

International  
OCD  
Foundation



2022  
ANNUAL REPORT

# From the president



**1500+**

attended Annual  
OCD Conference

**\$1.6m**

awarded to researchers  
through grant program

**3 million**

families and  
individuals served

## DEAR FRIENDS AND SUPPORTERS,

During my time as President of the IOCDF's Board of Directors, I have had the privilege of helping to shape and guide the organization's strategy and mission. Each year we continue to grow and expand our reach and in 2022 we were able to provide resources to over 3 million families and individuals worldwide.

On that note, 2022 was a tremendous year for the IOCDF and I am delighted to share our newest annual report with you! Some of my favorite highlights from this year include:

- Over 1,500 attendees returned to our in-person Annual OCD Conference in Denver, CO
- Over \$1.6 million awarded to researchers through our Research Grant Program
- Our inaugural Behavior Therapy Training Institute (BTI) for Treating OCD in Communities of Color in Washington, DC
- The 10th annual One Million Steps for OCD Walk series — a celebrated milestone
- Two new Resource Centers were launched for Perinatal OCD and Faith & OCD, providing much-needed educational resources to previously underserved groups

- Our quarterly OCD Newsletter is now FREE to anyone seeking community, support, and education without the barrier of a membership fee

I am proud to help lead the IOCDF in our mission to build a supportive, engaging community, end the stigma around OCD, and help more people access the treatment and resources they need to ensure that no one with OCD or related disorders suffers alone. Thank you to all the donors, partners, stakeholders, and community members who made 2022 possible — together we will continue this amazing work next year and beyond!

Sincerely,

A handwritten signature in black ink that reads "Susan M. Boaz". The signature is fluid and cursive, with a long, sweeping line extending from the end of the name.

Susan Boaz  
President, IOCDF Board of Directors



# Who we are

The IOCDF provides up-to-date education and resources, strengthens community engagement, delivers quality professional training, and advances groundbreaking research. Headquartered in Boston, MA, USA, we have 31 local Affiliates nationwide and 17 global partner organizations around the world.

## MISSION

The mission of the IOCDF is to ensure that no one affected by OCD and related disorders suffers alone. Our community provides help, healing, and hope.

## VISION

Our vision is that everyone impacted by OCD and related disorders has immediate access to effective treatment and support.

## Snapshots of 2022

**3,000,000+** unique visitors  
to IOCDF suite of websites

**330** clinicians trained through the  
Behavior Therapy Training Institute

**200,000+** Peace of Mind virtual  
community livestream views

**2,500+** Grassroots Advocates

**1,500+** in-person Annual  
OCD Conference attendees

**30+** One Million Steps for OCD  
Walks with **3,000+** walkers

**5** virtual & hybrid conferences  
with **3,300** combined attendees

**9** research grants totaling  
**\$1.6 million** awarded

# Our global community

In our commitment to improving access to resources for all communities, in coordination with our DEI (Diversity, Equity, and Inclusion) Action Council we worked to expand DEI-focused initiatives.

This year’s initiatives included:

- The continuance of the **BTTI scholarship program**, by awarding six scholarships per BTTI to therapists who speak another language, and/or therapists who work with a significant portion of underserved patients.
- Organizing the first **BTTI for Treating OCD in Communities of Color** in Washington, DC with Dr. Monnica Williams serving as the Clinical Director for the first BTTI training for BIPOC clinicians by BIPOC faculty.
- Offering the **Conferencia de TOC Online** for the third year in a row, a virtual conference entirely in Spanish for people with lived experience with OCD and their supporters, therapists, and students/trainees.
- Introducing the first virtual **Spanish-language BTTI**, which trained 30 Spanish-speaking therapists from around the world in OCD treatment best practices.



## IOCDF SPECIAL INTEREST GROUPS

- Acceptance and Commitment Therapy (ACT)
- Chronic Illness/Disability and OCD
- OCD/Autism
- BDD
- Faith & OCD
- Helping Professionals with OCD
- LGBTQ+
- Pediatric
- Professional Networking
- OCD/SUD Recovery Is Possible
- Therapists & Trainees with OCD
- Trauma & PTSD in OCD
- Vintage OCD Voices
- Young Adults

## IOCDF ADVOCATE PROGRAM

**2,500+** Grassroots Advocates

**30** IOCDF Advocates

**4** Lead Advocates

**2** National Advocates





# Research grant program

## MICHAEL JENIKE YOUNG INVESTIGATOR AWARD WINNERS



### EMILY OLFSO, MD, PHD

Yale School of Medicine (New Haven, CT)  
Expanding the Genetic Landscape of Pediatric OCD

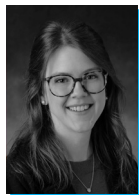
Award Amount: \$49,993



### DANIEL RAUTIO, MSC, PHD CANDIDATE

Karolinska Institutet (Solna, Sweden)  
Improving Access to Evidence-based Interventions for Adolescents with Body Dysmorphic Disorder

Award Amount: \$49,750



### REBECCA COX, PHD

University of Colorado, Boulder (Boulder, CO)  
Examining Circadian and Non-circadian Phenotypes in Obsessive Compulsive Disorder with Delayed Bedtimes

Award Amount: \$49,933



### SHRUJNA PATEL, PHD

Sydney Children's Hospital Network (Sydney, Australia)  
A Modifiable Transcriptomic Signature of Immune Dysfunction in Pediatric Obsessive Compulsive Disorder (OCD)

Award Amount: \$50,000



### UĞUR AKCAN, PHD

Columbia University (New York, NY)  
Elucidating the Role of RXRA Factor in Myeloid Cells for Immune-mediated Mechanisms of OCD

Award Amount: \$50,000



### SAMANTHA HELLBERG, MA

University of North Carolina at Chapel Hill (Chapel Hill, NC)  
Perinatal Obsessive Compulsive Disorder: A Person-centered, Dynamic-Systems Approach

Award Amount: \$49,566

## IOCDF BREAKTHROUGH AWARD WINNERS



### EMILY STERN, PHD & MOHAMMED R. MILAD, PHD

Nathan Kline Institute for Psychiatric Research/Research Foundation for Mental Hygiene (Orangeburg, NY)



Neural Mechanisms of Active Avoidance in Obsessive Compulsive Disorder

Award Amount: \$500,000



### ERIC STORCH, PHD

Baylor College of Medicine (Houston, TX)  
CBT Augmentation to Promote Medication Discontinuation in Pediatric OCD

Award Amount: \$499,891

## IOCDF INNOVATOR AWARD WINNER



### DOROTHY GRICE, MD

Icahn School of Medicine at Mount Sinai (New York, NY)  
Dissecting the Temporal and Causal Relationships between OCD and Bipolar Disorder

Award Amount: \$300,000



## Why it matters

Research is vital to our goals of increasing our understanding of OCD and related disorders, improving treatment, and reducing stigma. To help achieve these goals, the IOCDF awards research grants for promising studies through generous donor-funded support. Since 1994, the IOCDF has awarded nearly \$10 million in research grants, and continues to offer research grant awards annually.

Adding to our research portfolio, our newest grants examined topics including:

- Exploring the common genetic and environmental risk factors between co-occurring OCD and bipolar disorder
- Examining approaches to discontinuing serotonin reuptake inhibitor (SRI) medication following cognitive behavioral therapy (CBT) in the treatment of pediatric OCD
- Understanding the relationship between OCD avoidance behaviors and activity in the brain
- Providing insight into how genetic variation impacts risk of developing OCD and BFRBs
- Examining the effectiveness of Internet-based CBT in the treatment of young people with BDD
- Discovering evidence for a biomarker of immune dysfunction in children with PANS
- Understanding the development of perinatal OCD and differences in its presentation across individuals using personalized smartphone assessments
- Illuminating potential genetic markers related to inflammation and the development of PANDAS
- Exploring the role of circadian rhythms in later sleep timing in OCD

# Highlights

## ANNUAL OCD CONFERENCE

This year we saw our triumphant return to the in-person Annual OCD Conference in the Mile-High City of Denver, CO. It was amazing to see individuals and families living with OCD, mental health professionals, and researchers in the community reuniting with old friends and colleagues and meeting new people who came with hope and courage. The weekend was packed with informative presentations on OCD and related disorders, community-building opportunities, and fun after-hours activities.

For the keynote address, Toby, Simon, Mali, and Oliver of the Kinberg family shared their family's story with OCD and mental health, and the unique experience that being part of a high-profile family can have on a family's healing.

**1,520**

People attended  
the Conference

**53**

US states and  
territories represented

**11**

Countries  
represented



### 2022 ANNUAL OCD CONFERENCE AWARD WINNERS

- Outstanding Career Achievement Award: James F. Leckman, MD, PhD
- Patricia Perkins Service Award: Sabine Wilhelm, PhD
- IOCDF Hero Award: Kyle King
- IOCDF Youth Hero Award: Alex Rosenberg

### 2022 VIRTUAL & HYBRID CONFERENCES

In addition to the in-person Annual OCD Conference, our hybrid and virtual conferences provided opportunities to gather, learn, and find community—from any location.

- Online OCD Camp for Kids & Families
- Faith & OCD Conference
- IOCDF Research Symposium (Hybrid)
- Spanish Online OCD Conference
- Online OCD Conference

## OCD AWARENESS WEEK

OCTOBER 9–15, 2022

Throughout the second full week in October, the IOCDF joined together with members of the OCD and related disorders community to celebrate International OCD Awareness Week. Led by IOCDF Advocates, this year's programming included a mix of panel-based livestreams, social media live takeovers, and interactive Zoom events, with livestreams totaling over 8,000 views across all platforms this week alone—the most yet!

## PEACE OF MIND VIRTUAL COMMUNITY

This year, the Peace of Mind Virtual Community continued to thrive with our weekly livestreams being cast to hundreds of viewers across platforms each week. These livestreams feature IOCDF Advocates and include the Community Conversations, Town Halls, Ask the Experts, Lunch & Learn for mental health professionals, and roundtables for Research, Faith & OCD, and Diversity. The My OCD Community forum on HealthUnlocked, a free, anonymous online forum for users to share their stories and get support, continues to grow with almost 7,000 members.





## Resource highlights

### PERINATAL OCD RESOURCE CENTER

To address a disparity in resources for parents experiencing perinatal OCD, the IOCDF partnered with 2020 Mom, a leading maternal mental health nonprofit organization, to form the Perinatal OCD Task Force. This task force brought leaders in both the OCD community and the perinatal mental health community to address perinatal OCD from a variety of avenues. This task force helped put together our online, freely accessible Perinatal OCD Resource Center, which contains information and resources for people with lived experience, their loved ones/supporters, clinical providers, and the general public.

### NEW-AND-IMPROVED FAITH & OCD RESOURCE CENTER

Working with a Faith-based taskforce of OCD experts, religious/spiritual leaders, and those from a variety of religious backgrounds who live with OCD, we expanded upon the new Faith and OCD Resource Center, an online resource focused on both moral/religious scrupulosity and the ways OCD may interfere with an individual's religious practices and/or treatment. This resource provides specific content for those living with OCD in faith-based communities and faith leaders and mental health professionals working with this population in an effort to bridge the gap between faith and mental health.

### ONLINE RESOURCE DIRECTORY UPDATES

Responding to the increased demand for teletherapy treatment options, the IOCDF completed an Online Resource Directory integration, adding teletherapy and hybrid in-person/teletherapy providers to complement the existing in-person location-based listings so users can find providers that work best for their individual needs.

## ONE MILLION STEPS FOR OCD WALK

This year marked the 10th anniversary of our flagship event dedicated to raising awareness, funds, and hope! Since the inaugural One Million Steps for OCD Walk in Boston a decade ago, our OCD Walk program has grown exponentially, with IOCDF Affiliates hosting Walks in 34 locations around the country this year.



**3,040**  
walkers



**\$250,000+**  
fundraised for programs



**35**  
total walks



**"These days mental health challenges are getting more attention, but people with OCD and their families often feel very isolated. The One Million Steps for OCD Walk is an important reminder that we are not alone and that help is available. When my daughter and I participated in the Walk, there was a feeling of joy in the air. How wonderful to be seen and accepted."**

— HILLARY TWINING, OCD WALK PARTICIPANT

# Our financials

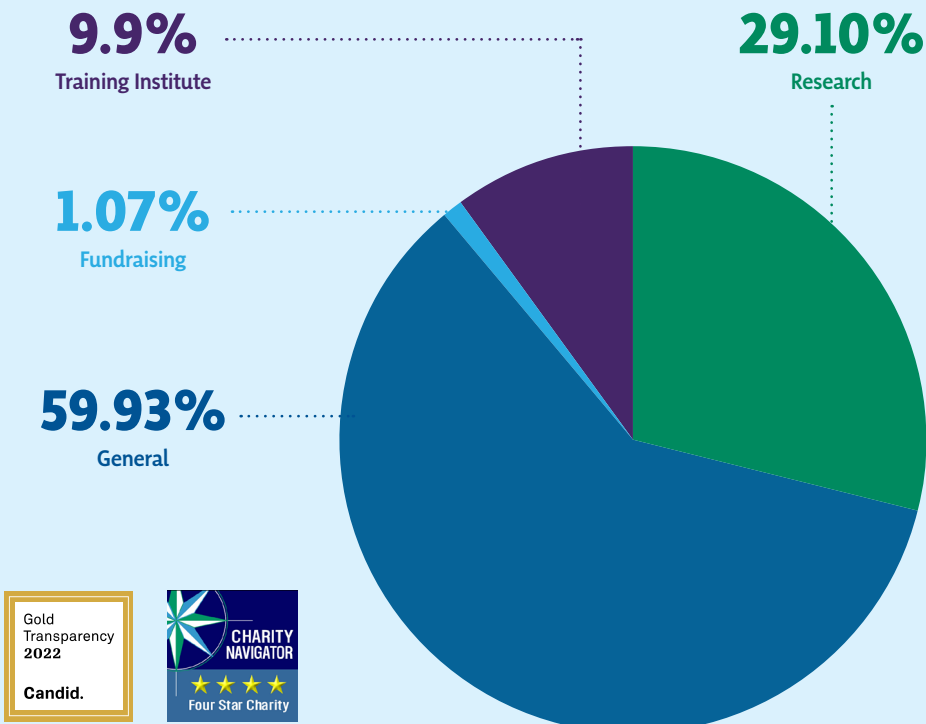
## EXPENSES

ITEM	COST
Research	\$1,172,179
General, Administrative, and Event	\$2,414,503
Fundraising	\$42,994
Training Institute	\$398,978
<b>Total Expenses</b>	<b>\$4,028,656</b>

## REVENUE AND SUPPORT

ITEM	COST
General Revenue	\$3,606,229
Research Revenue	\$1,127,375
<b>Total Revenue</b>	<b>\$4,733,605</b>

<b>NET PROFIT</b>	<b>\$704,948</b>
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## THANK YOU TO OUR 2022 EVENT SPONSORS!





# Our people

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- OCD Arizona
- OCD Arkansas
- OCD Colorado
- OCD Connecticut
- OCD Jacksonville
- OCD Central and South Florida
- OCD Georgia
- OCD Kansas
- OCD Louisiana
- OCD Massachusetts
- OCD Mid-Atlantic
- OCD Michigan
- OCD Midwest
- OCD Twin Cities
- OCD New Hampshire
- OCD New Jersey
- OCD New York
- OCD North Carolina
- OCD Oregon
- OCD Pennsylvania
- OCD Rhode Island
- OCD Sacramento
- OCD SF Bay Area
- OCD Southern California
- OCD South Carolina
- OCD Texas
- OCD Twin Cities
- OCD Utah
- OCD Washington
- OCD Wisconsin

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- OCD China
- OCD & Anxiety Support Hong Kong
- AFTOC (France)
- OCD Ireland
- OCD Japan
- OCD Ohanashikai (Japan)
- OCDnet (Netherlands)
- The Institute of Counseling in Nigeria
- Norwegian OCD Foundation, Anake
- OCD Network Singapore
- The South African Depression and Anxiety Group
- Asociación TOC Granada (Spain)
- Asociación TOC Zaragoza (Spain)
- Svenska OCD-forbundet
- Ananke (Sweden)
- OCD Action (United Kingdom)





International  
OCD  
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# Thank you!

As a largely donor supported 501(c)(3) nonprofit, your generosity makes all of this possible and fuels our vision of a world in which everyone impacted by OCD and related disorders has immediate access to effective treatment and support.



Powered by our community of donors, you can help us continue to work towards accomplishing this vision. Click or use the QR code on the left to make a contribution today.

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- [Attend a Community Event](#)
- [Join the Peace of Mind Virtual Community](#)