

April 13, 2026

BOARD OF DIRECTORS

Susan Boaz
President
David Calusdian
Vice President
Ron Prevost
Treasurer
Denise Egan Stack, LMHC
Secretary
Shawn Assad
Diane Davey, RN, MBA
Crystal Fulwood
Ben Gambrel
Elizabeth McIngvale, PhD, LCSW
Carol Taylor
Chris Trondsen, LMFT
Jo-Ann Winston
Jenny C. Yip, PsyD, ABPP

EMERITUS BOARD MEMBERS

Denis Asselin
Joy Kant
Patti Perkins, JD

EXECUTIVE DIRECTOR

Rebecca Deusser

**SCIENTIFIC AND CLINICAL
ADVISORY BOARD (SCB)**

Sabine Wilhelm, PhD
Chair
Jonathan S. Abramowitz, PhD
Susanne Ahmari, MD, PhD
Thorstur Bjorgvinsson, PhD
L. Kevin Chapman, PhD
James Claiborn, PhD
Lisa Coyne, PhD
Darin Dougherty, MD
Denise Egan Stack, LMHC
Jamie Feusner, MD
Martin E. Franklin, PhD
Jennifer Freeman, PhD
Randy Frost, PhD
Wayne K. Goodman, MD
Jonathan Grayson, PhD
Benjamin Greenberg, MD, PhD
Jon Herschfield, LMFT
Jonathan Hoffman, PhD, ABPP
Robert Hudak, MD
Nancy Keuthen, PhD
Sony Khemlani-Patel, PhD
Adam B. Lewin, PhD, ABPP
Charles S. Mansueto, PhD
Carol A. Mathews, MD
Patrick McGrath, PhD
Dean McKay, PhD
E. Katia Moritz, PhD, ABPP
Tanya K. Murphy, MD
Gerald Nestadt, MD
Fugen Neziroglu, PhD
Bunmi O. Olatunji, PhD
Michele Pato, MD
Fred Penzel, PhD
Katharine A. Phillips, MD
John Piacentini, PhD, ABPP
Anthony Pinto, PhD
Christopher Pittenger, MD, PhD
C. Alec Pollard, PhD
Steven J. Poskar, MD
Peggy M. A. Richter, MD
Bradley C. Riemann, PhD
Carolyn Rodriguez, MD, PhD
Sanjaya Saxena, MD
H. Blair Simpson, MD, PhD
Gail Steketee, PhD
S. Evelyn Stewart, MD
Eric Storch, PhD
Kiara R. Timpano, PhD
Barbara L. Van Noppen, PhD
Odile A. van den Heuvel, MD, PhD
Aureen Pinto Wagner, PhD
Allen Weg, EdD
Monnica T. Williams, PhD
Robin Zasio, PsyD, LCSW

Assemblyman Weprin, Chair
New York State Assembly Insurance Committee
LOB 714
Albany, NY 12248

Senator Bailey, Chair
New York State Senate Insurance Committee

Dear Assemblyman Weprin and Senator Bailey:

I write to you as the Executive Director of the International OCD Foundation (IOCDF), the nation's largest organization solely dedicated to advocating for everyone affected by obsessive-compulsive disorder (OCD) and related disorders, including pediatric autoimmune neuropsychiatric disorders (PANDAS/PANS). The IOCDF wishes to convey our endorsement of both NYS Assembly Bill A9659 and NYS Senate Bill S2655A, which would require health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome rehabilitation treatment.

While we have known for many years that children can develop OCD, PANDAS/PANS have only recently been distinguished as illnesses that are unique from more typical cases of childhood-onset OCD. Researchers believe PANDAS/PANS is caused by a malfunctioning immune system that mistakenly attacks the brain instead of an infection. Unlike in typical OCD, where symptoms set in gradually over months or even years, symptoms in PANDAS/PANS appear rapidly following an infection (e.g., strep throat).

The symptoms of PANDAS/PANS resemble severe OCD and tic disorders. Affected children may become extremely anxious, act out in disruptive ways, or be unable to eat. The speed with which children develop these symptoms — seemingly overnight — is truly frightening to parents, and the intense needs of a child with PANDAS/PANS can leave families reeling. When left untreated, PANDAS/PANS can be permanently disabling or even deadly.

Treatments that work for children with OCD may not necessarily work for children with PANDAS/PANS. Thankfully, there are several therapies that scientific research has shown to be effective: cognitive behavioral therapy, antibiotics, plasmapheresis (TPE), and intravenous immunoglobulin therapy (IVIG) are among the best treatments currently available for PANDAS/PANS.

In mild and moderate cases of PANDAS/PANS, cognitive behavioral therapy and antibiotics are the recommended treatments. IVIG is recommended in moderate and severe cases, per treatment guidelines

BOARD OF DIRECTORS

Susan Boaz
President
David Calusdian
Vice President
Ron Prevost
Treasurer
Denise Egan Stack, LMHC
Secretary
Shawn Assad
Diane Davey, RN, MBA
Crystal Fulwood
Ben Gambrel
Elizabeth McGivale, PhD, LCSW
Carol Taylor
Chris Trondsen, LMFT
JoAnn Winston
Jenny C. Yip, PsyD, ABPP

EMERITUS BOARD MEMBERS

Denis Asselin
Joy Kant
Patti Perkins, JD

EXECUTIVE DIRECTOR

Rebecca Deusser

SCIENTIFIC AND CLINICAL ADVISORY BOARD (SCB)

Sabine Wilhelm, PhD
Chair
Jonathan S. Abramowitz, PhD
Susanne Ahmari, MD, PhD
Throstrur Bjorgvinsson, PhD
L. Kevin Chapman, PhD
James Claiborn, PhD
Lisa Coyne, PhD
Darin Dougherty, MD
Denise Egan Stack, LMHC
Jamie Feusner, MD
Martin E. Franklin, PhD
Jennifer Freeman, PhD
Randy Frost, PhD
Wayne K. Goodman, MD
Jonathan Grayson, PhD
Benjamin Greenberg, MD, PhD
Jon Herschfield, LCMFT
Jonathan Hoffman, PhD, ABPP
Robert Hudak, MD
Nancy Keuthen, PhD
Sony Khemlani-Patel, PhD
Adam B. Lewin, PhD, ABPP
Charles S. Mansueto, PhD
Carol A. Mathews, MD
Patrick McGrath, PhD
Dean McKay, PhD
E. Katia Moritz, PhD, ABPP
Tanya K. Murphy, MD
Gerald Nestadt, MD
Fugen Neziroglu, PhD
Bunmi O. Olatunji, PhD
Michele Pato, MD
Fred Penzel, PhD
Katharine A. Phillips, MD
John Piacentini, PhD, ABPP
Anthony Pinto, PhD
Christopher Pittenger, MD, PhD
C. Alec Pollard, PhD
Steven J. Poskar, MD
Peggy M. A. Richter, MD
Bradley C. Riemann, PhD
Carolyn Rodriguez, MD, PhD
Sanjaya Saxena, MD
H. Blair Simpson, MD, PhD
Gail Steketee, PhD
S. Evelyn Stewart, MD
Eric Storch, PhD
Kiara R. Timpano, PhD
Barbara L. Van Noppen, PhD
Odile A. van den Heuvel, MD, PhD
Aureen Pinto Wagner, PhD
Allen Weg, EdD
Monnica T. Williams, PhD
Robin Zasio, PsyD, LCSW

published in 2017.¹ The use of IVIG to treat PANDAS/PANS is supported by the results of multiple double-blind, placebo-controlled studies and numerous case reports.^{2,3} In one study, the children who received IVIG treatment experienced a 45% reduction in symptoms, and the vast majority continued to be improved when researchers followed up with them one year after treatment. TPE is also supported by research and was shown to reduce symptoms by 58%. However, it is a riskier and more costly treatment and is recommended only in extreme or life-threatening cases.

Out of pocket costs for IVIG or TPE are significant: IVIG can cost up to \$15,000 and TPE is even more expensive. The average family will struggle to afford the right treatment for a child with moderate to severe PANDAS/PANS if their insurer does not provide coverage. By mandating coverage for the full spectrum of available evidence-based treatments, NYS Assembly Bill A9659 and NYS Senate Bill S2655A will ensure that every child in New York with PANDAS/PANS has a chance at recovery.

On behalf of our members and all New York families who are caring for a child with PANDAS/PANS, we respectfully ask the New York State Assembly Insurance Committee to pass these bills. Should any Assembly members have questions about PANDAS/PANS or its treatments, please do not hesitate to contact us.

Sincerely,



Rebecca Deusser
Executive Director
International OCD Foundation

¹ Frankovich, J., Swedo, S., Murphy, T., Dale, R. C., Agalliu, D., Williams, K., Daines, M., Hornig, M., Chugani, H., Sanger, T., Muscal, E., Pasternack, M., Cooperstock, M., Gans, H., Zhang, Y., Cunningham, M., Bernstein, G., Bromberg, R., Willett, T., Brown, K., Farhadian, B., Chang, K., Geller, D., Hernandez, J., Sherr, J., Shaw, R., Latimer, E., Leckman, J., & Thienemann, M. (2017). Clinical management of pediatric acute-onset neuropsychiatric syndrome: Part II—use of immunomodulatory therapies. *Journal of Child and Adolescent Psychopharmacology*, 27(7), 574-593.

² Eremija, J., Patel, S., Rice, S., & Daines, M. (2023). Intravenous immunoglobulin treatment improves multiple neuropsychiatric outcomes in patients with pediatric acute-onset neuropsychiatric syndrome. *Frontiers in Pediatrics*, 11, 1229150.

³ Prus, K., Weidner, K., & Alquist, C. (2022). Therapeutic plasma exchange in adolescent and adult patients with autoimmune neuropsychiatric disorders associated with streptococcal infections. *Journal of Clinical Apheresis*, 37(6), 597-599.