INTERNATIONAL OCD FOUNDATION

OCD Newsletter

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FROM THE FOUNDATION

Over 1,000 Attendees Hear Stories of Hope and Take Part in Experiential Workshops at the IOCDF's 17th Annual Conference

Ret. Lt. Col. Shannon Shy during the Keynote Address

Messages of hope and overcoming adversity were common themes at this year's Annual Conference in Washington, D.C. From our inspirational keynote speaker, Ret. Lt. Col. Shannon Shy, who discussed overcoming OCD while on active duty in the Marines, to the moving stories from the "Teen Success Panel," many who attended this year's conference left with a newfound courage to fight OCD in their own lives.

No better examples of this were the breakthroughs that occurred during Dr. Jonathan Grayson's "Making Mudpies" workshop and his now-famous "Virtual Camping Trip," the

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International OCD Foundation Announces 2010 Research Award Recipients

The International OCD Foundation (IOCDF) is committed to finding and promoting effective treatment for everyone with OCD. Research is vital to understanding more about OCD and related disorders and is a means of improving treatment. Since 1994 the IOCDF has awarded several million dollars in research funding. This year a total of $136,648 was raised, all of which comes from generous donors within the IOCDF community. Thank you to all who contributed!

This year the IOCDF received 30 proposals, which were reviewed by the Grant Review Committee led by Sabine Wilhelm, PhD, Vice Chair of the IOCDF Scientific Advisory Board. Recommendations by this committee were submitted to the IOCDF Board of Directors, who made the final selection. Thank you to all who contributed their time and energy. Please turn to page 20 for a list of the winners and a brief description of each study.

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FROM THE FOUNDATION

(IOCDF's 17th Annual Conference, continued)

latter of which was the subject of a CNN piece that aired on July 26 (a link for this video is available through our Facebook page). These conference fixtures were just part of the reasons why Dr. Grayson was honored with this year's Patricia Perkins Lifetime Achievement Award for his dedication to the IOCDF's mission and programs.

> *"As a first-timer, it was so heart-warming to see all these people come together in such a loving, giving, and supportive way."*
>
> – First-time Conference Attendee

Every subtype of OCD and all of the Spectrum Disorders were covered at this year's conference. In addition, this year there was an emphasis on highlighting scrupulosity. Dr. Alec Pollard's Advanced Behavior Therapy Training Institute on scrupulosity and uncertainty attracted 69 mental health professionals, Dr. Ted Witzig Jr.'s scrupulosity support group drew an even larger crowd than last year's group, and Dr. Charles Mansueto's therapist/clergy panel gave consumers, family members, and professionals the chance to hear about scrupulosity from many perspectives.

Two new programs were also added to the conference this year: an OCD film festival and a group art therapy program. The film festival featured four movies, including the documentary "OC87," which was played to a standing room only crowd, and "PeaceLove is Possible," a documentary from PeaceLove Studios. PeaceLove was also the group behind the art therapy program on Saturday evening, where participants expressed their feelings and emotion through art and then displayed their work in the exhibit hall on Sunday morning.

Overall, this year's conference was an enormous success. More than half of this year's participants (53%) were first-time attendees and many stated that they will be back for next year's event. As with our previous two conferences in Boston and Minneapolis, the entire OCD community was represented; attendees included people with OCD, their family members, and mental health professionals, each group making up about 1/3 of the participants.

The mental health professionals in attendance also left the conference feeling motivated by hearing about cutting-edge research from our 39 poster presenters and by getting advice on how to treat difficult cases from some of the most-well known names in OCD treatment, including Drs. Edna Foa and Michael Jenike.

Reid Wilson, PhD, leader of the first-ever pre-conference on-site treatment program

We would like to thank our amazing speakers, dedicated volunteers, gracious sponsors, exhibitors and advertisers for making our conference possible. Your support of this program allows us to reach more people and to improve the experience of everyone in attendance. Thank you!

Finally, a special thank you to Dr. Reid Wilson who held our first-ever on-site treatment program on the two days leading up to the Annual Conference. Not only was the session highly praised by both the individuals who participated and the mental health professionals who observed, but Dr. Wilson donated the entire proceeds from the program, more than $4,000, directly to the IOCDF.

We look forward to seeing you in sunny San Diego, July 29-31, 2011 for our 18th Annual Conference! More information about the Annual Conference and the host city can be found at **www.ocfoundation.org/conference.aspx**.

Best wishes,

Mike Spigler, CHES
Program Director
International OCD Foundation

Message from the President

Dear Friends,

Thank you to all who attended our 17th Annual Conference in July! It was wonderful to participate in such a fantastic event. If you read Michael Spigler's front page article about the conference, I'm sure you were impressed! Once again, our national office staff did an unbelievable job with organizing this year's program. I am incredibly proud to work with such talented people. I especially enjoyed seeing old friends and meeting new attendees, who all had such great things to say about the conference program, staff, and speakers. It is truly a one-of-a-kind event, and it is always so gratifying to be a part of it.

Now that the conference is behind us for another year, we are turning our attention to other important programs. Our next two Behavior Therapy Training Institutes (BTTIs) in Boston and Los Angeles sold out in record time – the Los Angeles training sold out in just 90 minutes! – and we continue to have a long interest list for future trainings. This high demand for training opportunities highlights just how important our educational mission is. We will continue to provide as many BTTIs as we can in order to give all interested professionals the opportunity to attend. If you are interested in learning more about the BTTI and future training locations, please visit our website for more details.

In this issue you can also read about this year's Research Award recipients. We are so excited to be able to fund these important projects, which will hopefully lead us to a better understanding of OCD and how to treat it more effectively. I'd like to extend a warm thank you to Dr. Sabine Wilhelm and the Grant Review Committee for the time and effort that they put into reviewing all of our proposals. We look forward to hearing about the results of these projects.

In 2010 we are hoping to expand upon last year's first annual OCD Awareness Week. This year's Awareness Week will take place on October 11-17, and we are planning with our affiliates for many exciting events across the country. Please visit our website for more details about events in your area and how to get involved!

Another project we are embarking upon is a revamping of our popular OCD in the Classroom program, an educational tool for teachers and other school personnel about how to recognize OCD in school children. We are planning to take this project to the next level with improved content and updated delivery systems with the hope of reaching a greater audience. We have assembled a committee of dedicated people who will help us roll out this project over the next year. We have wanted to take this on for some time, so we are very excited about getting it moving.

It is with sadness that we say good-bye to two of our fabulous national office staff members, Rebecca Cyr and Emma Etheridge. Rebecca has been with us since our move to Boston in February 2008, and Emma has been with us since this January. They will be sorely missed, but they are both moving on to wonderful opportunities and we wish them the best of luck!

Patti Perkins during the Keynote Address

Finally, I want to welcome Patti Perkins, one of our Founders, back to the IOCDF. Patti has officially joined the Board of Directors as of July, and we are incredibly happy to have her back with us. Patti brings with her a wealth of knowledge and history about the Foundation, and we are so lucky to have her. For those of you who were able to see Patti at the conference, I'm sure you felt that it was like having a celebrity in our midst! Her dedication to the cause is unrivaled.

It would not be a President's Message without having me, once again, asking you to be generous to the Foundation with your donations. As you can tell, we are undertaking multiple projects that all serve our mission of education, support, and research. We cannot do it without your help. Thank you to all of you who continue to support us in so many ways.

Diane Davey

President, IOCDF Board of Directors

FROM THE FOUNDATION

The Americans with Disabilities Act: The Law and Tips for Working People with OCD

by Marilynn Mika Spencer, a California licensed attorney

Marilynn Mika Spencer and The Spencer Law Firm represent clients in the fields of labor and employment law. She is a graduate of the UCLA School of Law. Ms. Spencer is on the Executive Board of the California Employment Lawyers Association (the largest and most influential plaintiffs employment bar in California); a former Member of the Executive Committee of the Labor and Employment Section of the State Bar of California; and a 2007 San Diego SuperLawyer (Employment & Labor; Employment Benefits/ERISA). Ms. Spencer co-authored a chapter on the Americans with Disabilities Act (ADA) for the National Lawyers Guild publication Employee and Union Member Guide to Labor Law.

Note: This article is for general information only. It is not legal advice. Legal advice must be tailored to specific facts. For legal advice, please contact a licensed attorney in your state.

This year marks the 20th anniversary of the Americans with Disabilities Act (ADA). The ADA is a federal law designed to make it easier for people with disabilities to fully participate in society. The law is divided into five sections called "titles." Title I covers employment. Titles II, III, IV and V cover public services, public accommodations, telecommunications, and miscellaneous provisions.

In the two decades since the ADA was passed, working people have benefited enormously from the law's protection. At the same time, there is much the law does not do, even though it could and should. Many people with disabilities do not know how to take advantage of the ADA, or are afraid to use the law because they do not want to reveal their disability. Also, many employers are uninformed about their legal obligations. Added to this are the effects of stigma and discrimination, highlighting that the law has yet to reach its full potential.

This article provides a summary of the ADA, plus tips for working people with OCD.

What kind of workers does the ADA protect?
The ADA uses terminology with specific legal meaning but, in short, the law protects individuals with permanent or long-lasting physical or mental limitations if those limitations have substantial negative effects, and if the individuals can do the main parts of their jobs, even if they need some kind of help to get the job done.

Which employers have to comply with the ADA?
The ADA applies to private employers and religious entities with at least 15 employees, state and local governments, employment agencies and labor unions. U.S. government employees are covered by the Rehabilitation Act, which is very similar to the ADA.

How does the ADA help working people?
The ADA offers two benefits to people who work or want to work. First, the law forbids employers from discriminating against individuals with disabilities, and second, the ADA requires employers to provide reasonable accommodation to employees with known disabilities.

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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.

What is meant by "discrimination"?
To discriminate on the basis of disability means to treat a person with a known disability differently from, and worse than, other people who do not have a disability. This different, negative treatment might be found in applying for a job, or hiring, firing, advancement, pay, training, and all other parts of employment.

What does it mean to provide "reasonable accommodation?"
If an employer is covered by the ADA, it is also required to give people with known disabilities reasonable accommodation. "Reasonable accommodation" means to change some part of work so that a person with a disability can do the job. The change may include providing a quiet place to work; giving assignments and instructions in writing instead of orally; modifying work schedules; modifying equipment or devices; adjusting or modifying examinations, training materials, or policies; and more. The only limitation is if it would be an undue hardship on an employer to provide the accommodation; this usually means it is excessively expensive, given the resources of the employer.

What else does the ADA do?
The ADA requires covered employers to offer qualified individuals with disabilities equal access to all employment-related opportunities. This includes medical insurance, social activities, vending machines, rest rooms, and more.

In addition, the ADA limits the questions an employer can ask a job applicant before a job offer is made. Employers may not ask if the applicant has a disability. If the applicant tells an employer she has a disability, the employer cannot ask about the nature or severity of the disability. However, an employer can ask applicants about their ability to perform specific job functions. An employer can extend a job offer on the condition the applicant passes a medical exam, but only if the exam is required for all other new employees in similar jobs.

Under the ADA it is unlawful to retaliate or punish an individual who opposes or complains about disability discrimination, who files a discrimination charge, or who testifies or participates in any way in an ADA case or investigation.

Although an employer may not discriminate on the basis of disability, if an applicant or employee is a direct threat to the health or safety of him/herself or of others, an employer may treat that individual differently *due to the direct threat*. An employer must prove there is significant risk of substantial harm which cannot be reduced or eliminated by reasonable accommodation. An employer's assumption that people with disabilities are more prone to harm is not an excuse for discrimination.

How do you file a complaint against an employer who discriminates because of disability?
A claim of employment discrimination based on disability, failure to accommodate, or reprisal must be filed with the U.S. Equal Employment Opportunity Commission (EEOC) within 180 days of the date of discrimination or failure to accommodate, or within 300 days if in a state with a fair employment practices agency. A person cannot file a lawsuit until the EEOC has had the opportunity to investigate and resolve the claim, and issues a right-to-sue letter. These claims may be filed at any EEOC field office. For the appropriate EEOC field office, call the EEOC at (800) 669-4000 (voice) or (800) 669-6820 (TTY), or visit the EEOC web site at **www.eeoc.gov**.

Many states have laws that are similar to the ADA or are more favorable to people with disabilities. Some state laws provide more generous remedies, a longer time to file the claim, easier procedures, and more.

Practical tips for people with OCD

- ***To tell or not to tell***

Choosing if and when to disclose having OCD can be a hard choice to make. We are all aware of the stigma attached to mental disabilities. To reduce this stigma, organizations like the IOCDF are working hard to educate people with OCD and the public about this condition. And laws like the ADA help people with disabilities be more open about their disability because there is now some degree of protection against discrimination.

While many people with mental disabilities such as OCD can hide their condition from other people, it is harder to conceal OCD on the job. This is because one typically interacts with the same people every day, all day long, and the worker is expected to meet performance standards.

When employees with OCD are engaging in rituals or experiencing self-doubt and uncertainty, their

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FROM THE FOUNDATION

(Americans with Disabilities Act, continued)

bosses and co-workers might believe the employees are slow, incompetent, lazy, or not paying attention. If OCD is leading to poor performance reviews, counseling, discipline, or other problems at work, it is time to consider whether or not to disclose the disability and ask for reasonable accommodation. If your work is suffering because you need reasonable accommodation, the ADA can help. However, you must request accommodation; otherwise, your employer will not know the reason for your poor performance, and may have the right to discipline or even fire you.

• ***How to request accommodation***
A request for reasonable accommodation should be directed to an immediate supervisor, manager or to human resources/personnel. The request should identify the disability, state it is permanent or give the expected duration, and ask for reasonable accommodation. For example:

> "I request reasonable accommodation for my disability of obsessive compulsive disorder. My condition is permanent."

If the employee knows what accommodations he or she needs, it is a good idea to specify them in the request:

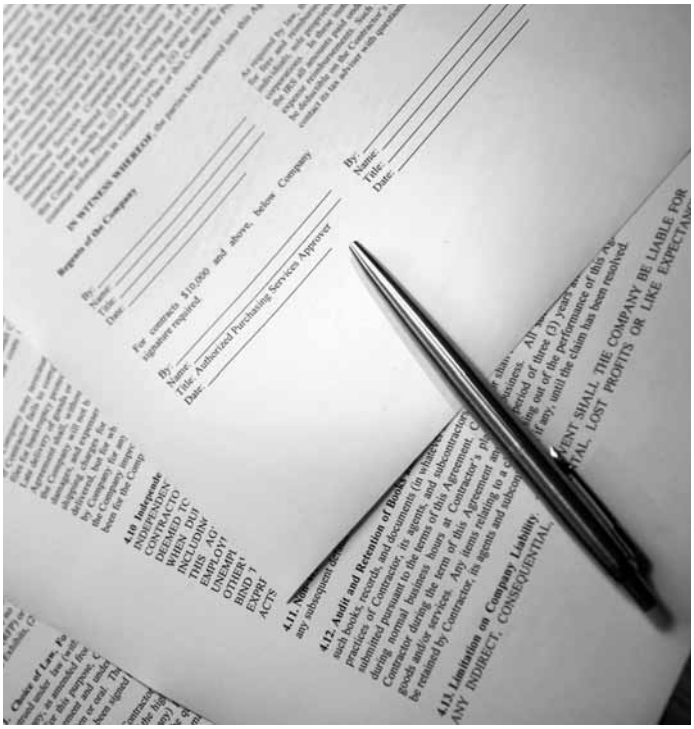
> "The accommodations I request are a white noise machine to eliminate distractions, and to be relieved of telephone duties for two hours every day, so I can concentrate on my work."

When an employer receives such a request, it is legally obligated to discuss possible accommodations with the person with the disability. Sometimes, the employer may request more information from your doctor, which is usually appropriate. If you believe the request is harassment or unnecessary, please consult with an attorney before refusing to cooperate.

All medical information an employer receives must be kept completely confidential by law, and disclosed only to those who have a work-related need to know. For example, if you request accommodation from the personnel office, your supervisor will also need to know. However, your co-workers do not have a need to know. You may choose to disclose your disability to your co-workers. Sometimes, it is a good idea to let your co-workers know so they do not assume that you are getting special treatment. It is best to give them factual information about the disorder and to let them know that you are doing what you can to learn to manage it. Enlist their help and support. General information about OCD can be found on the IOCDF website: **www.ocfoundation.org**.

• ***Protect your rights!***
All communications with your employer regarding your disability or request for accommodation should be done in writing. Be sure to date everything you write, and keep a copy. Keep all documents you receive from the employer regarding your disability, accommodation request, or work performance. Keep a log of any comments made or discussions that relate to your disability, including the date, what was said, who said it, and if anyone else was present. If your employer discriminates against you or refuses to accommodate you, this documentation will be very helpful in supporting your side of the story, and in triggering your memory.

• ***For more information***
The IOCDF is planning to add legal information to its website. Watch for more information on your legal rights at work, and more.



FROM THE FRONT LINES

My Battles and Victory over OCD

By Joseph Helm III

This is a story about me, Joseph Helm III, a 52 year old man who first developed OCD symptoms at the age of thirteen. It wasn't until seventeen years later that I was finally diagnosed with Obsessive Compulsive Disorder. I started having severe panic attacks in the seventh grade which would later give way to an aggravating choking feeling in my throat. However, with the Lord's help and just sheer determination, I was able to successfully complete my high school studies and graduate with honors. After I graduated from Marietta, Ohio High School, I enrolled at Ohio State University with the hope of being a journalist. Things went well for the first two quarters at Ohio State, but then in the last quarter of that year I developed severe depression and had to leave school to return to Marietta.

I had several jobs and eventually landed a spot at Union Carbide Construction, working as a pipefitter trainee. By that time I had started to use alcohol; I found out years later that I had used it as a way to medicate myself and relieve the anxiety and depression. Around this time I met a young social worker and fell deeply in love. Catherine and I were married in August 1982, and lived for three years in the Charleston, West Virginia area while I worked for Union Carbide. After I completed the project I was working on, I was laid off and we moved. Ironically, Catherine was working on her Masters Degree in Counseling when we met, but little did she know that she would find her most challenging case right behind her front door. I couldn't find work, so I enlisted in the U.S. Army. Things looked promising until it was time for me to ship out. I started having the most serious panic attacks I'd ever had in my life, and alcohol did nothing to stop them. After I got to boot camp in El Paso, Texas, I was quickly sent to Mental Hygiene where I was pulled from training and was asked how in the world I made it into the Army with my past history of panic attacks. Before this I had already been hospitalized twice and received some counseling. After returning home, I was hospitalized at Ohio State University, where I was put on medications for depression and sent back home. During the next few years, after nothing worked to help me, I received 14 electroconvulsive therapy (ECT) treatments that did nothing either. My marriage finally ended in 1991 because Catherine just couldn't take it any longer.

I was eventually accepted into an Anafranil study at Ohio State University and improved slightly for a while. The doctors had me try every medication known to man but still nothing worked, and I was sent back home to Marietta with no hope in sight. I just couldn't accept that this would be my fate, and after joining the OCD Foundation I began to look for other treatments. The OCD Foundation referred me to a doctor at the Cleveland Clinic, in a move that would save my life. This doctor was running a trial on a new kind of surgery called cingulotomy. I had three cingulotomies before I improved, and with treatments and medications prescribed by my doctor I was able to return home and enroll at Washington State Community College in Marietta. I earned a certificate in Diesel Mechanics and got a job in Columbus, Ohio with Penske Truck Leasing. After working there for two years while I continued to see my doctor at the Cleveland Clinic, I had to resign my job because I just couldn't handle the stress anymore. In 2001 my doctor left her practice, but referred me to someone else at Ohio State University. This move helped make me a new person. My doctor saved my life, and then put me in a position to be treated by another master in the field.

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Save the Date!

OCD Stories (Oct. 16, 7 PM EST)

On Saturday, October 16, doctors who treat people with OCD, family members of people with OCD, and those who suffer from OCD will engage in a night of true storytelling as a way to recognize OCD Awareness Week (Oct. 11-17.)

Presented by the International OCD Foundation, "OCD Stories: An evening of reflection, humor and education," is a national event that will give voice to those who are intimately affected by OCD.

To read more about OCD Stories, visit:
www.ocfoundation.org/awareness

FROM THE FRONT LINES

(My Battle, continued)

When I first saw this new doctor in 2001, I was still occasionally drinking too much on the weekends. He told me before he would continue treating me I would have to quit drinking. I knew I needed help, so I started going to AA and finally got off the booze for good. We made some significant changes in my medications, which made all the difference in the world. After seeing him for a while, I told him that I was having a lot of agitated depression and felt like just running my car off the road and ending it all. He doubled my dosage of Effexor, and this really turned my life around. For the first time since I was twelve years old, I felt like a normal human being. For the first time in years I felt like going back to Church, and started singing in the choir. I enjoyed this so much and realized that I had a really good voice, so I started singing solos in the summers when the choir was on break.

Now my Christian religion became a huge part of my life, because I realized that God had led me in the right path to find the right doctors so that I could finally get well for the first time in thirty-three years. I finally started to think about really living a normal life again, and a normal life starts with a job. At that point the Ohio Bureau of Vocational Rehabilitation became a huge help to me. They provided me with job training and job placement. My plan was to work at Wal-Mart and get started on the right path. But soon after this I started feeling that I wanted to go back to Ohio State University and finish a degree that I had started in 1976. Before I started my program of Diesel Mechanics in community college, I had taken courses in pre-nursing. These included a lot of science courses that transferred over to Ohio State University, and took care of most of my beginning requirements. In March 2003 I began my studies in Human Resources Management. But during the summer quarter, something happened to me that forever changed my life. During a dream one night, God spoke to me and told me to feed His sheep. I had been a Christian all of my life and did not need any proof that the Lord existed, but now I had been given a gift that might help others believe also.

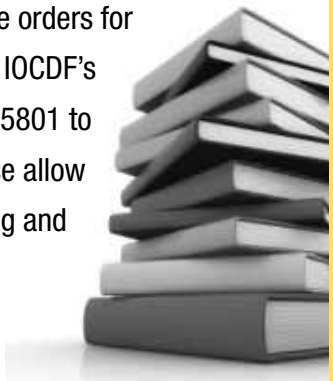
I enrolled at the Methodist Theological School in Ohio in January 2006 and started to prepare to become a United Methodist minister. Seminary was tough, mainly because my professors and fellow students were much more liberal that I was, and also because this was indeed graduate work. I finished my studies and graduated with a Masters of Divinity in May 2009, and headed out into the big world to feed God's sheep. The going was tough, mainly because I was not accepted into the Candidacy program in my District of the United Methodist Church. So I pursued other opportunities all over America, but found that all the appointments for ministers had already been taken. I am still pursuing ministry in the American Baptist Church, but what I would really like to do is write a book about my life and go all around the country and speak to people everywhere that still need inspiration in overcoming their own battles with mental illness. Maybe when God told me to feed His sheep, this was what He really wanted me to do.

Help Support our Programs by Ordering Books Directly through the Foundation!

The Foundation is now selling a limited number of OCD books, including copies of:

- Stuff: Compulsive Hoarding and the Meaning of Things, signed by Drs. Randy O. Frost and Gail Steketee
- Life in Rewind, signed by Dr. Michael Jenike

We are only accepting phone orders for these books. Please call the IOCDF's national office at (617) 973-5801 to order your copy today. Please allow 1-2 weeks for the processing and delivery of all orders.



YOUTH CORNER

International OCD Foundation: An Essay

by Max Mickenberg

This essay was written by 11-year-old Max Mickenberg of Cooper City, Florida. Max's fifth grade class raised money through various fundraisers and events for an assignment called the Legacy Project. At the end of the 2009-2010 school year, every child in the fifth grade wrote an essay about a social cause or an environmental issue. Each essay advocated for fundraising proceeds to go to a specific charity, and Max chose to share his personal story with OCD and how the International OCD Foundation helped him. Max and other finalists read their essays to the entire fifth grade during an assembly and students voted Max's as the best. The students raised $1,000, and on June 8 Max presented the check to the IOCDF Jacksonville affiliate at a school awards ceremony.

We would like to thank Max for being so brave to write a personal account of his experience with OCD and to share it with his school, and we also want to thank all of Max's classmates, who voted for his essay in their contest.

Picture this: It's time for bed. Say good night to each person, pet, and stuffed animal in the house. Walk to the bedroom, 48 steps, must end on an even number – wait is the back door closed? Go back and check. It is. Walk to the bedroom, 48 steps end on an even. Wait – when the backdoor was checked, did the front door maybe open? Go back and check. OK, front door is closed. Walk to the bedroom, 48 steps end on an even. Turn all the pillows facing the right way. Go into the bathroom and wash hands. Brush teeth. Okay, wash hands. Wait. Did I brush for 2 minutes? Brush teeth again for 2 minutes. Wash hands. Blow nose – really hard so I don't stop breathing while I'm sleeping. Wash hands. Go to the bathroom. Wash hands. Turn off light with elbow since hands are washed. Get in bed, 8 steps end on even. Wait – did I flush the toilet? Go check. Yes, toilet is flushed. Wash hands. Turn off light with elbow. Get back in bed, 8 steps end on an even. Wait, did I say good night to everyone? Say good night to everyone again, just in case. Crazy, huh? No – it's OCD.

OCD, otherwise known as Obsessive Compulsive Disorder, is a term that a lot of people use to describe odd behavior that can't be easily explained. However, most of us really don't know what OCD is and how real and difficult it can be for someone who is truly affected by it. OCD is not a disease – it is a disorder of the brain. There is a chemical in the brain called serotonin that affects someone's reasoning skills, but experts think that a person who has OCD does not have the right amount of serotonin. You most likely will not die from it but sometimes the symptoms are so bad that they can cause great harm. For instance, being afraid to eat because you do not know where the food has been or who has touched it can cause starvation. It is believed that 1 in every 200 kids and as many as 1 in every 100 adults may have OCD. Kids and adults often try to hide their symptoms because they are embarrassed. It can go for years without being recognized.

The International OCD Foundation is a not for profit organization that started about 25 years ago by people who were affected by OCD. The goal of the International OCD Foundation is to support research

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YOUTH CORNER

(An Essay, continued)

into the cause of OCD and to help educate the public and health care professionals about it in order to be able to provide treatment options. Unfortunately, there is no cure for OCD because no one knows the cause. But as the International OCD Foundation grows and awareness in the community grows, there are more and more treatments available that help people control the symptoms. These treatments include different kinds of therapy and medication.

Remember the description of OCD from my first paragraph? That came from personal experience and that was my routine every night. One of the main reasons I have gotten to know so much about OCD and why I am writing about this today is because I have OCD. Although I have had it for several years, it was only a couple of years ago that I found out I had it because no one really could figure out why I was behaving the way I was. It felt like there were 2 people living in my body, Max and OCD. They fought all day about everything and most of the time OCD won. It was exhausting for me and for my family. Thanks to the International OCD Foundation's research and the treatment options now available to me, I still fight OCD every day but most of the time I am able to win.

Most of the behavior that happens because of OCD is from fear. For example, most people lock doors because they don't want someone to break in and hurt them. Someone without OCD will lock a door and be comfortable. Someone with OCD will lock a door and then check it all night long because OCD tells them that there is a chance the door came unlocked. The fear of objects such as stuffed animals coming to life is very real to someone with OCD, but it is totally unreasonable to someone without OCD. Fear of germs, fear of dying, fear of something happening to a loved one, fear of making a mistake, all of these things can cause someone with OCD to develop patterns of strange behavior or rituals to overcome these fears. Hour long showers, rewriting the letter "A" until it is perfect, repeating phrases every night at the same time, checking appliances to make sure they are off or doors closed are odd behaviors to someone without OCD. These are all patterns developed to overcome the bad thoughts. They don't make sense, you know they don't, but you have to do them. It can take over your life.

There are actually many people that you all know who have OCD like, David Beckham, Howie Mandell, Jessica Alba, and Howard Stern. They all have OCD, but through treatment they have been able to become very successful and live normal lives.

The International OCD Foundation provided me and my family with information about my disorder and helped us understand what we needed to do to treat it. I hope that the International OCD Foundation will eventually find the cause of OCD and find new and better treatments so that others can live better with their OCD as well. Please help support the International OCD Foundation's efforts to find the cause, the cure and increase awareness for Obsessive Compulsive Disorder.

If you are 18 or younger and are interested in sharing your personal story, creative writing, or artwork relating to your OCD experience, please email your submission to **editor@ocfoundation.org.**

Help us Improve our OCD in the Classroom Program

If you are an adolescent or teen with OCD or a parent of a child with OCD, please visit: **www.surveymonkey.com/s/OCDinSchool** and fill out our online survey on OCD in the Classroom. Your personal experiences with OCD will be vital to the development of more effective programming to help school personnel recognize OCD in children and adolescents in the classroom setting.

We thank you in advance for your participation!

ORGANIZED CHAOS

Unique

By Bailey Fulton

As the bus turns into my bus stop at the neighborhood community center, I feel my heart beat faster. I look out the window, oblivious to anything else going on. It is like time has stopped. I see my mother in the car talking on her Blackberry. I snap back into reality as the bus comes to a fast stop. Before I get up to leave, I look around at the other kids on the bus and wonder what they will be doing after school today. Maybe they will go to sports practice, do their homework, or hang out with their friends. I envy them, wishing that was what I was doing after school today, but it is not. Today I am going to see Dr. Bell, whom I despise.

As I walk off the bus, I begin to think of ways in which I could get out of this – a hurricane could suddenly appear, the car could break down, or the sky could fall. None of these things ever seems to happen though. I get into the car and see my mom with an ear-to-ear grin across her face. She feels sympathy for me. She knows how much a dread this.

I see Dr. Bell once a week for Obsessive Compulsive Disorder treatment. He is supposed to help me get ride of it. Who knows how that is going? As we drive to his office, I look out the window. I always think about how everyone else is moving along to run errands, go home, or maybe go to work. I think about how different I am. It is like I have a tint, whereas others are clear. There is one thought that I always find myself coming back to: What if I am meant to be different? Maybe the world needs a variety of people and I got the bad end of the stick.

We arrive at his office in what seems like seconds. Once again I think about ways to keep me from going. I could fake a heart attack, punch myself really hard in the head, or simply lock myself in the car. I resist, knowing it will only get rescheduled and then I will have to talk about my aggressive behavior. I count the number of footsteps I take, which is what I always do. I make sure it is an even number of steps, because if it were an odd number, I would have a bad visit; not that they are ever good. I drag myself to the elevator and take a glance at my mom who is still smiling. I literally punch the "six" button on the elevator, which helps me relieve a bit of the anger building up.

Once I walk into the room, I keep my head down. I walk over to the front desk and sign in. I know what the secretaries are thinking. They're judging me. They are judging all of us here. I sit down and slowly lift my head which feels extremely heavy. I glance to the left of me at a forty-year old looking woman with her eyes closed. To the right is a small boy curled in a little ball in the chair. I make eye contact with him and give him a sympathetic look because I know exactly how he is feeling. Across the room from me, I see an old lady reading the paper, tapping her leg excessively. I realize at this moment that I am different, but who is not an outsider looking in? I say we all embrace it. There is no normal, and maybe "different" is a bad word to use. We are all unique. Yes, let's use "unique." I am unique.

THE THERAPY COMMUNITY

"Here's Looking at You, Kid": People Who Notice Things Too Much

By Fred Penzel, Ph.D.

Fred Penzel, PhD, is a licensed psychologist who has specialized in the treatment of OCD and related disorders since 1982. He is the executive director of Western Suffolk Psychological Services in Huntington, Long Island, NY, a private treatment group specializing in OCD and O-C related problems, and is a founding member of the IOCDF Science Advisory Board. Dr. Penzel is the author of Obsessive-Compulsive Disorders: A Complete Guide to Getting Well and Staying Well, a self-help book covering OCD and other O-C spectrum disorders. Dr. Penzel is also a frequent contributor to IOCDF's newsletter.

When Marie, a 35 year-old accountant, first came to my office, she was in a bad way. She looked every part a depressed and anxious person. "It's getting harder and harder to get myself to go to work," she related. "I'll use any excuse to stay home, and my boss is beginning to notice. I feel as if I'm losing my mind." I asked her what the difficulty was, and she then went on to describe her problem, prefacing her remarks with the statement, "I know you'll probably think I'm crazy or some kind of sicko." She said that she had been to a psychiatrist for a consultation, and that he had sent her to me, suspecting that this might, in some way, be related to OCD, although he wasn't entirely certain.

"I've always had this weird problem, but it's starting to get worse." "What's getting worse?" I asked. "It's really embarrassing to say this, but I have this thing about staring at people," she replied. "Why is that so bad?" I questioned. "It's quite normal for us to find other human beings interesting. Some people consider people-watching an art, and may spend hours at it," I offered. "Well, it isn't just that I stare at them," she replied. "It's the *way* I do it. I stare at women and men, and I feel as if I have to stare at them sexually in very specific ways. What I mean is that with women, I stare at their chests, and with men, I stare at their crotches. I feel as if I can't stop myself, as if my eyes are just drawn to these places. Sometimes I think I'm doing it without even being aware of it. When I stare at the women, I wonder if I am really gay. Also, the staring makes it hard to listen or talk to people at work, and it's affecting my concentration. Sometimes I avoid making eye contact. I'm sure people are noticing that I do this, and think I'm crazy." Marie added that she also suffered from strong doubts about whether or not she *was* staring at someone at a particular time. In an attempt to eliminate this doubt, she would then stare at the person on purpose to check the way it felt so she could determine if she really *had* been staring.

Marie explained that three years earlier, she had become aware that she was *noticing* other people's bodies, and that this had gradually progressed to pointedly staring at them. She was convinced that this behavior had already cost her a good job, where she believed that one of her coworkers had become aware of her staring and had complained to a supervisor. Obviously, Marie only found relief when she was home alone. In addition to avoiding going to work, she was becoming increasingly avoidant of going out for social occasions as well. Even going out in public on errands was becoming challenging. All of this added up to a great deal of anxiety on her part, not to mention feeling depressed about a behavior she couldn't seem to control.

OCD can occur in a great variety of forms, and I explained to Marie that this was another variant. I have observed over the years that there is another related form of the disorder in which people are seen to take excessive notice of particular objects, sounds, or people (or parts of people) in their environment, and cannot seem to stop looking at or listening to them. These were not your typical cases, but met the criteria for OCD nonetheless. In one case, a patient couldn't stop noticing how people's mouths moved when they spoke, and repeatedly looked at other people when they spoke. Another patient would notice how close people were to him, or in what position they stood relative to him. He would also try to determine if they were smiling, and would stare at their faces. In a third instance, a patient who worked in an open office couldn't stop listening to noises the copy machine made, and couldn't get his work done. He had the same problem with his refrigerator. In all cases, sufferers felt 'crazy' and 'abnormal.' Those targeting people in public places also feared criticism and negative judgments in case their behavior became noticeable (which it actually sometimes did).

In OCD, it is not unusual for some people to become overly preoccupied with what are normal, everyday things. What happens next is that they begin obsessing about these things, and almost have to look at or listen to them repeatedly so that they can double-check whether they actually *are* noticing them or not. They ask themselves, "Did I just stare at that person?" Then, they do stare at the person to be able to compare it to what it felt like before, so they can tell whether they did stare or not. This may then lead to more doubt, in a seemingly endless loop. If this sounds confusing, imagine what it must be like for someone constantly experiencing this.

I suspect that many such people may not receive proper diagnoses or treatments because their symptoms don't fit the usual stereotypes associated with OCD. Marie, herself, was surprised to find out that her problem turned out to be OCD. Like many others, she had thought of OCD sufferers as people who washed their hands excessively, or who arranged everything perfectly. At least her psychiatrist had a partial clue.

With that said, it should also be clarified that some forms of this behavior may lean more toward being impulsive than compulsive. They are performed in response to sudden urges, are done without purpose, and are tic-like. There are also some that have elements of both compulsions and tics. A colleague, Dr. Charles Mansueto, has referred to the forms that seem to have both compulsive and impulsive characteristics as *Tourettic OCD* (the subject of his article in the Winter 2008 *OCD Newsletter*). This is where sudden, impulsive acts that are more tic-like are performed in very particular (and sometimes ritualistic) ways to relieve the anxiety caused by obsessive, repetitive, doubtful thoughts. Tics are sensory in nature, and can cause discomfort if not performed immediately. It is likely that some of those people who find themselves having to stare, or listen to particular things may fall into this category. One factor that may reinforce this view is the possible antisocial and potentially sexual nature of some people's staring. It is not unusual for some of those who tic to feel that they have to sometimes perform tics that involve socially unacceptable things, or things that would be personally embarrassing. They do not consciously want to do these things, but feel as if their symptoms are directing them to act impulsively in these ways. All these things can make diagnosis a challenge, due to this gray area that exists between tics and compulsions.

In Marie's case, it was not too difficult to make a diagnosis. She denied the presence of urges or sudden impulses to stare or to feel that she had to do something on purpose that would embarrass her. Her symptoms seemed to be driven instead by doubt and feelings of anxiety. We learned that she wasn't sure she was really staring inappropriately, would get very anxious about the uncertainty, and would stare compulsively to relieve her anxiety.

Once a diagnosis has been made, there are fewer problems in choosing the appropriate treatment. Treatment can go in at least two different directions. One would be the familiar Exposure and Response Prevention (E&RP), in which sufferers are directed to face their fears and uncertainties in situations that are gradually more challenging, while simultaneously resisting urges to compulsively avoid or neutralize their fears. This leads them to develop a tolerance for what they fear, and for the fears to gradually diminish. Along with this, there is a decreased need to then do compulsions. I like to tell patients, *"The anxiety is not the problem – the compulsions are the problem."* When they stop doing compulsions, it causes them to stay with what they fear, which leads to developing tolerance. If they believe the anxiety is the problem, they will be more likely to keep doing compulsions to eliminate it. This, of course, never works. E&RP has a well-documented effectiveness in treating the symptoms of OCD. Interestingly, it has also been used successfully to treat tics in some cases. When used to treat tics, it helps sufferers build up a tolerance to the discomfort they feel when a tic is resisted. It also helps them accept the idea that they can observe and experience their impulses without having to always act on them. Should another approach be needed, there is the time-tested technique known as Habit Reversal Training (HRT). In HRT, the patient is trained to self-monitor when, where, why and how they perform their tics. As they record this information on a regular basis, they are then trained to relax, breathe, and center themselves, as well as being taught to use a muscular response that it incompatible with, and performed instead of, the tic.

In Marie's case, we opted for E&RP, as her symptoms appeared to fall into the OCD category. I had her gradually work up to deliberately staring at her coworkers in increasingly challenging ways, instead of avoiding them. I instructed her to do this inconspicuously and discreetly so she wouldn't draw attention to herself. Even before working at this level,

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(Here's Looking at You, continued)

she started by staring at pictures of men and women in her home, and then moved on to staring at people on TV or in videos. Later, she graduated to deliberately staring at strangers in public places, and eventually, as mentioned earlier, at coworkers. As she did this directed staring, she also had to heighten her exposure by telling herself that she was abnormal, perverted, and would be caught and have to suffer the consequences. She was further instructed to find information on the internet about voyeurism (she feared she was a voyeur), and about the social and legal consequences of doing this. She also listened to a graduated series of audio recordings (several times per day), telling her that she was some kind of pervert, a sex offender, and a thoroughly crazy person. I made the first recordings, and later, she learned to make her own. Another assignment was to view sex offender registries online. Over a period of several months, she gradually became habituated to the thoughts and feelings associated with her staring. Her tolerance for uncertainty about her behavior greatly increased. If she did stare occasionally, she was able to stay with any doubtful thoughts and get on with her day.

Along with her therapy, Marie took an SSRI-type antidepressant that helped lower the level of her intrusive thoughts and her anxiety, and improved her mood. The combination of therapy plus medication often works better than either one alone. Had her symptoms been more tic-like, she might also have been prescribed one of the medications used to treat tic disorders.

OCD is a disorder of a thousand faces, limited only by the imagination. There are clearly many forms of the disorder that lie beyond the popular notions of what it is supposed to be. A good hunch on the part of a psychiatrist led to a good outcome, but things could have just as easily not turned out well. It makes a good case for educating professionals and the public, alike, so that no one is denied effective treatment simply for lack of understanding.

Inference-Based Therapy (IBT) for Obsessions

By Kieron O'Connor, Ph.D., M.Phil., C.Psych. and Frederick Aardema, Ph.D., C.Psych.

More information on IBT can be found in Beyond Reasonable Doubt and The Clinician's OCD Manual: An Inference-Based Approach, a forthcoming book for clinicians. Both texts were written by Drs. O'Connor and Aardema and published by Wiley & Sons. If you are interested in further information, please e-mail the authors at **kieron.oconnor@umontreal.ca**, **kieron.oconnor@uqo.ca** *or* **faardema@crfs.rtss.qc.ca.**

What is IBT?

Inference-based therapy is a new cognitive approach to treating OCD that addresses the way in which people with OCD arrive at obsessional doubting inferences about themselves and the world. IBT considers obsessional doubts such as, "Maybe my hands are dirty" or "Perhaps the door is not shut" as the starting point of obsessions and the result of an obsessional reasoning process. IBT targets this obsessional reasoning.

What's different about IBT?

IBT focuses on the reasoning processes that create and maintain obsessional thought. This focus distinguishes it from conventional cognitive models, which consider that pre-existing beliefs about the importance of thoughts lead to otherwise normal thoughts becoming obsessions. According to IBT, changing the reasoning processes that lead people to infer doubt is sufficient to eliminate obsessions. If the initial doubt is eliminated, by logic so are all the consequences and appraisals that result from initial belief in the doubt.

The meaning of thoughts

Another key difference between IBT and the appraisal and acceptance-based models is the way in which the content of intrusive thoughts is viewed. In current cognitive and acceptance approaches, the tendency is to discourage attention to the content of initial obsessional thoughts in preference to looking at the reactions that the thoughts invoke. The idea is that people with OCD give thoughts importance and then act on them, or try to resist them, or suppress them, all of which are counter-productive. In contrast, people without OCD accept these intrusions, let them pass, and carry on with their lives. The argument behind this approach is that the content of intrusive thoughts is very similar in obsessional and non-obsessional populations and that thought intrusions as such are a near-universal experience; hence, if an event is normal, leave it alone, in accordance with the old maxim, "If it ain't broke, don't fix it."

Are obsessional thoughts normal?
There is considerable evidence to support the claim that the content of thought intrusions in obsessional and non-obsessional people shows considerable overlap. An exception seems to be the more bizarre schizotypal thought intrusions such as, "Maybe the devil will creep into my skin if I don't wash repeatedly" or "I touched a red painting, and since red is the color of blood, I could catch AIDS." But we've found in our research that even bizarre intrusions are surprisingly common.

However, content is only one parameter by which to match thought processes. Other parameters include frequency, associated emotions, and context. Here, we do find differences between those with and without OCD.

The context of intrusions
Even if the content of intrusions is "normal," the context in which they appear in OCD seems not "normal." People without OCD tend to experience thoughts such as, "Maybe my oven is still on" or "Maybe I left my door open" on the basis of evidence linked more directly to the here and now. For people with OCD, the link between these thoughts is more often indirect or remote from the here and now. It tends to be subjectively generated by a reasoning story which mixes up remote possibility with reality, a process we term *inferential confusion*.

Inferential confusion
Inferential confusion arises when people with OCD mix up what is actually perceptible in the here and now with what could be or might be there according to their 'obsessional intelligence.' So a person with OCD will see two garbage trucks go by and infer that therefore the road is contaminated with garbage rather than actually see garbage in the road and then infer that the garbage was dropped from a truck. In other words, the obsessional inference frequently goes against the perceptual senses. The road looks garbage free, the hands look clean, the door looks locked but the person with OCD doubts not because of evidence from the senses but because of a subjective or even imaginary narrative which leads to doubt.

Inferential confusion is defined as a reasoning process whereby the person confuses possibility with reality and so crosses over from the world of the senses into the subjective and the imaginary. A questionnaire we have developed to measure this process (the inferential confusion questionnaire – ICQ) shows that this process is particularly characteristic of OCD compared to other anxiety problems.

OCD themes
Another point supporting IBT is that obsessional thoughts tend to be thematic and frequently relate to a self-theme. People do not have obsessions in areas of life that are unimportant to them. The same content seems to consistently provoke the same anxious reactions. In contrast, a frightening possibility will not evoke an obsessional preoccupation unless it touches a personal theme.

OCD reasoning not only touches an idiosyncratic theme - it is also very selectively applied in everyday life. As an example, a person with OCD could fear making an error counting money, but not in filing a tax return. Similarly, someone with OCD might see mortal danger in touching a pole on a crowded train, but not in picking up his or her dog's poo while taking it out for a walk.

A more coherent account of this selective nature of OCD comes from identifying in each person with OCD an underlying idiosyncratic self-theme specific to the person's life experience which guides obsessional sensitivity. Someone who repeatedly checks for errors may have a self-theme such as "I'm the sort of person who could make errors," leading the person to doubt whether s/he could make an error, but not, for example, to doubt whether they will self-contaminate. Of course, this OCD created self-theme is addressed in IBT since it also is a product of inferential confusion. In reality, the person in reality is exactly the opposite of the vulnerable self created by obsessional thinking., and is not for example more prone to make errors than anyone else.

Inferences versus intrusions
For IBT, while intrusions may occur in both non-OCD and OCD groups, it is inferences which cause obsessions. Inferences come about through reasoning and do not just pop into the head. In addition, the inferences are always doubting inferences prefaced by 'maybe,' 'perhaps,' 'could be,' or 'possibly.' Hence, IBT begins with the initial doubting inferences – the 'maybes' which start the obsessional reasoning chain. Such initial doubting inferences are generally ignored by current cognitive and acceptance-based models.

To be or may be
OCD was of course for a long time called the

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(IBT, continued)

'doubting illness.' It may not be obvious that obsessions always begin with a doubting inference, since people with OCD may be focused on the anxiety generated by the consequences of the doubt.

A person who thinks, "I may have run over a child" will become immersed in the consequences if this is true. S/he may have visions of dead bodies, police, or prison – very scary things. So, it is sometimes necessary to ask the person to backtrack to the initial doubt by asking, "The consequences would happen if what state of affairs were true?" Once we have rewound to the initial doubt of "I could have run over a child," we are in a position to reveal the reasoning behind the doubt by asking the person to justify the doubt. This justification is particularly important because it often goes against the person's senses, common sense, and reality. This point helps the person to realize that it is a subjective narrative that gives undue importance to possibility in the face of reality.

OCD Story-time

It seems that OCD leads a person through a series of reasoning and rhetorical devices – what we can call an "OCD story" - to convince him/herself that a state of affairs, which at best is only remotely possible and at worst totally imaginary, is more likely than what is actually there. There it is again - inferential confusion. Just to get the flavour of this process, the following two real-life OCD statements illustrate a typical inferential confusion where a person's inference goes against his/her own sense and common sense. This conflict is resolved when we elicit from the person a subjective narrative which justifies the contradiction via personal logic. But this narrative convinces with a mix of associations and assumptions of what could be, all remote from what is actually there in the here and now.

<u>Examples of contradictions in OCD reasoning between the senses and obsessional doubt:</u>

• "My hands look perfectly clean" / "Maybe my hands are really dirty"
• "The door looks firmly closed" / "Maybe the door isn't shut properly"

<u>Examples of an OCD story justifying doubt in one's own senses:</u>

• Sense information: "My hands look perfectly clean… but… maybe…"
• OCD story: "There were invisible germs on the pole I touched and the invisible germs might have jumped onto my skin because microbes exist and the microbes might be capable of burrowing into my skin."
• Obsessional doubt: "So maybe my hands are really contaminated even if I sense nothing."

• Sense information: "The door looks firmly closed… but… maybe…"
• OCD story: "There is dust inside the lock that I can't see which makes it not shut properly and I remember reading about a person who thought the door was locked but then got robbed, so I'd better go back and check because…"
• Obsessional doubt: "Maybe the door isn't shut, even if I know I closed it."

Stages of the program

The principal steps in IBT involve:

- Awareness of the doubting process
- Distinguishing obsessional doubt from normal doubting
- Understanding the reasoning behind doubt
- The role of subjective narrative and imagination in obsessional thinking
- The selective nature of OCD logic
- Unravelling the self-theme behind OCD content
- Reality sensing
- Repositioning the self

Relapse prevention

In a nutshell, the IBT aim is to re-story the person with OCD to eliminate the credibility of the doubting story and to bring the person back to confidence in their senses (which, thankfully, never went away but were trumped by the doubting story). IBT also helps the person relate more firmly to the self they really are, rather than being defined by the self they might possibly become (if they believe the OCD story and adopt all the OCD driven safety precautions and rituals).

How effective is IBT?

IBT meets category 2 APA criteria of approved treatments with one randomized trial, several open trials and case studies demonstrating effectiveness. Its advantages over conventional CBT seem to be that it is equally effective in all subtypes of OCD including those with strong overvalued convictions. In a recently completed open trial, 80% of completers showed clinically significant improvement (decrease in symptoms by at least 30%) and 36% showed an end-point Y-BOCS score in the non-clinical range. But, of course, IBT does not work with everybody; 10% showed no improvement and 10% abandoned therapy. A larger scale randomized trial is underway.

Book Review:

Coping With OCD: Practical Strategies for Living Well with Obsessive-compulsive Disorder,

by Bruce M. Hyman and Troy Dufrene

Reviewed by John E. Calamari, Ph.D.

Dr. John Calamari is a professor of clinical psychology at Rosalind Franklin University of Medicine and Science in North Chicago, Illinois. He is a clinical psychologist who specializes in the treatment of obsessive-compulsive disorder (OCD) and other anxiety disorders. Dr. Calamari's research is focused on the identification of risk factors for OCD and related conditions and elucidating OCD heterogeneity.

Bruce Hyman and Troy Dufrene's recent self-help book for obsessive-compulsive disorder (OCD), Coping with OCD: Practical Strategies for Living Well with Obsessive-Compulsive Disorder, offers readers both a comprehensive and user-friendly guide for coping with one of the most complex psychiatric conditions. Dr. Hyman and colleagues have a well-established record in offering useful advice for people suffering with OCD. His earlier guide, The OCD Workbook: Your Guide to Breaking Free from Obsessive-Compulsive Disorder, is highly regarded by OCD sufferers and mental health professionals alike.

In Hyman and Dufrene's new guide, they provide many detailed case examples of the complex and difficult experiences of OCD. These case illustrations provide the reader with a vivid and personal picture of the OCD sufferer's experience. The many vignettes illustrate the different ways OCD becomes entangled in people's lives. These detailed case illustrations make the volume valuable both to mental health professionals with limited experience in treating the condition, as well to people with OCD and their families and friends.

Throughout the volume, the experiences of people with OCD are integrated with practical approaches for evaluating and treating the condition. Hyman and Dufrene set the stage for change by asking the person with OCD to examine carefully the impact of the condition on the quality of his or her life. Helping the individual make the many negative consequences of OCD salient is used to motivate the difficult changes in behavior and thinking that are the focus of cognitive-behavioral therapies (CBT). Hyman and Dufrene's volume differs from many self-help books in its skillful use of metaphor to elucidate OCD and the treatment process (e.g. "talking back to the doomsayer" and "learning to tell a false alarm from a real fire"), making the presentation understandable to those unfamiliar with CBT.

My only concern with Hyman and Dufrene's presentation is the liberal integration of Acceptance and Commitment Therapy (ACT) into their program. ACT is a multi-component treatment approach with similarities with CBT as well as important differences. There have been very few studies of the effectiveness of ACT for OCD. For example, the mindfulness (relaxation inducing and attention focusing) techniques they describe have been shown to be useful in addressing stress reactions, and for reducing rumination and depression relapse. One would assume that such a procedure would be helpful in treating a disorder characterized by reflexive and excessive attention to one's intrusive thoughts and the experience of severe distress. However, past attempts to treat OCD with interventions effective with other conditions have often been met with OCD failing to cooperate.

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Book Review:
What Every Professional Organizer Needs To Know About Hoarding,
by Judith Kolberg

Reviewed by Fred Penzel, Ph.D.

Along with the growth in the number of mental health professionals treating OCD, there seems to be an increase in the number of paraprofessionals whose work has inevitably led them to find ways in which they can help deliver therapy services. What Every Professional Organizer Needs to Know about Hoarding by Judith Kolberg is essentially a guide for those in the organizing service business who wish to work with compulsive hoarders.

The book begins with a basic rundown of the nature of compulsive hoarding (CH) and its various features, from both the biological/psychological perspective, and the professional organizer's perspective. It goes on to cover assessment, and finally how CH can best be remedied via a team approach that could include not only organizers and psychologists, but also community agencies, cleanout services, pest control companies, etc.. It finishes up with a practical collection of assessment scales, sample forms and agreements, and a list of resources.

With a growing awareness of OCD has come an increasing demand for effective treatment that present numbers of professionals cannot currently meet. It would seem that the type of multispecialty collaboration this book advocates may be the next wave in treatment. Much to the author's credit, she advocates for professional organizers to work with licensed CBT specialists, rather than trying to do it all themselves. She also recommends getting certification from either the National Association of Professional Organizers or the National Study Group on Chronic Disorganization. She also mentions different levels of certification and a certificate in hoarding, as well as a Board of Certification for Professional Organizers, and also supplies web addresses for these organizations.

This raises some larger important issues that the book unfortunately doesn't answer, such as:

- Who exactly are these boards, and who oversees them?
- How rigorous are their training procedures?
- What are their trainees taught?
- Who oversees those who have obtained certification?
- Can people simply read a book on the subject of organizing and then set themselves up as professional organizers, despite the presence of these boards?

The book is clearly and economically written, and draws on reputable sources of OC information, but its lack of answers to the questions above left me feeling uneasy. For example, as a licensed psychologist, I am subject to certain rules and regulations enforced by state law. An unlicensed individual is not subject to any professional discipline for poor practice or misconduct. Along with this new incorporation of other professions, we clearly will also need to expand regulation and protection for the public.

This book is for organizers seeking to begin their education about hoarding, and as an introduction. It covers all the bases, but this is just a beginning, not a complete study manual. This isn't the type of skill you can learn just by reading a book. Good training teaches you how much you don't know. It could be recommended for organizers looking to get their feet wet, while hoarders and their families would also find it informative.

IOCDF Institutional Member Updates

IOCDF Institutional Members are all programs that offer more than traditional outpatient therapy for those who need higher levels of care. We are pleased to announce the addition of two new Institutional Members:

OCD Institute of the Center for Understanding and Treating Anxiety at San Diego State University

Program Director: Nader Amir, PhD

Contact:
Nader Amir, PhD
6386 Alvarado Court, Suite 301
San Diego, CA 92120
Phone: (619) 229-3740
E-mail: **naderami@gmail.com**
Website: **http://nas.psy.sdsu.edu**

Mount Sinai Center of Excellence for OCD and Related Disorders

Program Directors: Wayne Goodman, M.D.

Contact:
Elisabeth Cordell
Mount Sinai Center of Excellence
for OCD and Related Disorders
One Gustave L Levy Place
Box 1230
New York, NY 10029
Phone: (212) 241-8177
Email: **Elisabeth.cordell@mssm.edu**
Website: **http://www.ocdscales.org**

Both the Center for Understanding and Treating Anxiety and the Mount Sinai Center offer an intensive outpatient program (IOP) and traditional outpatient services for children, adolescents, and adults.

Please see the announcements below for other program updates.

ILLINOIS
Center for Anxiety and Obsessive Compulsive Disorders Alexian Brothers Behavioral Health Hospital

1650 Moon Lake Boulevard
Hoffman Estates, IL 60169

The Center for Anxiety and OCD at Alexian Brothers Behavioral Health Hospital (ABBHH) now offers an evening and weekend intensive outpatient program (IOP). The hours of this program are 6:30pm – 9:30pm on Mondays, Tuesdays, and Thursdays, and 9am – 12pm on Saturdays. The program will run just like ABBHH's other IOP service, with ERP being the main focus of treatment. This program is designed for people who have difficulty getting out of work or child care duties during the day, but need more intensive treatment than the standard individual weekly therapy. For more information on the program, please call Alexian Brothers at (847) 755-8566 or email **anxiety@alexian.net**.

CALIFORNIA
Cognitive Behavior Therapy Center for OCD & Anxiety

990 A Street, Suite 401
San Rafael, CA 94901-3000

Drs. Paul R. Munford and Arna M. Munford at the Cognitive Behavior Therapy Center for OCD & Anxiety have developed a program to show parents and significant others how to help in the treatment of their loved ones. The topics covered are:

- The description of OCD and its treatment with exposure and response prevention (ERP) including demonstrations of ERP exercises with the patient
- Identifying and eliminating accommodations, which are doing or not doing things that are thought to help patients but actually maintain or intensify their obsessions and compulsions
- Eliminating repeated reassurance that obsessional fears are harmless because this kind of reassurance hinders treatment while eliminating it promotes treatment
- Using praise and rewards for effort and small successes
- The importance of continuing to practice ERP after discharge to further reduce symptom intensity and to prevent relapse

Please visit **www.cbtmarin.com** for more information.

RESEARCH NEWS

2010 Research Award Recipients, continued

NEURO-EXECUTIVE PREDICTORS OF COGNITIVE BEHAVIORAL TREATMENT RESPONSE IN YOUTH WITH OBSESSIVE COMPULSIVE DISORDER

Adam Lewin, Ph.D., Assistant Professor, Department of Pediatrics
University of South Florida College of Medicine

Grant Award Amount: $24,971

Cognitive behavioral therapy (CBT), along with exposure and response prevention (ERP), is a proven treatment for children and adolescents with obsessive compulsive disorder (OCD). Although CBT has some advantages over medicines (for example, improvements last longer after treatment ends and there are no negative side effects), not all youth improve following CBT. Consequently, this research aims to understand the factors that might influence whether or not a person responds to CBT. These factors could then be used to personalize treatment and enhance treatment outcome. Problems in '*executive functioning*' may limit the ability of a child to get the most out of CBT. Executive functioning refers to a set of cognitive skills that include the ability to plan/organize, to shift from one task to another, to stop certain behaviors/thoughts and certain types of memory, and mental flexibility. When a child has more problems with executive functioning, he/she may be less likely to do well in therapy due to the complexity of the treatment, the need to plan and organize homework and ERP exercises, or to understand the reasons for what he/she is being asked to do.

This project aims to recruit approximately 100 youth with OCD. Following a comprehensive diagnostic evaluation, individuals will complete detailed neuropsychological tests. Following these evaluations, a research-based CBT protocol lasting 14 sessions and tailored to children/adolescents is given by experienced clinicians. After treatment ends, the researchers reassess OCD symptom severity. If the neuro-executive factors that hinder a child's response to CBT can be found and corrected, our ability to increase rates of CBT response may improve. In summary, improving our understanding of the impact of executive dysfunction on CBT outcome offers the potential for improving outcomes in youth with OCD by offering more individually-tailored therapies.

AFFECTIVE RESPONSES AND INFORMATION PROCESSING IN COMPULSIVE HOARDING: A PSYCHOPHYSIOLOGICAL INVESTIGATION

Michael Wheaton, M.A., Doctoral Student, Department of Psychology
University of North Carolina at Chapel Hill

Grant Award Amount: $26,878

Hoarding is when a person gathers, and does not get rid of, large numbers of unneeded items. Hoarding can cause a lot of clutter, distress, and impairment and is increasingly being recognized as an important public health concern. Recent evidence suggests hoarding is not the same as Obsessive Compulsive Disorder (OCD). Unfortunately, how best to understand and describe hoarding is not clear. For example, is it a "fear-based" or "distress-based" condition?

Measuring the startle response to a loud sound represents a unique tool for investigating these issues. Our study aims to use two startle tests in order to better understand emotional and cognitive processing in people with hoarding problems. The first test measures emotional responses using affective valence startle modulation (AVSM). The second test measures information-processing using prepulse inhibition (PPI) of startle. We will recruit 30 adults with compulsive hoarding and 30 control participants and compare their AVSM and PPI startle responses. These two measures have recently been shown to distinguish between disorders characterized by fear and distress on emotional and cognitive levels. The results of this study will provide biological evidence for how best to understand and classify hoarding. These results will complement previous self-report and genetic studies on hoarding and may show testing of startle responses to be a powerful new tool for the study of hoarding.

Check **www.ocfoundation.org** later this fall for the dates of the 2011 research award submission period!

NEURAL CORRELATES OF EMOTIONAL RESPONSE INHIBITION IN OBSESSIVE COMPULSIVE DISORDER

Andrew Gilbert, M.D., Assistant Professor, Department of Psychiatry
Medical Director, Center of Excellence for OCD and Related Disorders
Mount Sinai School of Medicine

Grant Award Amount: $44,842

Obsessive compulsive disorder (OCD) is a disabling mental disorder characterized by recurring intrusive thoughts (obsessions), repetitive behaviors (compulsions), and severe anxiety and discomfort. A symptom of OCD is not being able to control thoughts, feelings, and behaviors. Several studies suggest that problems with inhibitory control (being able to stop yourself) are strongly related to OCD. Recent brain imaging studies of OCD patients have examined brain activity associated with inhibitory control as well as the processing of different emotions, such as fear and disgust. These two emotions seem to play an important role in patients with OCD who have obsessions and compulsions related to contamination. Studies suggest connections between the processing of disgust and a part of the brain called the insula, and the processing of fear and a part of the brain called the amygdala. Taken together, these studies suggest unusual differences in inhibitory control and emotion processing in patients with OCD.

The relationship between emotions, inhibition and the brain in OCD, however, is not fully understood. Using functional magnetic resonance imaging (fMRI), a surgery-free way to study brain activity, we will be looking for possible brain markers of abnormal emotional and inhibition processing in OCD. We have developed a task that measures the inhibition of emotions, called an emotional go/no-go paradigm, and we have specifically tailored it to study the control of fear and disgust. We hypothesize that we will find differences in brain activity in OCD subjects with contamination symptoms compared to healthy controls as they try to control their responses to disgust-related and fear-related images. We think that disgust processing will involve the insula in contrast to fear processing, which will involve the amygdala. These results will provide important evidence for emotion-specific inhibitory pathways in OCD, which may serve as possible targets for treatments as well as markers for the development and course of the disorder.

ATTENTIONAL PROCESSES IN SCRUPULOUS OCD

Jedidiah Siev, Ph.D., Post-Doctoral Fellow, Department of Psychiatry
OCD and Related Disorders Program, Massachusetts General Hospital

Grant Award Amount: $39,957

Scrupulosity is a common type of OCD in which a person has religious and/or moral fears. In Western cultures, as many as 1 in 3 people with OCD have religious obsessions, and such fears represent the main symptom in about 1 in 20. In some cultures, more than half of individuals with OCD experience religious obsessions. Although behavior therapy and medicines can work for many people with OCD, religious obsessions seem harder to treat. Still, very little is known about scrupulosity.
According to information-processing models of OCD, obsessions and compulsions come from problematic processing of threatening information, such as selective attention toward threat, difficulty disengaging from threat, and overall difficulty controlling attention (for example, choosing to pay attention to one thing and not another). To our knowledge, no studies have examined attention problems in scrupulosity despite (a) early evidence that attention may be particularly relevant to scrupulous obsessions, and (b) evidence that treatments targeting attention problems might help reduce symptoms.

The aim of this study is to look at how individuals with scrupulosity process information. There will be a particular focus on attention bias (a habit of paying too much attention to threatening material) and the ability to stop intended behaviors that have been learned. We will also evaluate the effect of an experimental attention training session. To do this, we will enroll participants with scrupulous OCD, as well as comparison groups of individuals with contamination-related OCD and healthy controls. Participants will complete clinical tests and computerized attention tasks.

This study will be one of the first to examine symptoms and information-processing in scrupulous patients. We hope to provide critical information about the nature of scrupulosity, and then to use these data as the basis for the development and implementation of new treatments for scrupulosity that target attention.

RESEARCH NEWS

Research Participants Sought

FLORIDA

Videophone CBT for Children & Adolescents with OCD
Based on our promising findings, the University of South Florida OCD program is conducting a research study to examine what factors predict treatment outcome to cognitive-behavioral therapy that is delivered via videophone. We are recruiting a group of children and adolescents with Obsessive-Compulsive Disorder (OCD). Our past research has found that as many as 80% of kids who received this type of CBT received some benefit. However, we want to know for whom this treatment is most appropriate because videophone-administered CBT may be a way to make treatment more convenient and affordable (less travel costs) and less time-consuming.

Your child must be between the ages of 7-17 and have problematic OCD symptoms to be able to participate in this study. You will have to travel to our facility for the initial evaluation (we cannot cover these costs); however, study treatment and evaluations will be provided at no charge. If he/she is eligible to participate in this study, he/she will either receive 14 90-minute sessions of videophone-CBT (twice a week for the first 4 sessions) and 3 psychiatric evaluations of varying lengths.

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

INDIANA

Paliperidone Study for Adults with OCD
Have you been diagnosed with a problem called Obsessive-Compulsive Disorder (OCD) and not responded to past medication or counseling treatment? If so, you may be eligible for a study examining if adding a medication called Paliperidone helps reduce your OCD symptoms. The Department of Psychiatry at IU School of Medicine is conducting this study.

To be eligible, you must be at least 18 years old and have problematic OCD symptoms despite having tried at least two OCD medications. If you participate in this study, you will be randomly assigned, that is by chance as in the "flip of a coin," to receive either the study medication (Paliperidone) or a sugar pill in addition to the medication you are currently taking. There will also be seven psychiatric evaluations that take place. Study medication and the evaluations will be provided at no charge. Financial compensation is available for qualified participants. Risks associated with the study will be disclosed prior to study participation. For more information call (317) 948-0038.

KANSAS

Telemedicine and OCD Assessment Research
The University of Kansas Medical Center and the Kansas City Center for Anxiety Treatment are seeking research participants for a study comparing traditional "in person" and videoconferencing administrations of the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS). Your child will receive a series of evaluations to assess anxiety and obsessive compulsive symptoms at no cost. You will be provided a valuable summary of their data, which you may choose to share with your child's mental health providers to inform treatment.

Eligibility: You and your child are eligible for this study if your child experiences OCD symptoms and is between the ages of 10 and 17.

What Is Involved?
You and your child will undergo 3 assessments on 3 separate days.

- Anxiety Disorders Interview Schedule for DSM-IV, Child Version: about 45-60 minutes
- In person CY-BOCS: about 60-90 minutes
- Videoconferencing CY-BOCS: about 60-90 minutes

Study Location:
Kansas City Center for Anxiety Treatment (KCCAT)
10540 Marty Street, Suite 200
Overland Park, Kansas 66212

It is important to note that the information gathered in the study is obtained solely for research purposes, and is not meant as a clinical evaluation or treatment for any disorder or symptom.

If you would like more information about this study, please contact Thao Bui, MA at (913) 588-2226 or by email at tbui@kcanxiety.com.

NEW YORK

Understanding Obsessive Compulsive Personality Features
Principal Investigator: Anthony Pinto, Ph.D.
NYSPI IRB Protocol #: 5979

Is perfectionism causing problems for you?

Do others complain about your rigidity?

Do you worry too much about order and details?

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

Are you constantly trying to control things?

Do you plan out every minute of your day?

Researchers at Columbia University Medical Center/ NYSPI in Manhattan are seeking participants (age 18-60) in the NY metro area with several of these features for a study designed to learn more about the obsessive compulsive personality style and ways of thinking, and how these features affect life functioning. Participants will receive a confidential evaluation at no cost and payment upon completion of an interview, questionnaires, and computer tasks. For more information, contact Jordan at #212-543-5938.

CANADA

UW Anxiety Studies researchers are currently seeking volunteers for our Anxiety Studies Participant Pool
You may be eligible if you experience any of the following:

- Recurrent thoughts or images that are unwanted, distasteful, inappropriate, intrusive or distressing, such as:
  - o The idea that you were dirty, contaminated or had germs
  - o Doubting that you turned appliances off or locked doors properly
  - o Fearing that you would act on some impulse
  - o Obsessions with sexual thoughts, images, or impulses
- The need to do something repeatedly without being able to resist doing it, like washing, cleaning, checking or counting
- The need to do things in a certain way even if another way would be more efficient
- The need to keep things you don't need
- Diagnosis of Obsessive-Compulsive Disorder

Participants who are eligible for the Pool (as determined by a 15-minute confidential phone interview) will be asked to complete:

- An in-person interview about symptoms of anxiety, depression, drug/alcohol use, unusual experiences and physical sensations (30-60 minutes)
- Self-report questionnaires about symptoms, mood, social experiences, thoughts about self, concentration and habits (45-60 minutes)

Participants will receive $40.00 in appreciation of their time.

Confidential inquiries can be made through the Anxiety Studies Division:
http://anxietystudies.uwaterloo.ca
519-888-4567, x35920
anxiety@uwaterloo.ca

ONLINE

How does the sibling relationship impact Obsessive-Compulsive Disorder?
We are looking for parents of children with OCD to participate in a research study! The title of this study is "How does the sibling relationship impact Obsessive-Compulsive Disorder?" The purpose of this study is to examine factors associated with the quality of the sibling relationship and how that relationship impacts a child with OCD. We are hoping to discover how the sibling relationship can benefit a child with OCD. We are examining this relationship – via parent-reports – in up to 150 youth with Obsessive-Compulsive Disorder. To participate, your child must be between 6 and 17 years of age and have OCD. In addition, you must be your child's parent or legal guardian and the child must have interaction with at least one of their siblings. You will be asked to complete a questionnaire about your children's behaviors, your child's symptoms related to OCD, and the relationship between that child and the rest of the family, as well as his/her overall quality of life. If you are interested in participating, please follow the link below to begin: **http://hsccm2.hsc.usf.edu/checkbox/Survey.aspx?surveyid=4656**.

If you would like to advertise your research study in this newsletter or on the IOCDF website, please email **editor@ocfoundation.org** for more information.

FROM THE AFFILIATES

Affiliate Updates

Our regional affiliates carry out the mission of the International OCD Foundation through programs at the local community level. All of our affiliates are non-profit organizations that are run entirely by dedicated volunteers. If you would like to find help in your community or would like to volunteer in grassroots efforts to raise awareness and funds locally, please contact one of our affiliates below.

We are pleased to announce the addition of 2 new IOCDF affiliates: OCD Mid-Atlantic and OCD New York.

OCD Mid-Atlantic, which debuted at our Annual Conference, will service Central and Northern Virginia, the District of Columbia, and Maryland. The new affiliate will be led by T. Carter Waddell and Dr. Charley Mansueto. If you are interested in volunteering with this new affiliate, or would like to help in some other way, please email **OCDMidAtlantic@ocfoundation.org**.

OCD New York, which will service the entire state of New York, will be led by Drs. Fugen Neziroglu and Sony Khemlani-Patel. If you are interested in volunteering with OCD New York, or would like to help in some other way, please email **ocdny@ocfoundation.org.**

Look for both affiliates to launch their new websites very soon. Links will be available through the general IOCDF website, **www.ocfoundation.org**.

NEW JERSEY
OCD New Jersey
www.njocf.org

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

Quarterly Meetings
All quarterly meetings are 7:30-9pm on the 2nd Monday of the month. Free refreshments are available.

- September 13, 2010
  Robert Wood Johnson Hospital, New Brunswick, NJ
  Dr. Marla Deibler: "Hoarding"
  Free and open to the public.
- December 14, 2010
  Robert Wood Johnson Hospital, New Brunswick, NJ
  Dr. Fran Rosenberg: "Hierarchy Construction for ERP"
  Free and open to the public.

11th Annual Conference & Brunch

- October 24, 2010, 10am–3pm
  DoubleTree Hotel, Somerset, NJ
  Dr. Aureen Wagner: "Hard-to-Treat OCD in Children and Adolescents" plus, the "Living with OCD" panel
  Registration required.

PENNSYLVANIA
OC Foundation of Western PA
www.ocfwpa.org

The OC Foundation of Western PA would like to announce the following upcoming events:

Thursday, October 14, 7:00pm: Open Mike Night. Simultaneous events at Borders Penn Circle in Pittsburgh and Borders 2088 Interchange Rd. in Erie. Come join us for a night of inspiration and laughter as we open the stage to anyone in the OCD Community who would like to share their perspective on OCD. Everyone has a story so come on out and share yours. We invite individuals with OCD, their family and friends, as well as individuals who treat this community to join us. You need not feel that you need to share your story to join us. Contact Hilary Zurbuch at **hilzurbuch@gmail.com** for more information.

Thursday-Friday, October 14-15: Borders Benefit Days for the OC Foundation of Western PA. Proceeds from sales at the Penn Circle and Interchange Rd. Borders locations will be donated to OCFWPA. You will need to provide a coupon noting that you are participating in the program for your purchase to be eligible. Email us at **info@ocfwpa.org** or call (412) 363-6231 for a copy of the coupon.

Saturday, November 6, 9:30am: 4th Annual Dirt Monster 5 Mile Trail Race and 1 Mile Trail Walk. Grant Pavillion, North Park. Participate in this benefit race either as a runner, walker or volunteer to help. Information is available at **www.ocfwpa.org** or email Elaine Davis, PhD, at **edavis@ocfwpa.org**.