

# Taking strides to beat OCD.



We believe that there is **HOPE** for people living with Obsessive Compulsive Disorder (OCD) and related disorders — to live a life that is full and productive — without the burden of OCD. This is our message to everyone.

We **BELIEVE** that life will improve for people living with OCD if they are able to receive proper treatment, resources, and have a supportive environment in which to heal and thrive.

We believe that we are stronger **TOGETHER** as a community of people living with OCD, families, friends, and treatment providers. We believe that if we band together we can do great things to end the stigma and misunderstanding that surrounds OCD and related disorders and help people reclaim their lives in spite of the devastation OCD has caused them.

# Dare to Believe..... that together we can beat OCD.





Dear Friends and Supporters of the International OCD Foundation,

The year 2012 marked a lot of changes and growth at the Foundation, and a big step forward for the IOCDF and the OCD Community. From a record-breaking conference in Chicago, and a heartfelt outpouring of support for one family's struggle with BDD, to an OCD Awareness Week that truly put the "International" in International OCD Foundation — 2012 was a year to remember.

The Foundation staff welcomed two new positions to further help us reach our goals: Director of Development, Jeff Smith, and Director of Communications, Carly Bourne, MA. Both of these staff members come to the Foundation with years of experience in fields of development and communications, and we are so excited to have them on board our team, where they are already making a tremendous impact to the OCD community.

The year brought transitions to the Board of Directors as well: After four years as President, Diane Davey, RN, passed the torch to Denise Egan Stack, LMHC. Denise has been involved in the



Foundation for the past dozen years and has been on the Board of Directors for the past 5 years. Denise is an OCD therapist specializing in home-based treatment and was an integral part of development of McLean Hospital's OCD Institute. Diane has transitioned into the role of Secretary while Susan Dailey mother of a child with PANDAS — is now the Vice President. Michael Stack has stayed on in his capacity as Treasurer.

One of the pivotal events of 2012 was the Walking with Nathaniel Project and the corresponding OCD and BDD Awareness Rally held in Boston in June 2012. The Walking with Nathaniel Project was started by a father grieving the loss of his son to suicide and looking for a way to channel that grief into something positive. Denis Asselin decided to just start walking — and to tell the people he met along the way about his son, Nathaniel, and about his struggles with OCD and severe BDD. Denis ended up walking over 500 miles for the cause, raising money for the IOCDF as he walked. Read more about Denis' inspiring story, and the amazing response from the OCD community, and beyond, on page 10 of this report.

Another big story of the year was our 19th Annual OCD Conference held in Chicago, which became the best-attended conference to date, with 1,175 attendees! This conference had a truly international feel, with attendees from 10 countries on 6 continents, and our first international Keynote Speaker, Liz. Liz had previously volunteered in the IOCDF office when traveling in the United States from Australia. We knew that Liz had a powerful story to tell and she didn't disappoint. At the conference we were also very excited to recognize Joy Kant with the Patricia Perkins Service Award in honor of her many years of dedication to the IOCDF including four years as President of the Board. We also honored Dr. Wayne K. Goodman, co-founder of the IOCDF and a pioneer in the field of OCD treatment and research, with the IOCDF Outstanding Career Achievement Award. Read more about the Annual OCD Conference on page 6.

One of my favorite programs at the IOCDF is the Behavior Therapy Training Institutes (BTTIs), which provides in-depth training for mental health professionals about how to effectively treat and diagnose

OCD and related disorders. In 2011, all 4 of of the BTTIs offered sold out, showing a great need and demand for this training. As a result, we offered an additional training in 2012, bringing our total to 5 BTTIs held across the country in 2012 — which also sold out! That means that 150 more mental health therapists are now familiar with effective diagnostic and treatment strategies for OCD and related disorders. Dr. C. Alec Pollard, Founder and Director of the Saint Louis Behavioral Medicine Institute Anxiety Disorders Center, continues to direct and oversee the BTTI. See page 14 for a detailed list of the trainings and faculty.

Our 4th annual OCD Awareness Week was a major success this year, with dozens of affiliate groups across the country — and the globe, including our partners in Canada and the United Kingdom — hosting activities during the week of October 8th through 14th to educate their communities and the public about OCD and related disorders. Here in Boston, the IOCDF hosted "A Night to Believe" featuring the winners of the OCD Awareness Week creative expression contest . The event's program included presenters who were selected from dozens of entries through a public voting contest on the International OCD Foundation website. Read more about OCD Awareness Week and the contest winners on page 12.

And last, but not least, the IOCDF continued its commitment in 2012 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, and this year, a total of \$139,587 was awarded. Thank you to all who contributed, and to Dr. Sabine Wilhelm, the chair of the Grant Review Committee. Take a closer look at all of the research we funded in 2012 on page 16.

The mission of the International OCD Foundation remains the same:

- 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.
- Advocate for the OCD community.

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 this very important mission.

Sincerely,

My Millio

Jeff Szymanski, PhD Executive Director International OCD Foundation



## 19th Annual OCD Conference — July 27–29, 2012 in Chicago

The IOCDF's Annual OCD Conference is one of the largest programs at the Foundation. It brings together individuals living with OCD and related disorders, families, treatment providers, and leading experts for 3 days all in one location. We believe that it is the ideal way in which we can disseminate information about OCD, new treatments, and research, and to provide a network of support to the entire OCD community.

The 19th Annual OCD Conference was held at the Marriott Hotel in Chicago, IL, from July 27–29, 2012. Attendance hit a record breaking 1,175 attendees! The conference program included workshops and presentations for individuals with OCD (adults, adolescents, and children), family members, and friends, treatment providers, and researchers. In addition, there were kids and teens art therapy rooms led by art therapists from Rogers Memorial Hospital. These rooms gave kids and teens with OCD (and family members) an opportunity to meet, support each other, and feel part of a community. Additional activities at the 2012 conference included an "Improv for Anxiety" pre-conference workshop, a ping pong tournament, and a Spanish-language mini-track.

Over 50% of our attendees this year were first-time conference goers, and evaluations completed by attendees were very positive. People with OCD found out that they weren't alone and learned about medications and techniques they could use to manage their OCD. One first-time therapist attendee was overheard at the end of the conference saying: "I'm going to have to rethink everything I do now when treating my clients with OCD!"

#### ABTTI

On Thursday, July 26, before the official start of the conference, the Foundation put on an Advanced Behavior Therapy Training Institute (ABTTI) to provide more in-depth and advanced training for mental health professionals who treat OCD and related disorders. This year's training was called, "Promoting Treatment Engagement and Managing Non-Adherence in OCD," and was a 4.5 hour workshop given by Dean McKay, PhD, Professor and Associate Chair of Graduate Studies at Fordham University.

#### KEYNOTE

Our Keynote Speaker at this year's conference, Liz, hails from Brisbane, Australia, making her our first international Keynote Speaker. Liz's struggle with OCD began during her first year of high school, when she was bullied by her peers. As the bullying continued through high school, and her four older siblings gradually left home, her grades plummeted and she became a full-time "employee" of the disorder. She had no idea that OCD existed and the depth of her self-stigma and shame stopped her from seeking help, so she suffered in silence. Eventually her cover was blown and she became bed-ridden and needed 24-hour support.

Already feeling that her own suggestions were discredited and demeaned by so-called expert "help," she was finally told her only option for treatment was institutional care. This prospect became the catalyst Liz needed to commence her personal journey of recovery, with the unfailing support of her devoted parents. Liz vowed that when she recovered, she would devote the rest of her life to educating kids and adults about mental health and that is exactly what she has done. She has subsequently become a grade and middle school teacher who works to educate school communities about mental health, and is an adult mental health educator, delivering training on mental illness and suicide intervention. Liz has





also devoted much time and effort as a volunteer at the IOCDF headquarters in Boston. Liz's impact on the OCD community has been big indeed.

#### **IOCDF PATRICIA PERKINS SERVICE AWARD**

Each year, the International OCD Foundation (IOCDF) Board of Directors presents the Patricia Perkins Service Award to a distinguished member of the organization. The award is intended to honor anyone who has stood out as a long-time, active contributor to the organization in multiple ways and in the intrepid spirit of IOCDF co-founder, Patricia Perkins. This year, the award was given to Joy Kant.

Joy and her husband Doug Kant joined the IOCDF in 2001 after their son, Jared, was diagnosed with severe OCD. The IOCDF provided the Kant family with guidance, community and, most importantly, a sense of hope. Joy's gratitude for this quickly translated into passion for helping the IOCDF realize its mission. Almost immediately, she became involved in significant ways.

Joy played a prominent role on the IOCDF Board of Directors for eleven years. During her tenure, she served on 13 different committees and task forces, some as Chair or Co-Chair, and held several officer positions. Joy was also an active fundraiser for the organization. She hosted the first "house party" fundraiser, launched the Behavior Therapy Training Institute Scholarship Fund, and personally wrote hundreds of thank you notes to donors. Most notably, Joy was President of the Board during the organization's transition from Connecticut to Boston in 2008. Joy's tireless effort and leadership during this tumultuous period helped to successfully establish the organization in Boston, laying the foundation for the robust organization that it is today. The strength of the IOCDF lies in its members and donors. Joy

and her family have made an enormous difference for the OCD community. We are fortunate to have the support of the Kant family and many others like them who are committed to the IOCDF mission. We simply could not do this work alone.

#### IOCDF OUTSTANDING CAREER ACHIEVEMENT AWARD

Dr. Wayne Goodman, co-founder of the International OCD Foundation, is a leader in the field of psychiatric disorders. Dr. Goodman has a long track record of research having published more than 250 articles while also serving on the editorial board of several medical journals.

Dr. Goodman's research has helped to increase our understanding of obsessive compulsive disorder (OCD) as well as



Award winners Wayne Goodman, MD (left), and Joy Kant (right).

the neurobiology and treatment of OCD. He is also the principal developer of the Yale-Brown Obsessive Compulsive Scale (Y-BOCS), the gold standard tool for assessing OCD.

Dr. Goodman led the Division of Adult Translational Research and Treatment Development at the National Institutes of Mental Health and served as a member of the FDA's Neurological Devices Advisory Committee. He has previously taught at Yale University and the University of Florida, and he is currently a professor and Chairman of the Department of Psychiatry at the Mount Sinai School of Medicine. Dr. Goodman is truly a pioneer in the field of OCD and his impact will be felt for many years to come.

## One Teen's Conference Success Story

Michael is one of five teens that made up the Teen Success Panel at this year's conference in Chicago. This panel is one of the most popular among teens and young adults, and is important because it allows other teens and young adults to hear about their peers' experiences with OCD and related disorders from a number of unique perspectives. By sharing their struggles and success in overcoming their compulsions, others can gain hope and strength in knowing that with proper treatment it is possible to live a full and happy life.

Michael is 15 years old and a sophomore in high school. He began to have compulsions in the 3rd grade. Fortunately for Michael, his mother was able to locate a therapist who was knowledgeable about OCD and Exposure and Response Prevention Therapy (ERP) and over the course of a year Michael slowly began to gain control of his compulsions... and ultimately, his life. At the time, his parents knew very little about OCD. Michael says, "At the time, finding a therapist was a shot in the dark. The therapist showed me how to do ERP and taught my mom and dad how to be a coach for me." Working closely with his therapist, it took Michael a year to really feel better and get a handle on his compulsions. Today, Michael is doing well. While he still gets the urge to do his compulsions, with the help of his parents and ERP that he learned in therapy they have not gotten worse and they no longer interfere with his daily life.

Michael and his family began attending the IOCDF conference in 2010, in Washington D.C. As Michael said, "Because my mother made us." Even though it was his parent's decision at first, Michael now says that he wouldn't miss it for anything. "I have found new friends here and look forward to seeing them each year." Michael said that he was even able to help another kid at the conference: "He never tried ERP," explained Michael. "I helped him sit through a few minutes of a talk, which at first he was not able to do because of his OCD." "

"My parents also enjoyed meeting other parents and all of the education. My mom says the conference gets better each year. We have a little family game that we recently started playing. We try to guess where the next convention will be. All three of us have different guesses."

"Going to the conference each year makes me feel good about OCD. It's like taking something negative and turning it around to look at it in a positive way."



The 2012 Teen Success Panel at the 19th Annual OCD Conference in Chicago.



## Walking with Nathaniel Project and OCD/BDD Awareness Rally

There are many heroes in the struggle against OCD. So many heroes that emerge are parents of kids who are suffering — for, we know that when one member of the family unit suffers — the entire family suffers along with them. Such is the story of the Asselin family of Pennsylvania. We first learned of their story when Denis Asselin telephoned the IOCDF office to say that he wanted to walk from his home in Pennsylvania to Boston in memory of his son, Nathaniel. Denis was asking if he could raise money along the way to help support the work of the Foundation, as well as spread the word about OCD and Body Dysmorphic Disorder (BDD). The IOCDF is incredibly grateful to Denis for sharing not only Nathaniel's story, but for including us in his vision and mission to help others that are suffering from OCD and BDD. Nathaniel's story is a story of struggle, love, compassion, and ultimately tragedy. Denis was determined to use his family's tragedy to help others.

On 15 April 2011, the lives of Denis, Judy and Carrie Asselin were forever changed. Their son and beloved brother Nathaniel chose to end his 13-year struggle with BDD because he could not go on living another day like the one before.



Brother and sister, Nathaniel and Carrie Asselin, in June 2010.

When he was in fifth grade, a healthy interest in running turned into an obsession which then turned into him spending hours upon hours a day studying himself in the mirror.

His mother said that during the "rollercoaster" of his life, he would tell them: "I can't do this anymore, I can't wake up in my bed in the morning and do this all over again."

He was hospitalized several times and tried many treatments, but none of them worked. He started to isolate himself and hopes of becoming an emergency medical technician — because he dreamed of being a hero — BDD shattered his dream.

In May 2011, following the death of Nathaniel, the Asselin family flew to Spain to walk the Camino de Santiago, the ancient pilgrimage route, to reflect on Nathaniel's life and walk in his memory. Upon returning from the trip, Nathaniel's dad, Denis, caught "Camino Fever," as he puts it, and developed the irresistible urge to walk. Denis explains, "Putting one foot in front of the other was a metaphorically powerful symbol for me — how to move forward after the most tragic experience.... It's a conduit for some of the pain and sorrow deep inside. And you are moving, not sedentary. It's like a cleansing that's happening — and you are doing something."

It was during one of his many long walks that the idea for the Walking with Nathaniel Project was born. On April 24, 2012, Denis began walking from Cheyney, PA to Boston, MA, site of the International OCD Foundation office. On the 500-plus mile route, Denis stopped at various hospitals, clinics, doctors' offices, and treatment facilities — the places that his son Nathaniel frequented during his affliction with OCD and BDD. Denis also included places of joy that held significance in Nathaniel's life, such as the Bryn Mawr Birth Center, Goshen Friends School, Westtown School, The Shipley School, and the West Goshen EMS Ambulance unit where he often volunteered. Denis' journey took him several weeks, and culminated in Boston on June 6th, when he arrived at Christopher Columbus Park on Boston Harbor and was greeted by family members, friends, and members of the OCD community who walked literally or in spirit with Denis on his journey.

To celebrate Denis' achievement, the International OCD Foundation organized a rally to welcome Denis to Boston. The day was created to honor Nathaniel, celebrate Denis' amazing accomplishment, and raise awareness around BDD, OCD, and related disorders. ABC Boston's weatherman David Brown emceed the rally, and we were honored to have the Vice President of the Boston City Coucil, Sal LaMattina, attend and issue a city proclamation from the Mayor of Boston, Thomas M. Menino, in recognition of the Walking With Nathaniel Project. Dr. Michael Jenike of the OCD Institute at McLean Hospital and Massachusetts General Hospital was also on hand to speak about BDD. Nancy Farrel from the American Foundation for Suicide Prevention spoke about grief, loss, and turning adversity into an opportunity for advocacy. It was truly an inspirational day. Thank you to Denis and the entire Asselin family for their inspiration and for sharing their story with so many people. We are grateful for the generosity of all those who gave to the IOCDF in honor of Nathaniel.

Denis said of the project, "My primary goal was to pay it forward — to raise much needed money to support research and education into this crippling brain disease. With the help of the IOCDF, I will meet with medical professionals to learn more about how treatment for patients with this brain disorder has evolved since Nathaniel's death." Denis hoped that through this very personal, and yet public, pilgrimage that he was able to put Nathaniel's face and story on OCD and BDD and, through doing this, to help others along the way.

Denis reached not only the IOCDF and the OCD community with his prilgrimage — his story, and the story of Nathaniel, was featured in the media across the country. CNN, ABC, the LA Times, the Boston Globe, the Daily Mail, Parenting Magazine, and many other publications and websites covered Denis' walk and the importance of raising awareness about BDD and OCD. Denis truly touched the hearts of the nation with his journey — and we at the IOCDF were so honored to be a part of this tremendous advocacy effort.





## OCD Awareness Week 2012

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.

In addition to the events held at affiliates and partners across the country, we increasingly turned out attention to social media during the 2012 OCD Awareness Week, to help spread our message of awareness through Facebook and Twitter, online videos, hashtags, and calls for support across the community. We hosted our first ever Twitter Chats to answer questions about OCD from our followers, featuring guest experts including some of the leaders in OCD treatment and research. These chats were so successful, we have made them a recurring event!

In Boston, we hosted our 2nd annual "Night to Believe" event, to honor four individuals with OCD for their winning forms of creative expression about living with OCD. Winners were selected from dozens of entries through a public voting contest on the International OCD Foundation website. Winners received a free trip to Boston to participate in the event. The winning works fell into three categories: writing, music, and short film. Our winners included Jennifer Cullen from Virginia for her children's story "Ranger Ben Discovers Mr. OCD", Jackie Lea Sommers from Minnesota for her short story "Tipping Point", Vincent Christofferson from New Zealand for his song "Till I'm Down", and Claire Watkinson from England for her short film "Living With Me and My OCD".

In 2012, IOCDF also introduced the IOCDF Hero Award, an award to acknowledge someone in the OCD and related disorders community who really stood out as an advocate and voice on behalf of those affected by these disorders. Members of the OCD community nominated candidates in the weeks leading up to OCD Awareness Week, and we honored the winner at "A Night to Believe" in Boston. The inaugural Hero Award went to OCD and BDD advocate Denis Asselin — we couldn't think of a more fitting recipient! Read more about Denis' inspiring advocacy efforts on page 10.



## Till I'm Down

by Vincent Christoffersen, aka Split Screen Multiplayer

The following are lyrics from the winning song, Til I'm Down, written and performed by Vincent Christoffersen at the 2012 A Night to Believe celebration. Vincent is a musician and university student from Napier, New Zealand, who uses his music to cope with the day-to-day struggles of life with OCD. Vincent hopes the positive message of his music will help others who may also be struggling with OCD.

#### CHORUS

I won't stop till the end of the days. Till I'm down, down, down, down. I won't stop till the end of the days, When I fear I am gone, and my prides gone away I'ma try, I'ma wait till I die till I fade Till I'm down, down, down, down Till I'm down, down, down, down and out. my soul is music

I won't stop till the end of the days Till the flame it fades. I gotta few words to say, for this flow it raids, and yo' you can't stop the train. I'm the one like Neo spittin my rhymes, gotta find that chi flow killing my time, making vibes that'll blow ya mind I define the line, for my work is fine. From time to time I sit back relax get caught up in the tracks, that'll rax and tax the facts that made you relax in the first place what is this? a mind trip. I look back to the sky, I fall to the floor and all that, it's a metaphor, tryna say we all feel bad sometimes

you gotta combat things that we just can't take it's overwhemling.

#### [CHORUS]

I'ma try, I'ma wait till I die till I fade Till I'm down, down , down, down till I'm down down down down and out my soul is music

I won't stop till the end of days till the flame it fades. Don't hold back, cause your gonna pull through

for you've got me and i've got you.

Yeah we all got, something or nothing and if you've got nothing then make it a something.

Cause I do not want see sad on your face no you just don't deserve it, thats just not your

place Don't frown, ya smile is great and makes you look so vibe

jiggy-down-d-down-d-down.

Not down in a way that means the down is down, like down in a found way, go with it.

Look into my eyes,

know you can call and I'll chat

when feelin' ya low, tryna say we all feel bad sometimes

you gotta combat things that we just can't take it's overwhemling

#### [CHORUS]

I'ma try, i'ma wait till I die till I fade Till I'm down, down, down, down till I'm down down down and out my soul is music. I won't stop till the end of the days I won't stop till the end of the days Till I'm down, down, down, down Till I'm down, down, down, down I won't stop till the end of the days I won't stop till the end of the days I won't stop till the end of the days Till I'm down, down, down Till I'm down, down, down, down





## Behavior Therapy Training Institute (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 and Exposure Response Therapy. Since 1994, the International OCD Foundation has been conducting Behavior Therapy Training Institute (BTTI) trainings in different cities around the country. We bring leading experts in OCD and related disorders together to train therapists in all regions of the country. Each BTTI training is attended by 30 therapists, allowing 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 entirely supported by individual donors.

Led by the Chair of the BTTI faculty, C. Alec Pollard, PhD, the BTTI is a three-day intensive course on the diagnosis and treatment of OCD and related disorders designed by members of the Foundation's Scientific and Clinical Advisory Board. The subjects covered in the first two days of didactics include an introduction to OCD and related disorders; effective treatment modalities including cognitive behavior therapy, especially Exposure and Response Prevention and medications that have been proven effective; and a section on treating children and adolescents with OCD. On the third day of the Institute, attendees break up into small groups of five or six. A member of the BTTI faculty leads each group. In these sessions, attendees develop treatment plans for a current OCD patient they are working with. All attendees then have three follow up phone sessions with the leader of their group following the completion of the formal three-day Institute. Due to the success of BTTI's in previous years, we expanded this program in 2012 to include a fifth training. Thank you to all of our faculty and participants for making this a world-class experience.

#### **BTTI TRAININGS WERE HELD IN:**

#### PASADENA, CA — UNIVERSITY OF SOUTHERN CALIFORNIA

*Host*: Special thanks to Drs. Michele Pato and Barbara Van Noppen and the University of Southern California for hosting this BTTI.

*Faculty*: Michele Pato, MD; Barbara Van Noppen, PhD; C. Alec Pollard, PhD; Rodney Boone, PhD; Susanna Chang, PhD; John Piacentini, PhD, ABPP; & Gerald Tarlow, PhD, ABPP.

#### VANCOUVER, BRITISH COLUMBIA, CANADA — BC CHILDREN'S HOSPITAL

Host: Special thanks to Dr. S. Evelyn Stewart and the BC Children's Hospital for hosting this BTTI.

*Faculty*: S. Evelyn Stewart, MD; C. Alec Pollard, PhD; Karen Cassiday, PhD; Maureen Whittal, PhD; Robin Zasio, PsyD, LCSW; & Sheila Woody, PhD.

#### NEW YORK, NY — MOUNT SINAI HOSPITAL

Host: Special thanks to Dr. Wayne Goodman and Mt. Sinai Hospital for hosting this BTTI.

*Faculty*: Wayne Goodman, MD; C. Alec Pollard, PhD; Fred Penzel, PhD; Steven Friedman, PhD, ABPP; Aureen Wagner, PhD; Dean McKay, PhD, ABPP; & Fugen Neziroglu, PhD.

#### OCONOMOWOC, WI — ROGERS MEMORIAL HOSPITAL

*Host*: Special thanks to Dr. Bradley Riemann and Rogers Memorial Hospital for hosting this BTTI.

*Faculty*: Bradley Riemann, PhD; C. Alec Pollard, PhD; Cheryl Carmin, PhD; Karen Cassiday, PhD; David Jacobi, PhD; Patrick McGrath, PhD; Stephanie Eken, MD.

#### BOSTON, MA — MASSACHUSETTS GENERAL HOSPITAL

Host: Special thanks to Dr. Sabine Wilhelm and Massachusetts General Hospital for hosting this BTTI.

*Faculty*: Sabine Wilhelm, PhD; C. Alec Pollard, PhD; Thröstur Björgvinsson, PhD; Martin Franklin, PhD; Michael Jenike, MD; Nancy Keuthen, PhD; & Randy Frost, PhD.

5 trainings held in the U.S. and Canada

> +100 therapists trained on treating OCD



C. Alec Pollard, PhD, (left), Chair of the BTTI Faculty, and Dean McKay, PhD, ABPP, BTTI faculty member, leading a training for mental health professionals.



Promoting research into the causes and treatment of OCD and related disorders is a top priority of the International OCD Foundation. In 2012, the Foundation granted three Research Awards that amounted to \$139,587. The funding for these yearly Research Awards is 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. The Award winners and their affiliations and topics are listed below:

#### INVESTIGATION OF VISUAL PERCEPTUAL DEFICITS IN BDD USING EEG

Wei Li, Doctoral student University of California – Los Angeles Award Amount: \$40,079

Goal: To see whether visual distortions for individuals with BDD are a result of how the visual centers in the brain are working or due to differences in attention. This will help us better understand our earlier fMRI results as well as serve as the first EEG investigation on visual processing in BDD.

over

\$3 Million

in

Research

Grants

funded

since

1986!

#### COMPARISON OF BRAIN ACTIVATION PATTERNS IN HOARDING DISORDER AND NON-HOARDING OCD

Carol A. Matthews, MD, Associate Professor University of California – San Francisco Award Amount: \$49,928

Goal: Our research group has evidence to suggest that people with Hoarding Disorder (HD) have specific abnormalities in how they process information that differ from those seen in OCD. This study will extend our early work to compare the brain activation patterns of individuals with HD to those with OCD and to identify areas of overlap and areas of separation, eventually allowing for more targeted treatments and other interventions.

#### TITLE: STRESS REACTIVITY AS A MECHANISM OF TREATMENT RESPONSE IN PEDIATRIC OCD

Tara Peris, PhD, Assistant Professor UCLA Semel Institute

Award Amount: \$49,580

Goal: Because children and adolescents with OCD in unstable home environments have been found to predict poor response to treatment, and separate research links this heightened reactivity to disrupted learning and the maintenance of fear/avoidance behaviors, our goal is to better understand the specific mechanisms in which family functioning interferes with treatment.

## 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 on OCD and related disorders. SCB members are involved in the IOCDF in multiple ways, including participation on a Grant Review Committee to review OCD research proposals submitted for possible grant funding, participation as speakers in the Annual Conference, participation as faculty for the Behavior Therapy Training Institute, and contributing articles to the quarterly OCD Newsletter. Below is a list of our 2012 SCB members:

Michael Jenike, MD, Chair Massachusetts General Hospital, Boston, MA OCD Institute, McLean Hospital, Belmont, MA

Sabine Wilhelm, PhD, Vice Chair Massachusetts General Hospital, Boston, MA Harvard Medical School, Boston, MA

Jonathan S. Abramowitz, PhD University of North Carolina at Chapel Hill

Thröstur Björgvinsson, PhD The Houston OCD Program, Houston, TX McLean Hospital, Belmont, MA

**Dennis S. Charney, MD** Mount Sinai School of Medicine, New York, NY

James Claiborn, PhD South Portland, ME

Darin D. Dougherty, MD Massachusetts General Hospital, Boston, MA OCD Institute, McLean Hospital, Belmont, MA

Jeanne Fama, PhD Massachusetts General Hospital, Boston, MA

Jamie Feusner, MD University of California at Los Angeles

**Edna B. Foa, PhD** University of Pennsylvania, Philadelphia, PA

Martin E. Franklin, PhD University of Pennsylvania, Philadelphia, PA

Randy Frost, PhD Smith College, Northampton, MA

Wayne K. Goodman, MD Mount Sinai Medical Center, New York, NY

Jonathan Grayson, PhD The Anxiety and OCD Treatment Center Philadelphia, PA

Benjamin D. Greenberg, MD, PhD Butler Hospital, Providence, RI

John H. Greist, MD Madison Institute of Medicine, Madison, WI

William A. Hewlett, MD, PhD Vanderbilt University Medical Center, Nashville, TN

Bruce M. Hyman, PhD, LCSW OCD Resource Center of Florida, Hollywood, FL Nancy J. Keuthen, PhD Massachusetts General Hospital, Boston, MA

Lorrin M. Koran, MD Stanford University Medical Center, Stanford, CA

**Bruce Mansbridge, PhD** Austin Center for the Treatment of OCD, Austin, TX

Charles S. Mansueto, PhD Behavior Therapy Center of Greater Washington, Silver Spring, MD

**Patrick McGrath, PhD** Alexian Brothers Behavioral Health Hospital, Hoffman Estates, IL

**Dean McKay, PhD** Fordham University, Bronx, NY

Tanya K. Murphy, MD University of South Florida, St. Petersburg, FL

Gerald Nestadt, MD, PhD Johns Hopkins Hospital, Baltimore, MD

Fugen Neziroglu, PhD Bio-Behavioral Institute, Great Neck, NY

Michele Pato, MD University of Southern California, Los Angeles, CA

David Pauls, PhD Harvard Medical School, Boston, MA Massachusetts General Hospital, Boston, MA

Fred Penzel, PhD Western Suffolk Psychological Services, Huntington, NY

Katharine A. Phillips, MD Rhode Island Hospital, Providence RI

Steven Phillipson, PhD Center for Cognitive Behavioral Psychotherapy New York, NY

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Susan Swedo, MD National Institutes of Health, Bethesda, MD

Barbara L. Van Noppen, PhD University of Southern California, Los Angeles, CA Aureen P. Wagner, PhD Director, The Anxiety Wellness Center, Cary, NC

Allen Weg, EdD Stress & Anxiety Services of New Jersey East Brunswick, NJ

Robin Zasio, PsyD, LCSW The Anxiety Treatment Center, Sacramento, CA



## **IOCDF** Affiliates

#### What is an IOCDF Affiliate?

Our affiliates carry out the mission of the International OCD Foundation through programs at the local, community level. Each 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.

For more information, and contact info for each affiliate, please visit: www.ocfoundation.org/affiliates

#### MAP OF U.S. 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

#### South

- OCD Texas
- OCD Northwest Arkansas
- OCD Jacksonville
- OCD Georgia

#### East Coast

- OCD Massachusetts
- OCD MidAtlantic
- OCD New Jersey
- OCD New York
- OCD Philadelphia
- OCD Western PA

## Puerto Rico

OCD Puerto Rico

## **IOCDF Global Partners**

At the 2009 Annual OCD Conference in Minneapolis, MN, we formally announced that the Obsessive Compulsive Foundation had become the International OCD Foundation. In part we adopted the new name in order to emphasize the international directions we had already begun to take. For example, the Genetics Collaborative Board is a group of genetics investigators from North America, South America, Europe and Africa. The Collaborative currently has more than 50 members and has been in operation since the Foundation's Annual Conference in 2002.

In addition, we have had an increase in inquiries from countries all over the world via mail and email. Approximately 25% of our website hits and 10% 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 psychoeducation about OCD into different languages, to helping others around the world find the limited resources

available for the treatment of OCD.

#### **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 (www.stpatrickshosp.ie).

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-FORBUNDET 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.





## Statement of Activities

2012

2011

	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Support and Revenue						
Contributions and Private Grants	\$ 515,586	554,848	1,070,434	\$ 512,566	449,966	745,866
Dues	210,682	-	210,682	194,595	-	194,595
Conference	299,473	2,900	302,373	217,177	-	217,177
In-kind contributions	140,563	-	140,563	101,114	-	101,114
BTTI fees	52,598	-	52,598	31,575		
Net realized and unrealized investment Gains (losses)	-	-	-	-	3,462	3,462
Miscellaneous	2,041	-	2,041	4,285	76	1,029
Net assets released from restrictions	382,664	(382,664)	-	368,176	(368,176)	-
Total Support and Revenue	1,603,607	175,084	1,778,691	\$ 1,429,488	85,328	1,514,816
Expenses						
Research and Education	1,194,324	-	1,194,324	\$ 1,214,497	-	1,214,497
Fundraising	170,533	-	170,533	112,572	-	112,572
General and Administrative	264,286	-	264,286	226,056	-	226,056
Total Expenses	1,629,143	-	1,629,143	\$ 1,553,125	-	1,553,125
Change in Net Assets	(24,466)	180,388	154,922	(123,637)	85,328	(38,309)
Net Assets, Beginning of Year	184,997	559,527	744,524	411,366	371,467	782,833
Net Assets, End of Year	\$ 159,531	739,915	899,446	\$ 287,729	456,795	744,524

International OCD Foundation EIN 22-2894564





## IN MEMORIUM FRANCES SYDNEY 1944 – 2012

The opening of 2012 saw a significant loss for the IOCDF. Fran Sydney, a founding member of the International OCD Foundation, then known as the Obsessive Compulsive Foundation (OCF), died on February 26, 2012, after a long and courageous battle with cancer. Throughout the years, Fran contributed to the development and management of the Foundation in many significant ways. Most notably, Fran served on the Foundation's board of directors from its inception in 1986 until she passed away. Even when she was too sick to travel, Fran participated in every board meeting via conference call. She was also the first Treasurer of the board, helping to put in place the policies and procedures that enabled the IOCDF to become the premier national group for people affected by OCD that it is today.

Until the Foundation had its first permanent office and meeting place in November of 1988, Fran regularly opened her house to the Foundation's directors and members to work on building the organization. In March of 1988, 20/20 ran a feature on OCD, the first of its kind. Fran staffed the Foundation phone at her house, which was set up to respond to calls about the show. She stayed in her nightgown for two straight days after the segment aired in order to answer the deluge of calls from people with OCD and their family members. In addition to sharing information about the disorder and its treatment, Fran gave the callers hope by telling them about her own personal struggle with OCD.

Fran was instrumental in establishing and promoting the Foundation's research program. Every year, along with soliciting funds to underwrite the Foundation's research program, she participated in selecting the researchers to whom the grants were to be given. Today, the research program awards about \$150,000-200,000 in grant money each year and is considered to be an important resource for researchers in the field. For 26 years, Fran devoted herself to helping people with OCD.

In honor of Fran, the IOCDF Board of Directors created the Frances Sydney Conference Scholarship Fund. If you would like to donate to this fund please contact the main office at (617) 973–5801 or go online to donate at www.iocdf.org/donate and be sure to make sure you mention the Frances Sydney Memorial Scholarship Fund in the notes of your donation.

Scholarship Funds will be used to reduce conference registration fees for those who would otherwise not be able to attend.

## **INTERNATIONAL OCD FOUNDATION 2012**

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(pictured below left)

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