



BUILDING A COMMUNITY **ANNUAL REPORT 2013**





The mission of the International OCD Foundation is to help individuals with obsessive compulsive disorder (OCD) and related disorders to live full and productive lives. Our aim is to increase access to effective treatment, end the stigma associated with mental health issues, and foster a community for those affected by OCD and the professionals who treat them.

BUILDING A COMMUNITY

Building A Community... One Person at a Time



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International
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Foundation

Dear Friends and Supporters of the International OCD Foundation,

A conservative estimate is that as many as 1 in 200 kids and teens have OCD. This means 4 or 5 kids with OCD are likely to be enrolled in a typical elementary school. In a medium to large high school, there could be 20 students struggling with the challenges caused by OCD. Unfortunately, on average it can take 14–17 years from the time someone with OCD first notices symptoms to the time that person gains access to effective treatment. For all of us in the OCD community, this is simply unacceptable.



For 27 years, the International OCD Foundation (IOCDF) has worked diligently to change this reality by funding OCD research, developing quality and innovative programming for people affected by OCD, and educating mental health and medical professionals and the community about this condition.

For example, as many of you know, our Behavior Therapy Training Institutes (BTTI's) are very successful three day, intensive trainings for mental health professionals. Dr. C. Alec Pollard, Founder and Director of the Saint Louis Behavioral Medicine Institute Center for OCD & Anxiety Disorders, continues to direct and oversee the BTTI program on behalf of the IOCDF. He recruits experts from all over the country to train other professionals through the BTTI program. In fact, the IOCDF held 5 BTTI's across the country in 2013, each selling out within hours of being announced. That means that 150 more mental health therapists are now familiar with effective diagnostic and treatment strategies for OCD and related disorders (see page 12 for a detailed list of the trainings and faculty).

One of these BTTI's was new, however. In 2013, the IOCDF began to place increased focus on pediatric OCD and as a result held our first Pediatric BTTI this year. Again, under the leadership of Dr. Pollard, a new curriculum for the Pediatric BTTI was developed in conjunction with leading pediatric experts and IOCDF Scientific and Clinical Advisory Board Members: Dr. Eric Storch, Dr. Aureen Wagner, Dr. Martin Franklin and Dr. Evelyn Stewart. We look forward to many more of these trainings!

A second pediatric-focused initiative included the development of two comprehensive informational brochures about Pediatric OCD. The first brochure, *Does My Child Have OCD*, was developed as a general informational resource designed especially for parents that explains pediatric OCD symptoms and treatment options. The second brochure focuses on Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS). In both instances, children and teens experience a sudden, rapid-onset of obsessive compulsive symptoms following an infection. The IOCDF exhibited at the most prominent conference for pediatricians in the country (the American Academy of Pediatrics), and in addition to distributing these new brochures, the IOCDF had the opportunity to survey pediatricians regarding their knowledge of OCD. Not surprisingly, many were not adequately equipped with the appropriate knowledge to diagnose and refer into treatment their patients who may have OCD or a related disorder. Information from this survey is currently being used to develop more pediatrician-based outreach programs. Stay tuned!

The IOCDF's largest event, the 20th Annual OCD Conference, was held in Atlanta, GA this year and was one of our largest with over 1,100 attendees! With the popularity of the Kids and Teens Track and additional support groups for families and teens, the conference really took on a "family affair" feeling. There were many family-related activities such as the OCD Film Festival, the Kids & Teens Fashion Show, and Ping Pong 4 OCD, as well as a new storytelling event with Dr. Allen Weg. These activities were a great way for many people to begin developing connections with other attendees that in some cases become long-lasting friendships. Plus, these events were really fun! Long standing favorites of the conference rounded out the offering for families — including the kids and teens art therapy rooms and evening support groups. And this year, we added a companion event especially for kids and parents to compliment Dr. Grayson's Virtual Camping Trip.

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Also at the Annual OCD Conference, we got to experience an amazing Keynote Speaker. Shala Nicely, MS, LAPSC, NCC, has had OCD all of her life. However, it wasn't until she accidentally stumbled upon our 2010 conference in Washington, DC that she realized she wasn't getting proper treatment. Following the conference, Shala was able to access effective care for her OCD symptoms, and then returned to school. Now Shala is an OCD therapist at Cornerstone Family Services in Atlanta, GA. She is also the co-founder and spokesperson for OCD Georgia, an IOCDF Affiliate. In her Keynote speech, Shala shared her experience living with OCD through the telling of 11 stories, each representing a chapter in her life. Her talk entitled "Is Fred in the Refrigerator?" both moved and inspired the audience.

The Annual OCD Conference is also the best place to acknowledge those who stand out contributors to the IOCDF and the OCD and related disorders community. We were pleased to recognize Julian and Ina Spero with the Patricia Perkins Service Award in honor of their many years of dedication and leadership for one of the IOCDF's longest running affiliates, OCD New Jersey. Additionally, the IOCDF honored Randy Frost, PhD and Gail Steketee, PhD with the IOCDF Outstanding Career Achievement Award. Drs. Frost and Steketee are pioneers and leaders in the field of hoarding disorder and animal hoarding treatment and research. You can read more about the Annual OCD Conference on page 6.

The 5th annual OCD Awareness Week was a major success this year, with many of our Affiliates across the country — and the globe, including our partners in Canada and the United Kingdom — hosting activities during the second week of October to educate their communities and the public about OCD and related disorders. Several IOCDF Institutional Members also participated by encouraging their staff members to hold signs supporting OCD Awareness Week then posting photos online and in social media.

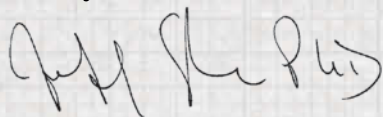
With another nod to the importance of pediatric OCD, this fall the IOCDF launched the inaugural "Pediatric Campaign 4 Hope". This fundraising campaign was developed to raise the necessary support for developing new pediatric programs. A long time donor of the IOCDF agreed to match every dollar raised for the campaign up to \$25,000. Through the combined generosity of donors, the campaign raised \$70,000. The matching donor was so impressed by the response to the campaign that they doubled their match to \$50,000, bringing the grand total to \$120,000!

The IOCDF continues its commitment to finding and promoting effective treatment for everyone with OCD and related disorders through our Research Grant Program. Research money comes from generous donors within the IOCDF community. This year, \$157,128 was awarded to four different projects. Thank you to all who contributed, and to Dr. Sabine Wilhelm, the chair of the Grant Review Committee. Read more about research projects funded by the IOCDF on page 14.

The mission of the International OCD Foundation is to help individuals with obsessive compulsive disorder (OCD) to live full and productive lives. Our aim is to increase access to effective treatment, end the stigma associated with mental health issues, and foster a community for those affected by OCD and the professionals who treat them.

I want to thank our donors, members, Board of Directors, Scientific and Clinical Advisory Board members, affiliates and volunteers for their dedication, time, and energy spent helping the IOCDF fulfill our very important mission.

Sincerely,



Jeff Szymanski, PhD
Executive Director



The 20th Annual 2013 International OCD Foundation Conference

"A Family Affair" and Life Changing Event

The 20th Annual OCD Conference was held at the Hyatt Regency Hotel in Atlanta, Georgia on July 19 – 21, 2013. Attendance hit 1,140 making this one of the largest conferences to date. Since 1993, the IOCDF Annual Conference has been the only national meeting focused solely on obsessive compulsive disorder (OCD) and related disorders. The unique event allows people with OCD and their loved ones to experience the latest OCD information alongside the mental health professionals who care for them.

The 20th Annual OCD Conference featured more than 100 presentations, workshops, and seminars as well as nearly two-dozen support groups. The presenters include some of the most experienced and knowledgeable clinicians and researchers in the field, as well as people with OCD and family members who are willing to share their story. The goal of our Annual OCD Conference is to both provide up-to-date information and education about OCD and related disorders and effective treatment options, but even more so, the OCD conference is about creating a community for those affected by OCD and related disorders as well as the professionals who treat them. The Annual OCD Conference is incredibly powerful. From internationally known OCD researchers, to individuals with OCD telling their own personal success stories, to experiential activities for kids and teens designed to help them battle their OCD, the presentations and workshops are always the highest rated aspect of the conference in the written evaluations we receive. However, the community created at the conference is equally important. The conference may be the first time an individual with OCD meets another person facing the same challenges. There are support groups for parents and family members, social activities for kids and teens, networking opportunities professionals learning new and more effective ways to treat individuals with OCD and related disorders, as well as graduate students and trainees, who make career connections with senior therapists and researchers in the field. All in all, a lot happens at this conference!



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Notable additions to this year's conference included the Annual Hoarding Disorder Meeting. This new resource began with two pre-conference trainings one for mental health professionals treating hoarding disorder (HD), and one for the countless other professionals who encounter individuals with HD in their work as professional organizers, housing authority staff, public safety officers, firefighters, case managers and others. Pioneers in the Hoarding field, Drs. Gail Steketee and Randy Frost, along with Dr. Christiana Bratiotis led these trainings. Following these pre-conference trainings were Hoarding Disorder workshops throughout Friday and Saturday providing a comprehensive look at research, treatment, and community-based interventions for individuals with Hoarding Disorder, their family members and loved ones, and professionals who work with them. Finally, we offered two support groups on Saturday evening: one for individuals with HD, and one for their family members and loved ones.

Also new this year was a Young Adult track for individuals in their late teens and twenties to discuss the challenges of attending college, starting careers, and dating with OCD.

One of these first-time Young Adult attendees, Henry had an amazing transformation at the conference. On Friday, he came to talk to staff at the conference registration desk, clearly anxious — he couldn't find his parents or any of his new friends. He told us he really didn't like being alone. One of our conference ambassadors offered to help him try to find his friends and parents, riding up and down the escalators with him until he finally found someone. On Saturday Night, our registration desk staff saw Henry again, only this time, he wasn't anxious or worried. Instead, he was dancing with his new friends and complete strangers out on the dance floor at the Saturday Night Social, having a blast. On Sunday, we talked with Henry's parents and they told us that it had taken them two days to drive from where they live to attend the conference, but that it was worth every minute – they were so grateful to have had this experience!



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IOCDF Outstanding Career Achievement Award



Gail Steketee, PhD
Dean and Professor
Boston University School of Social Work

Dr. Gail Steketee has been a leader in the field of Cognitive Behavioral Therapy for OCD with an emphasis on family aspects and cognitive treatments since 1987. She is currently the Dean of the Boston University School of Social Work, Scientific and Clinical Advisory Board Member of the IOCDF, and an Editorial Board member for various scholarly publications. Dr. Steketee is an internationally recognized expert on OCD and hoarding disorder and has published more than 200 scientific articles, books, and book chapters on these topics. Along with Dr. Randy Frost she has helped increase understanding surrounding the hoarding of

objects and of animals with colleagues in a variety of disciplines (veterinary medicine, psychiatry, social work, psychology, public health, animal control, and others). Also in collaboration with Dr. Frost, she is seen as being largely responsible for the inclusion of hoarding disorder in the fifth edition of the Diagnostic and Statistical Manual (DSM-5).



Randy O. Frost, PhD
Harold & Elsa Siipola Israel Professor of Psychology
Smith College

Dr. Randy Frost received his PhD from the University of Kansas in 1977 and is currently the Harold and Elsa Siipola Israel Professor of Psychology at Smith College. He is an internationally recognized expert on perfectionism, OCD, and hoarding disorder and has published more than 160 scientific articles, books, and book chapters on these topics. Dr. Frost also serves on the Scientific and Clinical Advisory Board of the International OCD Foundation. As a clinical psychologist, Dr. Frost has conducted pioneering research on the nature and treatment of hoarding disorder and contributed to the understanding of OCD. He

has helped to develop peer-led interventions that show excellent potential to aid many people with serious hoarding problems. Along with Dr. Steketee, Dr. Frost also helped to coordinate 50 researchers in a multi-national effort to develop a standardized measure of beliefs important in the development and persistence of OCD (Obsessive Beliefs Questionnaire), which is now widely used in many OCD clinics and has been translated into 13 languages

Patricia Perkins IOCDF Service Award



Julian & Ina Spero

After struggling to get proper treatment for their young adult son who suffered with OCD, Ina and Julian Spero decided to co-found OCD New Jersey (originally called the New Jersey Affiliate of the OC Foundation) with Dr. Allen Weg in 1998. Ina served as the President and Julian served as the Treasurer from 1998 until early 2013 when they stepped down to enjoy their retirement. Ina took care of all the business issues concerning the organization, from filing paperwork to securing venues for their annual conferences and quarterly

presentations. She was also solely responsible for the phone referral services 12 hours a day and aggressively pursued media awareness and recognition of OCD and OCD New Jersey. As treasurer, Julian managed the organizational finances and educational materials. Together, they both took care of the fundamental basics of running an affiliate: Folding newsletters, stuffing envelopes, affixing address labels, delivering it all to the post office and even hosting virtually every Board of Directors meeting! The IOCDF is forever indebted to the Speros for their outstanding contributions.

One Family's Story | by Liz Lindley

There are certain events from the past that are seared into my memory. Some good. Some bad. Some terrifying... for example, as I watched my 12-year-old son deteriorate as his world became increasingly controlled by OCD. Commanding all of his attention and effort, his OCD was destroying him and our family with an assault of frightening intrusive thoughts.

Jack was a typical happy child, involved in activities and friends. Then fear began to creep into his life. He began to intensely fear almost everything. His brother, who he adored, was three at the time and he became obsessed that he might harm him, which was polar opposite of his personality. As hard as he tried, he couldn't convince his brain of the absurdity of this scenario.

After his diagnosis, his father and I spent long hours urging, bribing, and pleading with him to engage in Exposure Response Prevention (ERP) therapy. He had access to one of the best therapists in the nation. Jennifer Wells was trained at an IOCDF Behavior Therapy Training Institute and has a strong relationship with the IOCDF. In 2011, she suggested we attend a conference and, thankfully, we followed her advice.

I can recall many details of our first conference in San Diego, especially the moment at Virtual Camping event when Dr. Grayson was leading a large group outside and shouted, "Who has a problem with knives?" as he held one high above his head. These people get it! Jack was astonished that he wasn't the only one. How did he know about his worst fear? Feeling renewed hope, strength, and determination, I watched from behind the crowd as he joined the exposure and successfully faced his worst fear with one of the leading experts in OCD treatment. It was dramatic but I knew in that moment, eventually Jack would succeed and OCD would not take away his life.

Acceptance. Hope. Transformation.

After Virtual Camping, then attending Dr. Penzel's teen support group and just hanging out with other teens like himself, Jack understood that he was not alone. He also realized that the ERP therapy he was receiving from Jennifer was not available to all who suffered from OCD. Moving forward, he would take advantage of this opportunity. Many of the teens he met did not have access to quality care close to home and he listened while they told stories about their hardships and the relief that they had felt attending the conference.

Remarkably, the keynote speakers that year were a mother and son! With a message of hope and inspiration, the Trondsens would become a highlight at future conferences. Jack had the opportunity the following year to personally talk with Chris Trondsen. Our connection with the IOCDF continues to have a very personal, profound, and lasting effect on me as a mother. Just like Jack, I found I wasn't alone in my suffering. I found relief at the first support group meeting with the guidance of a very skilled facilitator and mother. Ali gave me hope with her words of comfort, acceptance and understanding.

Because research has indicated a complex pattern of genetic influences, it wasn't surprising to see signs of OCD in another one of my four children. Although not as intense and vastly different from her brother's OCD, anxiety and compulsive behaviors started to affect my 11-year-old daughter. I did not hesitate to take her to the Atlanta 2013 conference where she met kids her age that shared the same types of fears. They faced them together for three amazing days.

I was asked once what someone will find at the conference and I responded, "It's like the best support group you have ever been to for three and half days. You get this energy back. If you are in a really bad place, it takes you to a good place fast. If you are in a good place it takes you to a whole new level and it makes you excited to see everybody next year."

We were in a very bad place in 2011. We have since participated in three conferences and presented programs with the guidance of Jennifer, Dr. Charles Brady, and Dr. Patrick McGrath. Jack has served on a teen success panel twice. Jennifer continues to provide support and ERP therapy when necessary. We look forward to next year's conference. We are now enjoying the "good place."

There is no cure, but treatment has allowed them to dream bigger and beyond OCD, participating fully in life and enjoying their achievements. We are free from the stigma and sense of loss. As I recall events of these past years, I feel extremely blessed. Our involvement with the IOCDF and the conference has enriched our lives beyond my expectations by providing unique friendships, connections and extraordinary opportunities to learn from the best researchers and clinicians in the world. These experiences have given my entire family a new purpose and strength and I am forever grateful.

"I watched from behind the crowd as he joined the exposure and successfully faced his worst fear with one of the leading experts in OCD treatment. It was dramatic but I knew in that moment, eventually Jack would succeed and OCD would not take away his life."



OCD Awareness Week

OCD Awareness Week is an opportunity for the IOCDF and the entire OCD community to turn our attention outward with the goal of educating our friends, coworkers, families, the media, and the public at large about what it really means to have OCD. We understand that for many people, spreading awareness about OCD can feel like a catch-22: it is hard to be open about mental health issues because significant stigma still exists in pop culture and the general public, yet it is so important to be open about OCD in order to help reduce that stigma and increase awareness and understanding. That is why the IOCDF created OCD Awareness Week, and why we will keep working — with your help — to raise awareness about OCD and related disorders throughout the year.

This year's OCD Awareness Week (OCDWeek) represented a shift in strategy from other years.

The launch of OCDWeek in 2009 had as its focus an emphasis on media stories. In 2010 we launched OCD Stories – a live, “streamed” event aimed at bringing the OCD community together via the Internet. In 2011 we built on this strategy and launched “A Night to Believe” utilizing a creative expression contest to showcase OCD expressions in order to raise awareness. This too was live streamed – which in combination with the contest gave the feeling of bringing together the OCD community virtually. In 2012 there was more emphasis on increasing affiliate participation (i.e., encouraging affiliates to hold local events) and upgrading the “Night to Believe” event.

This year we decided to again shift our strategy with a goal toward continuing to maximize our outreach and impact. As a result we focused our time and energy on getting our affiliates more active. In particular, we assisted 3 affiliates in raising the quality of their events and increasing their impact. OCD New York held state wide OCD Screenings, OCD Texas ran two successful conferences and an online OCD book festival, and OCD Massachusetts had an event each day of the week ranging from participation in our online chat to a Saturday night bowling/pizza social. Our goal is to partner with three more affiliates next year.

The quality of events and participation by affiliate and other groups across the country was a notable improvement over last year. In addition, along with the internet-based creative expression contest, we increased our social media presence including 5 very successful online chats, and an explosion of OCD Awareness acknowledgment across Facebook. We had groups in 17 states and the UK very active in OCDWeek this year as well. Several Institutional Members also participated this year by having staff members hold signs supporting OCDWeek and posting online (notably staff from OCD pioneer Dr. Edna Foa's clinic and Harvard Professor and Vice Chair of the IOCDF's Scientific and Clinical Advisory Board, Dr. Sabine Wilhelm's clinic).



1 Million Steps 4 OCD Walk

On Saturday, June 8, 2013, members of the OCD community gathered in Boston and in their communities around the world to participate in the 1st annual 1 Million + Steps 4 OCD Awareness Walk. This Walk is an awareness-building and fundraising event to support the work of the IOCDF to help individuals with OCD and related disorders live full and productive lives. Our aim is to increase access to effective treatment, end the stigma associated with mental health issues, and foster a community for those affected by OCD and the professionals who treat them. The event raised vital funds for IOCDF programs, while also increasing visibility for the Foundation and awareness about OCD and related disorders.

More than 300 participants (200 in Boston and 100 in communities all over the country) raised \$75,000 and walked 8.3 million steps in Boston and in their own communities all over the country.

When we first announced the 1 Million+ Steps 4 OCD Awareness Walk in April, we weren't sure exactly what to expect. The IOCDF had never organized a Walk before, and had never asked our members or the OCD community to fundraise in quite this way. But from the very beginning, members, donors and supporters began pledging to walk hundreds and thousands of steps for OCD awareness, and started fundraising at their schools, offices, among family and friends, and on social media. With that enthusiasm, we were able to raise double the original fundraising goal!

We initially thought of the walk as primarily a fundraising event. However, as we watched people build "teams" we recognized how strongly this opportunity to "create an OCD community" resonated with everyone. It generated a group of OCD and related disorders advocates, who by banding together could raise awareness and tell their own unique story. Using a voice in the form of a Walk, a new group of advocates had a way to invite an entirely different group of individuals into the cause: "Support me in my efforts to raise awareness and together we can make a difference." The Walk allows us to begin a dialogue with our family, friends and colleagues about OCD. For many of us, it is an opportunity to share our story and perhaps shatter some of the misunderstanding and perceptions of OCD and related disorders. By sharing our experience we are educating others about OCD and we are inviting them to join us by supporting us in our efforts to raise awareness and make a difference. For many people, taking part in this kind of event is a gateway to real advocacy. We are grateful to our Walk sponsors: Brooks Running, Massachusetts General Hospital OCD and Related Disorders Program, and the Body Dysmorphic Disorder Program at Rhode Island Hospital for helping to make the walk possible.

The Walk increased awareness around OCD and related disorders and made a powerful statement about our shared commitment to help people living with OCD and raise the dollars that make it possible for the IOCDF to develop, fund, and facilitate much-needed programs. The programs can improve the lives of individuals and families...programs that provide hope.



Our Inspiration:

In 2012, Denis Asselin walked over 500 miles — or roughly one million steps — from his home in Cheyney, PA, to Boston, MA, in memory of his son Nathaniel. Nathaniel took his own life at just 24, after a long struggle with severe body dysmorphic disorder (BDD) and OCD. After Nathaniel's death, Denis decided to embark on a pilgrimage to honor Nathaniel and to raise awareness about the disorder that stole his young son's life. On June 5, 2012, Denis completed his walk in Boston, and was greeted by staff of the International OCD Foundation, as well as friends, family, and members of the OCD community at a rally honoring Denis and supporting OCD and BDD awareness. To carry on this tradition, the 1 Million Steps 4 OCD Awareness Walk was created. This year, Denis walked from his home to Washington D.C., raising awareness a long the way. On June 8, 2013, Denis and his family joined those walking in Boston as Grand Marshall for the Walk.

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C. Alec Pollard, PhD leading a BTTI

Behavior Therapy Training Institutes (BTTI)

At the core of the IOCDF mission is helping people living with OCD to find qualified treatment providers who are trained in Cognitive Behavioral Therapy (CBT) and Exposure Response Prevention (ERP) therapy. Since 1994, the International OCD Foundation has been conducting Behavior Therapy Training Institutes (BTTIs), bringing leading experts in OCD and related disorders together to train therapists in all regions of the country.

Led by the Chair of the BTTI, C. Alec Pollard, PhD, the BTTI is a three-day intensive training on the diagnosis and treatment of OCD and related disorders designed by members of the Foundation's Scientific and Clinical Advisory Board. Each BTTI training is attended by 30 therapists, which allows the IOCDF to train 150 therapists each year. The IOCDF is committed to making the BTTI an affordable training, keeping registration costs low. As such, a significant portion of the cost of this valuable and one of a kind program is generously supported by individual donors.

We know that on average many children and adolescents may go years without proper diagnosis and treatment of their OCD or related disorder. In response to the unique needs of kids with OCD, the IOCDF has developed a full BTTI program dedicated to special issues involved in treating the pediatric population. Chaired by Eric Storch, PhD, a specific pediatric-focused BTTI curriculum was created in consultation with leading pediatric OCD experts including Dr. Aureen Wagner, Dr. Martin Franklin and Dr. Evelyn Stewart, and Dr. Alec Pollard. The first Pediatric BTTI was held September 12- 15, 2013 at Rogers Memorial Hospital in Oconomowoc, Wisconsin. A second Pediatric BTTI will soon follow in early 2014.

Over the past 2 decades, over 1,000 therapists have been trained in the treatment of OCD and related disorders through the BTTI. There are many training needs that still need to be addressed. The IOCDF is unwavering in its commitment to training and making sure that people living with OCD have access to clinicians who have received appropriate training on OCD and related disorders.

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**BTTI in St. Petersburg, FL,
January 18th - 20th, 2013**

*Hosted by: Eric Storch, PhD and
the University of South Florida*

BTTI Faculty:

C. Alec Pollard, PhD
Gary Geffken, PhD
Bruce Hyman, PhD, LCSW
Tanya Murphy, MD
Jonathan Hoffman, PhD
Eric Storch, PhD
E. Katia Moritz, PhD, ABPP

**BTTI in Houston, TX
March 22nd - 24th, 2013**

*Hosted by Thröstur Björgvinsson, PhD, ABPP and
the Houston OCD Program*

BTTI Faculty:

Thröstur Björgvinsson, PhD, ABPP
Joyce Davidson, MD
Bruce Mansbridge, PhD
C. Alec Pollard, PhD
Melinda Stanley, PhD
Constantina H. Boudouvas, LCSW
Aureen Wagner, PhD

**BTTI in Boston, MA
May 17th - 19th, 2013**

*Hosted by Sabine Wilhelm, PhD and
Massachusetts General Hospital*

BTTI Faculty:

Sabine Wilhelm, PhD
Thröstur Björgvinsson, PhD, ABPP
Martin E. Franklin, PhD
Michael Jenike, MD
Nancy Keuthen, PhD
C. Alec Pollard, PhD
Randy O. Frost, PhD

**BTTI in Pasadena, CA
November 8th - 10th, 2013**

*Hosted by Barbara Van Noppen, PhD, Michele Pato, MD
and the University of Southern California*

BTTI Faculty:

Rodney P. Boone, PhD
Susanna Chang, PhD
Michele Pato, MD
John Piacentini, PhD, ABPP
C. Alec Pollard, PhD
Gerald Tarlow, PhD, ABPP
Barbara Van Noppen, PhD



Eric Storch, PhD leading a BTTI

**Pediatric BTTI in Oconomowoc, WI
September 13th - 15th, 2013**

*Hosted by Bradley C. Riemann, PhD and
Rogers Memorial Hospital*

BTTI Faculty:

Karen L. Cassiday, PhD, ACT
Stephanie Eken, MD, FAAP
Martin E. Franklin, PhD
C. Alec Pollard, PhD
Bradley C. Riemann, PhD
Eric Storch, PhD
Aureen Wagner, PhD



Research Funding for OCD and Related Disorders

Promoting research into the causes and treatment of OCD and related disorders is a top priority of the International OCD Foundation. In 2013, the Foundation granted four Research Awards that amounted to \$157,128. The funding for these yearly Research Awards comes from contributions of the Foundation's members and friends. A committee led by the Vice Chair of the IOCDF Scientific and Clinical Advisory Board (SCB), Sabine Wilhelm, PhD, and composed of members of the SCB and other OCD experts, reviewed each research proposal and made recommendations to the IOCDF Board of Directors who made the final decisions.

We all know how important research is in helping find the causes of OCD and related disorders and in helping to develop new and more effective treatments. Funding for these yearly research awards would not be possible without the generosity of Foundation donors who designate a gift to the OCD Research Fund. One hundred percent of contributions to the Research Fund are used directly to fund winning Research Grant Award applicants.

Beginning in 2004 the IOCDF began to fund research projects that focused on diagnosing and treating OCD and related disorders in children and adolescents. And as a result, the first Pediatric Research Grants were awarded in 2004. Since then we have funded 10 more grants focused on pediatric OCD and related disorders. In 2011, realizing that many donors may be interested in a particular area of research, the IOCDF made it possible to direct a gift in support of a specific area of OCD or related disorders, these include:

- Hoarding Disorder
- Body Dysmorphic Disorder (BDD)
- Genetics
- Pediatric OCD
- PANDAS/PANS

In 2013 the Grant Award winners were:

Adam Lewin, PhD
Assistant Professor
University of Southern Florida
Award Amount: \$43,838
Stepped Care CBT for Pediatric OCD

This is a pilot study to develop and assess how feasible and effective "stepped care" cognitive behavioral therapy might be for the treatment of pediatric obsessive compulsive disorder. This study represents an innovative approach to tailoring treatment to each child and family's needs by developing a less costly, lower intensity intervention as a first step of treatment and "stepping-up" care for those patients requiring more intensive, personalized care. Without accessible and effective treatment, youth with OCD are at risk for a developmental trajectory of impairment and chronic distress that places undue burden on the child and family, and imposes significant societal costs.

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Noah C. Berman, MA

Doctoral Student

Massachusetts General Hospital

Award Amount: \$29,661

Cognitive Biases in OCD: Mechanisms of Generational Transmission

Cognitive biases refer to ways in which threatening information is processed. As such, identifying the factors that contribute to OC-related cognitive biases may help tailor prevention and intervention programs to meet the individual needs of those who carry specific and measurable risk factors. No research, however, has investigated the risk factors that predict attention and interpretation cognitive biases in youth at risk of developing OCD. The current study, therefore, will administer self-report and individual-specific behavioral measures to a diagnostically assessed group of individuals who are vulnerable to the development of OC-related cognitive biases (i.e., the offspring of a parent with OCD). We aim to better understand the complex processes associated with offspring's cognitive biases in order to improve the early detection and prevention of OC symptoms.

James A. Knowles, MD, PhD

Professor of Psychiatry

University of Southern California

Award Amount: \$43,629

Replication of Genome-wide Association Findings of OCD

The International OCD Foundation Genetics Collaborative, a multi-national group established to discover genetic variation predisposing to OCD, has conducted the most extensive genetic study of OCD to date (half a million chromosomal locations in 1,465 affected individuals and 5,557 ancestry-matched controls). Results of this initial study suggest an interrelated set of genes that may predispose individuals to OCD. We want to extend these initial findings by adding at least 1,348 OCD-affected individuals and 1,349 ancestry-matched controls to unequivocally identify a genetic locus (gene) for OCD and to provide a set of molecular targets for development of "small molecule therapeutics" for OCD.

Tomek (Tomasz) Banasikowski, PhD

Post-Doctoral Fellow

University of Pittsburgh

Award Amount: \$40,000

**The Role of Deep Brain Stimulation on Excessive Avoidance in Rats:
A Mechanistic Window to Therapeutic Action in OCD**

Research using animal models of avoidance learning and extinction is changing the way we think about the causes and treatment of anxiety disorders such as obsessive compulsive disorder (OCD). Recently, deep brain stimulation (DBS), a neurosurgical technique where high-frequency electrical impulses are applied to a specific brain region (called the ventral striatum), has been shown to have potential therapeutic effect in treating refractory OCD symptoms in humans. However, little is known about DBS and how it affects the brain and its impact on behavior, emphasizing the need for translational animal studies.

The proposed studies will examine the role of DBS, using a novel animal model of acquired avoidance. We will test the theory that DBS gradually disrupts excessive avoidance behavior by reducing the value and salience of anxiety-triggering stimuli. We will also record electrical activity from brain regions implicated in compulsive behavior we will be able to examine DBS effects on a brain circuit-level in freely-behaving animals. The results from our studies will have a significant impact on understanding i) the neuronal mechanisms involved in compulsivity and its extinction, especially related to anxiety and avoidance reported in OCD, ii) system-level changes in response to DBS and iii) how such activation leads to adaptive behavior.



IOCDF Scientific and Clinical Advisory Board

Members of the IOCDF Scientific and Clinical Advisory Board (SCB) are among the best clinicians and investigators in the United States who treat and/or conduct research in the field of OCD and related disorders. SCB members are involved in the IOCDF in multiple ways, including participation on a Grant Review Committee to review research grant proposals submitted for possible grant funding, participation as speakers in the Annual OCD Conference, participation as faculty for the Behavior Therapy Training Institute, and contributing articles to the quarterly OCD Newsletter and our websites. Below is a list of our 2013 SCB members:



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Stress & Anxiety Services of New Jersey
East Brunswick, NJ

Robin Zasio, PsyD, LCSW

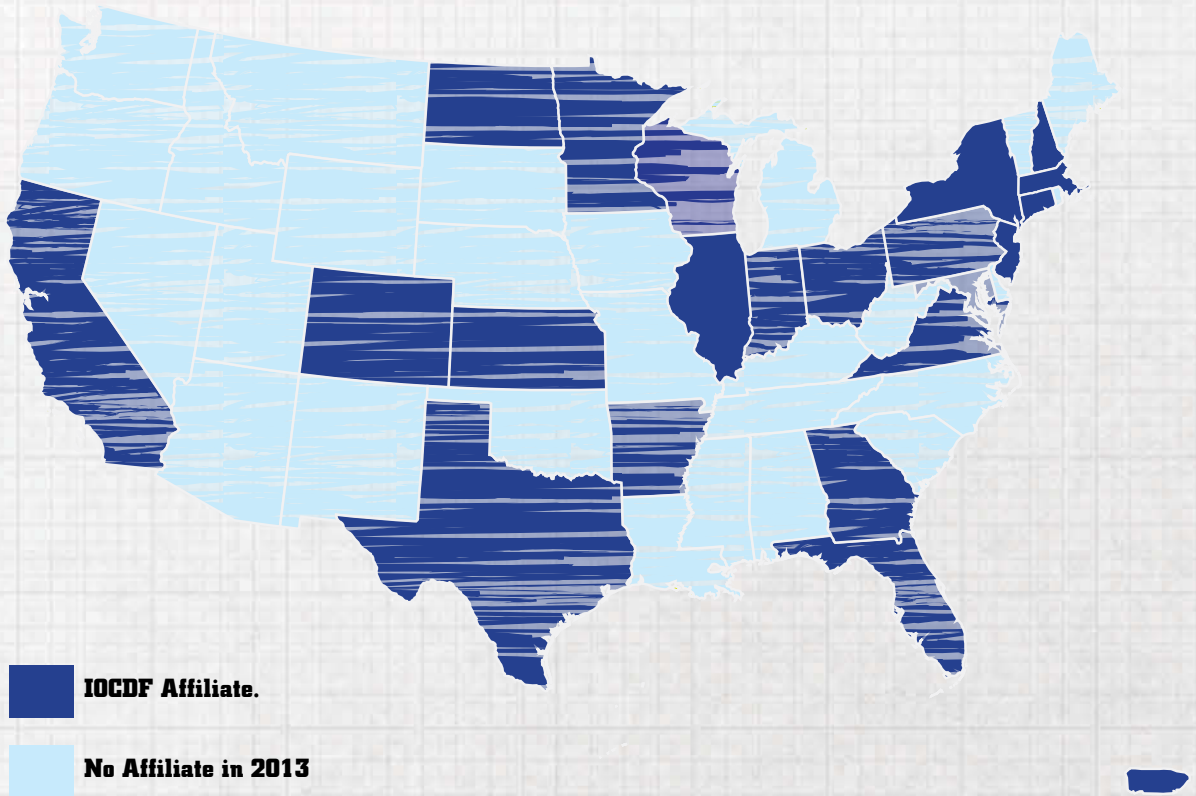
The Anxiety Treatment Center, Sacramento, CA

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IOCDF Affiliates



West Coast

- OCD San Francisco Bay Area
- OCD Sacramento
- OCD Southern California

Rockies

- OCD Greater Denver

Midwest & Great Plains

- OCD Kansas
- OCD Midwest
- OCD Twin Cities
- OCD Texas
- OCD Northwest Arkansas
- OCD Jacksonville
- OCD Georgia
- OCD Wisconsin

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- OCD Massachusetts
- OCD Mid-Atlantic
- OCD New Hampshire
- OCD New Jersey
- OCD New York
- OCD Philadelphia
- OCD Western PA

Puerto Rico

- OCD Puerto Rico

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IOCDF Global Partners

The IOCDF receives inquiries from all over the globe from persons living with OCD looking for help, or their family, friends and treatment providers seeking information. Approximately 33% of our website hits and 3,200 of our Facebook friends are international as well. The inquiries have ranged from individuals looking for services in their own country to requests for guidance on how to set up a foundation like ours in their country. As a result, we began contacting other OCD foundations around the world to help coordinate efforts. These efforts range from collaborating on OCD Awareness Week, to translating psycho-education about OCD into different languages, to helping others around the world find the limited resources. Below is a list of our Global Partners:

Canadian OCD Network

Mission and goals: Founded in 2011 by a group of people dedicated to increasing awareness and support for Canadians that have OCD. Goals are to increase public awareness, provide opportunities for clinician training, improve communication, and support research.

OCD Ireland

Mission and goals: OCD Ireland is a non-profit organization, which began in 2003, whose primary goal is to provide support to people with Obsessive Compulsive Disorder (OCD), Body Dysmorphic Disorder (BDD) and Trichotillomania (TTM or Trich) as well as to their family and friends. OCD Ireland also collaborates with and is partnered with St Patrick's University Hospital, Dublin.

In order to achieve this aim, OCD Ireland provides free informational talks about these disorders, advertises local support groups, and works with media to develop positive messages and images associated with these disorders.

Anxiety Support (New Zealand)

Mission and goals: Anxiety Support at MHAPS is a non-profit organization for people who experience, or support others who have OCD or any other form of anxiety and who are aged 18-65 living and in Canterbury. All of our staff have personal experience of anxiety and their journeys are often helpful to others who are seeking to recover or to live well in spite of it. Our services are free to anyone in Canterbury without the need for a referral and include, information, education and change programmes and various forms of online and individual peer support. We also provide access to various client run peer support groups.

The South African Depression and Anxiety Group

Mission and goals: Celebrating 15 years of mental health and advocacy in 2010, the South African Depression and Anxiety Group is the country's largest and most recognized mental health initiative. As the nation's leading advocacy and educational voice on mental health, SADAG has been tirelessly committed to improving the mental health and well being of thousands of South Africans. Mental illness, and the stigma surrounding it, is a crucial issue in South Africa, and as such SADAG is at the forefront of patient advocacy, education and destigmatization of mental illness in the country. Its expertise lies in assisting patients and callers throughout South Africa with mental health queries. SADAG's programs include a network of over 180 Support Groups throughout South Africa, a phone counseling service, educational materials, newsletters, a referral service to appropriate treatment, workshops and training programs, and work with school systems.

Svenska OCD-Fobundet Ananke (Sweden)

Mission and goals: The Swedish OCD Association of Ananke is a nationwide non-profit organization founded in 1989 with the task of supporting people with obsessive compulsive disorder (OCD) and related conditions such as Tourette syndrome, Trichotillomania and body dysmorphic disorder (BDD) and their relatives.

OCD-UK (United Kingdom)

Mission and goals: We work with, and for children and adults with Obsessive Compulsive Disorder, health professionals and researchers to develop and share our experiences and knowledge to help people increase their understanding about Obsessive-Compulsive Disorder and to help reduce the effect of OCD on the lives of those that suffer with this debilitating illness. It is our belief that everyone affected by Obsessive Compulsive Disorder should receive the most appropriate and the highest quality standards of care, support and treatment. Goals of our organization include advocacy, raising awareness, lobbying, and education.



International OCD Foundation 2013

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(pictured below)

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My Story | by Jackie Lee Sommers

I was only seven years old when OCD kicked down the doors of my mind and stormed in, uninvited.

Up until then, my childhood had been idyllic, full of books and kittens and a rope-swing in the barn on my parents' little hobby farm in rural Minnesota. My parents were (and are!) funny, generous, charming, and deeply devoted to me and my younger siblings.

Suddenly, I was plagued by "bad thoughts." Confession quickly became my go-to compulsion to escape the ugliness that was pushing in on my young, innocent mind. My parents had no idea what was happening, only that their clever, creative, once-happy daughter was being tortured by her own thoughts and facing invisible demons that they couldn't save her from.

Fifteen years later, I was diagnosed with OCD.

Five years after that, I was finally introduced to the Exposure and Response Prevention (ERP) therapy that would give me back peace, joy, and freedom.

Sadly, those twenty years in slavery to OCD are not an anomaly: it takes an average of fourteen to seventeen years for OCD sufferers to obtain appropriate treatment. Frankly, that's just not okay.

Contrast my story with the following.

Madeline was eleven when the "bad thoughts" started for her. Her parents went online, searched, and found my blog. As they read my story, they quickly realized that Madeline's obsessions and compulsions had a stunning similarity to mine. They read everything they could about OCD, took Madeline to a professional therapist to be officially diagnosed, and immediately enrolled her in an intense ERP program in Minnesota. While here, they even drove to the Twin Cities so that I could spend some time with their family and they could learn all they could from my personal experiences.

Madeline improved immediately after ERP therapy and has now been free from the obsessions and compulsions for over a year. I would never negate the intense agony of the months that she suffered, but I'm delighted that it could be kept to months instead of years.

Sadly, there are still too many stories that echo mine instead of Madeline's—years and years of pain and in bondage because the world still remains largely unfamiliar with pediatric OCD. I so appreciate the International OCD Foundation's commitment to educating family physicians and pediatricians on how to recognize OCD and in training mental health professionals to diagnose and treat OCD in kids and teens. With their efforts, I believe we can have more stories like Madeline's—quick access to resources, accurate and early diagnoses, and skillful and successful treatment.

Then back to the kittens and rope-swing, while they're still young.

Jackie Lea Sommers is a young adult author living in Minneapolis. Her OCD has been "in remission" for the last six years—the best six years of her life—after ERP therapy. Jackie is the communications director for OCD Twin Cities, a guest contributor to the IOCDF blog, and she blogs about OCD and ERP at www.jackieleasommers.com. Follow her on Twitter at @jackieleawrites.

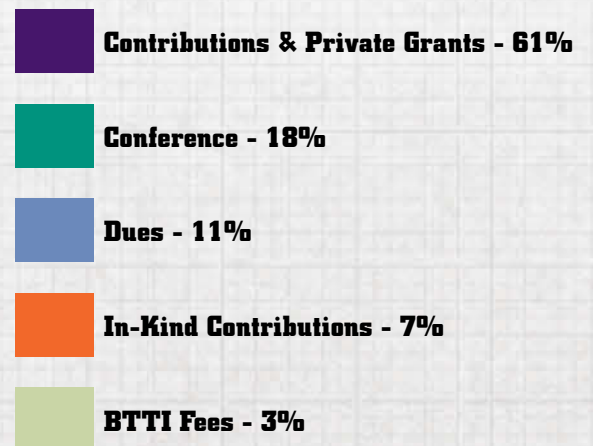
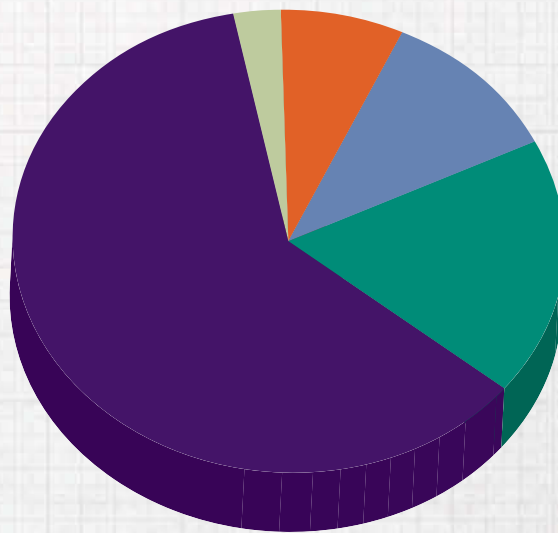


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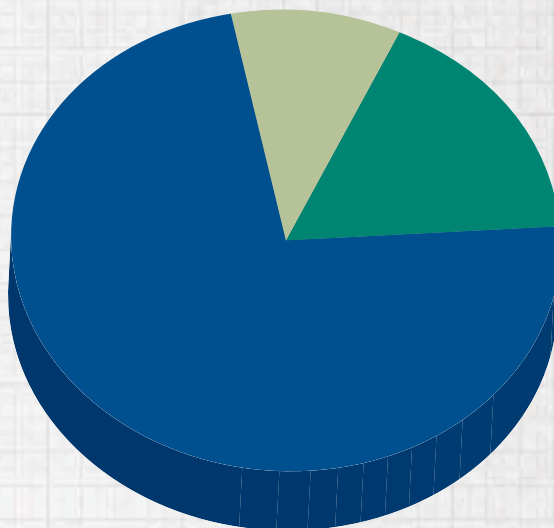


International
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2013 Support and Revenue



2013 Expenses



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Statement of Activities

	2012			2013		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Support and Revenue						
Contributions & Private Grants	\$515,586	\$554,848	\$1,070,434	\$714,924	\$263,637	\$978,561
Dues	\$210,682	\$0	\$210,682	\$182,390	\$0	\$182,390
Conference	\$299,473	\$2,900	\$302,373	\$282,505	\$550	\$283,055
In-Kind Contributions	\$140,563	\$0	\$140,563	\$116,110	\$0	\$116,110
BTTI Fees	\$52,598	\$0	\$52,598	\$49,665	\$0	\$49,665
Net Realized & Unrealized Investment Gains	\$0	\$0		\$0	\$0	\$0
Miscellaneous	\$2,041	\$0	\$2,041	\$2,110	\$0	\$2,110
Net Assets Released From Restrictions	\$382,664	-\$382,664	\$0	\$351,071	-\$351,071	\$0
Total Support & Revenue	\$1,603,607	\$175,084	\$1,778,691	\$1,698,775	-\$86,884	\$1,611,891
Expenses						
Research & Education	\$1,194,324	\$0	\$1,194,324	\$1,254,614	\$0	\$1,254,614
Fundraising	\$170,533	\$0	\$170,533	\$305,244	\$0	\$305,244
General & Administration	\$264,286	\$0	\$264,286	\$166,716	\$0	\$166,716
Total Expenses	\$1,629,143	\$0	\$1,629,143	\$1,726,574	\$0	\$1,726,574
Change in Net Assets	-\$24,466	\$180,388	\$154,922	-\$27,799	-\$86,884	-\$114,683
Net Assets, Beginning of Year	\$184,997	\$559,527	\$744,524	\$159,531	\$739,915	\$899,446
Net Assets, End of Year	\$159,531	\$739,915	\$899,446	\$131,857	\$662,150	\$794,007

International OCD Foundation
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International OCD Foundation

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