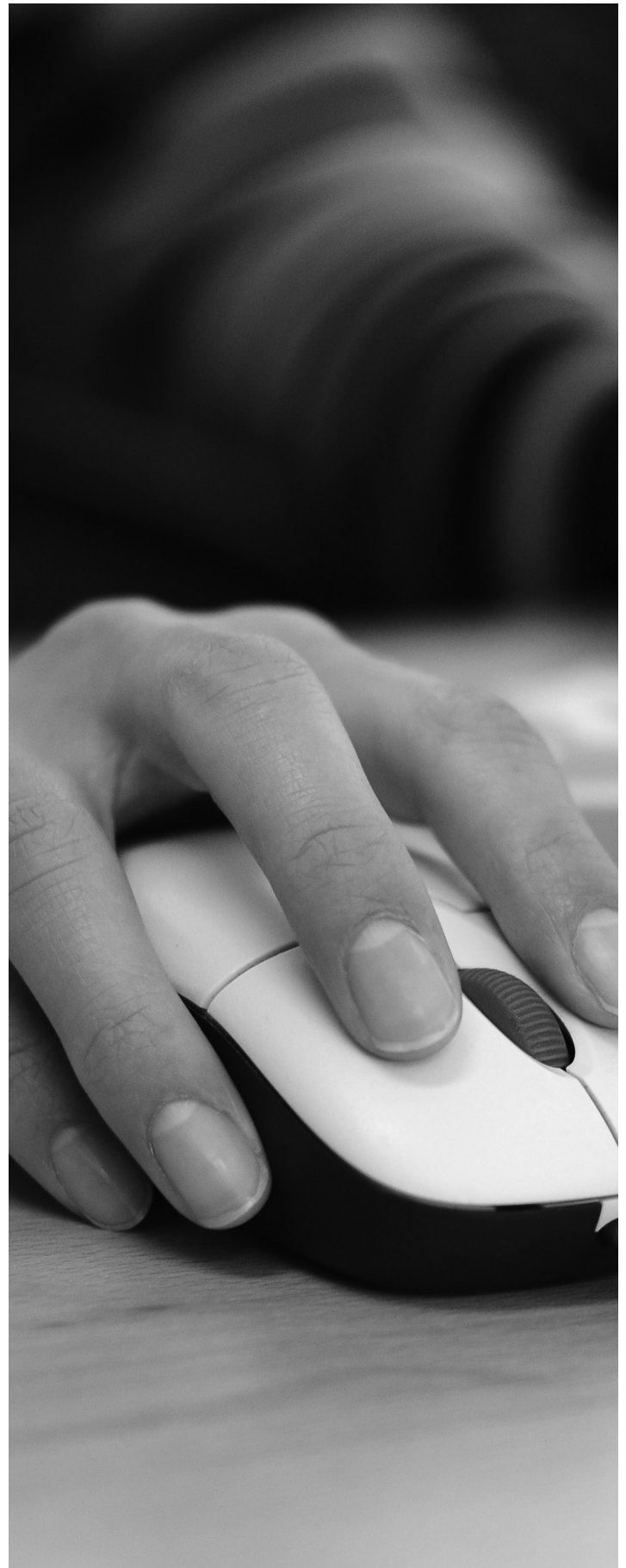
RESEARCH NEWS

The new version of BT Steps also features a clinician's portal that lets physicians and therapists who have referred patients to BT Steps and therapists who assign the program as "homework" between therapy sessions to monitor their patients' progress and provide guidance when appropriate.

Updates to the BT Steps web application are designed to increase patient involvement in the program and allow clinicians to better incorporate BT Steps into their practices. However, improvements to program itself are only part of the picture. Non-computerized resources, combined with computerized CBT programs, can greatly improve the effectiveness of these programs. For example, research shows that patients using computerized CBT programs benefit from periodic "coaching", which can include discussion of the program, collaborative goal-setting, progress review, and encouragement and motivation. Because these coaching activities are not therapeutic in nature, coaches do not necessarily need to be therapists. Starting in early 2012, Waypoint will work with the Center for Psychological Consultation to carry out a research study funded by the National Institute of Mental Health (NIMH) to evaluate whether coaching improves the effectiveness of BT Steps, and whether coaching by a trained non-therapist can be as effective as coaching by a qualified cognitive behavior therapist. Determining the best amount and type of coaching for BT Steps will increase the value of the program to patients with OCD.

The telephone-based version of BT Steps started and verified computerized treatment for OCD and set the stage for continued research and development. The newly updated web-based version of BT Steps and its upcoming trial are designed to expand the usability and usefulness of the program for both patients and clinicians. Our hope is that we can make computerized care for OCD a widely available treatment option for OCD sufferers and the clinicians who support them.

The Center for Psychological Consultation is recruiting patients and therapists for the BT Steps research study. Please see our advertisement in the "Research Participants Sought" section of this newsletter, and on the IOCDF website. Alternatively, please contact Revere Greist at (608) 556-0766 or rgreist@centerforpsychconsulting.com for more information about this research study.



RESEARCH NEWS

Association Splitting

by Steffen Moritz, Ph.D., Birgit Hottenrott, Dipl.-Psych, & Lena Jelinek, Ph.D.

According to the World Health Organization, six out of ten patients with obsessive-compulsive disorder (OCD) do not seek treatment. Those who do seek help normally have to wait 11 years until OCD is properly treated. There are several reasons why so many patients do not get treatment. For example, many patients have feelings of shame because of the nature of their obsessions. Others are put off by certain kinds of treatment. Another frequent reason is the lack of necessary funding, as many patients are not properly insured.

The good news for patients who are unable or are currently unwilling to see a therapist is that there are many self-help therapies available. These programs can be followed at home or on the internet.

Association splitting

Our present study dealt with “association splitting”, which is a self-help technique developed by our group. It aims to help patients to control their obsessive thoughts. The association-splitting program can be downloaded at no cost in several languages from our web site: www.uke.de/assoziationspaltung (scroll down to select English).

In short, the program teaches patients to make neutral or positive associations for their fear-related OCD beliefs. Typical OCD beliefs are, for example, fear of blood, cancer, death, fire and/or HIV. New, more neutral associations should help patients to create some distance to their OCD-related concerns. The patient should make the new associations when he or she is not having an obsessive thought. However, the technique should not become another type of obsessive ritual. As an example, patients who are preoccupied with the fear of catching HIV often become stuck worrying about words like “blood”. Combining the word or the image “blood” with other words or meanings such as “blood brothers”, “blood orange”, “blood diamonds” (movie with Leonardo DeCaprio) helps to decrease the OCD fear. Visual material can aid the process (see figure 1).

Association splitting clearly does not fully eliminate the association between blood and HIV, but rather strengthens associations that are more neutral. This

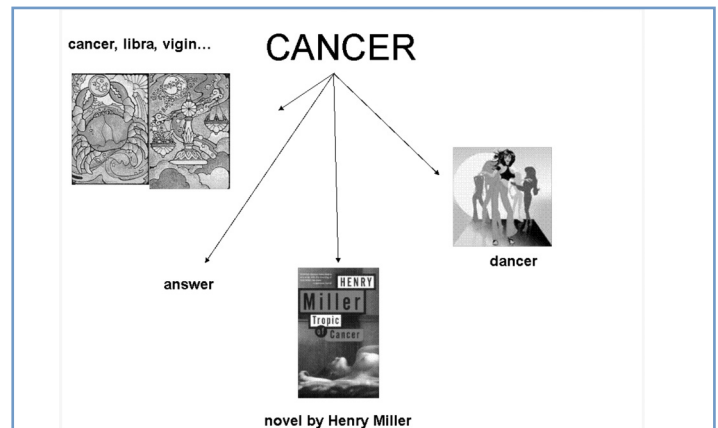


Figure 1: Example of positive and neutral associations relating to “cancer”

should decrease the patient’s fears and lessen the associated behavioral impact. This in turn may help the patient in situations, where he or she perceives a threat linked with “blood” or HIV. The patient may now relate the situation to a larger and less negative association for “blood” (for more information about this please refer to the manual that can be downloaded from our website mentioned previously). The technique conveys a cognitive model of OCD, suggesting that obsessive concerns are not caused by an inner evil drive. Rather, certain learning principles and unhelpful coping strategies that contribute to OCD are in fact amendable to change.

The evidence so far

First evidence for our approach comes from an (uncontrolled) study, which we conducted over the internet. The study examined the effectiveness of association splitting in 38 people with OCD. Patients’ ratings and the comparison of scores obtained before and after intervention revealed that one out of three participants greatly improved. However, as no control condition existed, some positive effects may not have been caused by association splitting, such as motivation to change.

New study

To address the shortcomings of the prior study, this present study compared association splitting in its latest version to a waitlist control group. The association-splitting group received the manual immediately after the baseline survey. The wait-list group had to

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wait until after the post-survey. Our group posted invitations for an internet-based self-help trial aimed at reducing OCD symptoms on several British and American websites dedicated to OCD (including the IOCDF). The major inclusion criteria (or requirements participants had to meet) for participation in the study were the presence of obsessive thoughts and partial insight of illness. The technique was explained using a treatment manual. Participants filled out standard symptom scales at the start of treatment and then four weeks later. Among these were two OCD scales (Obsessive-Compulsive Inventory-Revised, Yale-Brown Obsessive Compulsive Scale) and one depression scale (Beck Depression Inventory).

Forty-six participants with OCD completed the first survey. At random, participants either received the association splitting manual or had to wait. Four weeks later, 34 participants completed the final assessment. Across all scales, the association-splitting group made strong improvements compared to the wait-list group. Significant differences were found for the two OCD measures score reflecting greater symptom decline in the association-splitting group, especially for obsessions. The depression score also declined significantly (i.e., not due to chance) in the association splitting group but not in the control group.

Participant Feedback

All patients in the association-splitting group stated that they could understand the manual. In addition, the vast majority appraised evaluated the technique as adequate for self-administration. Four out of ten patients credited the technique with their symptom decline. None reported that their symptoms got worse because of association splitting. Four out of five patients claimed that they would continue to use association splitting.

Limitations

In conclusion, the present study found that association splitting is a feasible, safe, and effective self-help approach for some patients with OCD. The results suggest good effects of association splitting on OCD and depression. However, the results fall behind the response rates expected for face-to-face therapy. Therefore, we would like to acknowledge several critical points.

Firstly, we obtained data over the internet. While outside confirmation of diagnosis and symptom severity is desirable in research, an online study is without an alternative if one tries to “treat the untreated”. Clinical interviews in a hospital environment would have turned off many potential participants. Secondly, at this point we can only assume that improvements are stable over time. Currently, we are testing whether association splitting done by a therapist has a larger effect than association splitting alone. Thirdly, more patients in the association-splitting group as compared to the wait-list group did not take part in the final assessment. While we cannot rule out that a number of participants did not complete the post-survey due to lack of improvement, other reasons may also apply. In particular, there were more male participants in the association-splitting group and males are more prone to cancel trial participation than females. In addition, the association-splitting group had the least to gain from the final assessment, as they had already received the manual. The wait-list group received the manual after the post-assessment and thus was perhaps more motivated to participate.

Outlook

In our view, self-help is no substitute to standard therapy, but is an important option to reach patients that are unwilling or unable to do traditional therapy. Association splitting may be especially valuable for patients for whom behavioral challenges are hard or even impossible to start. The technique can also be done by therapists and may complement standard therapy.

For more information please contact:

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Tel: ++49 40 7410 56565

FAX: ++49 40 7410 57566

RESEARCH NEWS

Research Participants Sought

MASSACHUSETTS

Do You Pull Out Your Hair?

Dr. Nancy Keuthen is conducting a genetics research study of compulsive hair pulling at Massachusetts General Hospital. You may be eligible if you are 18-65 years of age and frequently pull out your hair.

If eligible for this research study, you will come to MGH for one study visit that will include an interview, several self-report scales, and a blood draw. Study participation will take 3-6 hours of your time. You will be paid \$50 for participating.

If interested, please call MGH Trichotillomania Clinic at (617) 643-8464

MASSACHUSETTS

Cognitive Behavioral Therapy and Supportive Psychotherapy for BDD

(PI: Sabine Wilhelm, PhD)

Anne Wilson

(617) 643-4357

www.mghocd.org/bdd

AWILSON15@PARTNERS.ORG

The purpose of this research study is to learn more about two different forms of therapy to help individuals with BDD: cognitive behavioral therapy (CBT), a promising new treatment for BDD, and supportive psychotherapy (SPT), the most commonly received therapy for BDD. The investigators would like to find out which treatment is more effective for BDD. Participants will be randomly assigned (like the flip of a coin) to receive 22 sessions (over 24 weeks) of either CBT or SPT.

ONLINE STUDY

Study of Web-based Treatment for OCD

Do you have obsessive-compulsive disorder or think you might? Have you had trouble finding treatment for your OCD? Do you use the Internet? If you answered "yes" to these questions, you might be eligible to participate in a research study conducted by Dr. Kenneth Kobak of the Center for Psychological Consultation.

This study will evaluate a new, web-based treatment program for obsessive-compulsive disorder called BT Steps. BT Steps teaches participants skills from cognitive behavior therapy and is based on an earlier, telephone-based program that was shown to be effective in a research trial. In the current research study, we will assess the effectiveness of BT Steps alone, or supported by coaching from either a trained coach or a cognitive behavior therapist. This study is supported by a grant from the National Institute of Mental Health.

To participate in this study, you must be at least 18 years old, have OCD, and use or be willing to use the Internet. Participants will be compensated up to \$150 for their participation.

If you have any questions or would like to learn more about this study please contact Revere Greist at (608) 556-0766 or rgreist@centerforpsychconsulting.com.

ONLINE STUDY

Romantic Partners' and Adult Children's Views: OCD and Relationships

The goal of this study is to gain information about the relationships of individuals with OCD and those who hoard from the perspective of romantic relationship partners and adult children. To do so, we are asking romantic partners and adult children of individuals with OCD and/or hoarding to fill out on surveys including questions about what it is like to be in a relationship with an individual who has OCD and/or hoards. The survey also includes questions about the individual with OCD's anxiety symptoms and questions about your own emotions, anxiety, and depression. You must be at least 18 years old to participate in this study.

At the end of the survey you will have the option to enter your name and contact information during the completion of the study in order to enter a raffle to win one of two \$50 Target Giftcards, which will be awarded at the completion of the study. Your name and contact information will not be provided to anyone and will be kept entirely confidential.

It is important that you complete the survey in a quiet, private place free of distractions and interruptions.

RESEARCH NEWS

The information that you provide could help to understand more about the relationships of individuals with OCD and those who hoard. This could help to improve therapies for hoarding and OCD.

If you have problems accessing the study, please send an e-mail reply to **axp335@case.edu**.

The study can be accessed from the following address: **<http://filer.case.edu/~axp335/famocd.htm>**

ONLINE STUDY

Reactions to Hoarding

Principal Investigators: Martin M. Antony, PhD, C.Psych., & Valerie Vorstenbosch, MA
Email: hoardingstudy@psych.ryerson.ca

Do you or your partner have difficulties throwing things away? Researchers in the Department of Psychology at Ryerson University are seeking individuals to participate in a hoarding research project. The purpose of the project is to investigate significant others reactions to hoarding-related behaviors (acquiring, difficulty discarding, clutter).

You may be eligible to participate if:

1. You and your partner are between the ages of 18 and 75
- 2 You and your partner live together
3. You and your partner are both willing to participate
4. Only one partner has problems with hoarding

A brief telephone screen (which participants will not receive compensation for) is required to determine eligibility. If you and your partner are eligible to participate, you will both be asked to complete online questionnaires and a telephone interview. You will be compensated for your participation, if eligible.

If you are interested in participating in this study or would like more information about this study, please email Valerie at **hoardingstudy@psych.ryerson.ca**.

ONLINE STUDY

OCD and Relationships

The goal of this study is to gather information about the relationships of individuals with OCD and those

who hoard. To do so, we are asking people who have OCD and who hoard to complete questionnaires about their emotions and relationships. You must be at least 18 years old to participate in this study.

This study involves completing a Web-based survey. The survey includes detailed questions about you, your emotions, anxiety symptoms, depressive symptoms, and your relationships. It should take less than one hour to complete.

Some people may find it emotionally uncomfortable to think about their emotions and relationships. However, we would expect that any distress that you experience will last only for the duration of the study.

If you choose to participate, your privacy will be protected at all times during the study. You may enter your name and contact information during the completion of the study in order to enter a raffle to win one of two \$100 Target Giftcards, which will be awarded at the completion of the study. The research team will do everything possible to maintain your privacy and confidentiality. Only study personnel and members of the board that protects the rights of participants will have access to the information that you provide in this survey. Your questionnaire information will be transferred via the internet to the experimenter. All efforts have been made to maintain your privacy during this transfer, however, no guarantees can be made about other people (like hackers) trying to get the data when you send it by the Internet. Also, your contact information will be removed from the data as soon as it is downloaded but will be maintained in a separate list should you win one of the two gift cards.

It is important that you complete the survey in a quiet, private place free of distractions and interruptions.

The information that you provide could help to understand more about the relationships of individuals with obsessive-compulsive disorder. This information could improve therapies for people with obsessive-compulsive disorder

If you have problems accessing the study, please send an e-mail reply to **axp335@case.edu**.

The study can be accessed from the following address: **<http://filer.case.edu/~axp335/ocd.htm>**

FROM THE AFFILIATES

OCD Massachusetts

www.ocfboston.org

Les Groderberg Memorial Lecture Series
McLean Hospital, De Marneffe Cafeteria Building
Belmont, MA 02478

OCD Massachusetts, in conjunction with McLean Hospital, presents a series of preeminent speakers in the field of OCD and related disorders. Each presentation takes place from 7:00 – 8:00pm.

March 6, 2012

An Update in the Treatment of Hoarding
Gail Steketee, PhD
Boston University School of Social Work

April 3, 2012

Using ACT in the Treatment of OCD
Nate Gruner, LICSW
McLean Hospital OCD Institute

May 1, 2012

Meta Cognitive Therapy for OCD
Jim Claiborn, PhD
South Portland, ME

June 5, 2012

Treatment for Body Dysmorphic Disorder
Jennifer Greenberg, PsyD
Massachusetts General Hospital OCD Clinic

OCD Massachusetts is also happy to announce a new lecture series and psycho-education group starting on Cape Cod. Meetings will be held on the 3rd Wednesday of every month at the Hyannis Youth and Community Recreation Building (Shepley Room) from 6:30-8pm. For information, please contact Denise Egan Stack at (617) 872-0935.

OCD New Jersey

www.ocdnj.org

OCD New Jersey's most recent quarterly meeting was held on Monday, December 12, 2011 at the Robert Wood Johnson Hospital in New Brunswick, NJ. We had the pleasure of hosting Dr. Julia Turovsky as our speaker. Dr. Turovsky is currently in full time private practice in Millburn, NJ and has been treating patients with anxiety disorders for over 20 years. For her presentation, "OCD Across the Lifespan", Dr. Turovsky discussed how the interplay of OCD and the various transitions one

experiences during childhood, adolescence, adulthood, and advanced age bring about unique treatment challenges and special considerations for patients with OCD. For more information about OCD New Jersey and our upcoming events, please visit our website at www.ocdnj.org.

OCD Puerto Rico

We've been very happy with the progress that's been made during 2011. We've been looking for a new place to host our monthly support groups and through communication with the municipality of Bayamón, we were successful! Starting January 21, our monthly support groups will be held at the local library which has easy access to the nearby train station.

In addition, Juan (who was diagnosed with OCD at the age of seven) also developed a short film titled *Pensar Eterno* (Eternal Thought) which details his struggle with OCD upon being diagnosed. It's been shown around Puerto Rico over the past two months and it's received great feedback from OCD consumers and family members and even managed to receive an opportunity to present the film at SAMHSA headquarters in Rockville, MD in December. For those interested, the short film can be viewed online, free of charge, by visiting <http://nuestramente.org/PensarEterno>. It is in Spanish, but features English subtitles through YouTube (www.youtube.com/watch?v=R3xeYPPFusBQ). For more information about OCD Puerto Rico and its programs, please call (787) 294-6726.

OCD Midwest

OCD Midwest is looking for volunteers for all sorts of tasks and projects. If you would like to volunteer for the Midwest affiliate, please email Patrick McGrath at Patrick.mcgrath@alexian.net.

OCD MidAtlantic

www.ocdmidatlantic.org

The Mid-Atlantic affiliate is looking for more professional members in the region to volunteer and get involved in getting the affiliate more active in 2012. Anyone interested should contact Carter Waddell directly at tcwaddell5@yahoo.com.