

Uniting for a Cure: Experts and Advocates Push for Research Breakthroughs on Youth Neuroimmune Illnesses

DC gatherings target PANS/PANDAS solutions

WASHINGTON, DC, UNITED STATES, March 27, 2025 /EINPresswire.com/ -- Advocates, researchers and clinicians from around the country are set to gather in Washington, DC, April 10-12, to accelerate research and treatment breakthroughs on the infection-associated neuroimmune disorders known as [PANS/PANDAS](#).

The activities are being led by [The Alex Manfull Fund \(TAMF\)](#), a nonprofit organization founded by William and Susan Manfull in 2018 shortly after the death of their only daughter Alex, and the [National Alliance for PANS/PANDAS Action](#) (NAPPA), a national steering committee dedicated to driving PANS/PANDAS legislative efforts.

PANS and PANDAS typically develop after common viral and bacterial infections, like strep throat, the flu and even Covid, striking young people indiscriminately. In some, these infections trigger the immune system to dysregulate and create autoantibodies that attack healthy brain tissue, causing severe inflammation and a range of debilitating physical and mental symptoms. Early diagnosis and treatment lead to recovery, but when left untreated, PANS and PANDAS can cause progressive brain damage, lifelong disabilities—and even loss of life.

“The costs of delayed diagnosis and treatment are extremely high, making it imperative that we not only continue ongoing research and efforts to grow awareness, but that we expand our work as a matter of extreme urgency,” says Susan Manfull, Executive Director of TAMF.



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“The advocates coming to DC include individuals suffering from the disorders’ horrific effects and family members who have lost years of their lives seeking proper treatment or, tragically, they come on behalf of others such as Alex Manfull, who, in the prime of her life, died due to PANDAS. Decision-makers need to hear their stories. And we need to do everything we can to help researchers expedite their efforts to find even more targeted treatments.”



Medals to be awarded at The Alex Manfull Fund 5K

As part of its mission to advance critical research, TAMF will convene a working session of the world’s leading PANS/PANDAS practitioners and researchers on April 11 to facilitate knowledge-sharing and collaboration on the latest cutting-edge research. Expected attendees include the renowned Dr. Susan Swedo, credited with identifying PANDAS–Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus–at the National Institute of Mental Health in the mid-1990s.

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Susan Manfull, PhD, Executive Director of The Alex Manfull Fund

Other expected attendees include Dr. Jennifer Frankovich (Stanford University PANS Research Program), Dr. Beth Latimer (Private Practice Neurologist, Washington, DC), Dr. Juliette Madan (Dartmouth University, Neuroimmune Psychiatric Program), Dr. Kyle Williams (Director, Pediatric Neuropsychiatry and Immunology Program, Massachusetts General Hospital), Dr. John Gaitanis (Pediatric Neurologist, Hasbro Children’s Hospital), Dr. Herb Lachman (Albert Einstein College of Medicine), Dr.

Earl Harley (Pediatric Otolaryngologist, Georgetown University), and Dr. Tim Ubhi (Clinical Director & Founder of The London PANS Clinic), among others.

Later that evening, TAMF will host a dinner to recognize the crucial role that researchers and clinicians play in advancing understanding these disorders.

“This gathering of some of the world’s most consequential minds in the area of PANS/PANDAS is at the heart of what we’re aiming to achieve at The Alex Manfull Fund–identifying and implementing breakthrough solutions to treat these disorders early and effectively,” says Manfull.

The DC advocacy delegation, hailing from 18 states, will meet with Members of Congress on Capitol Hill on April 10-11. "Few legislators are aware of PANS/PANDAS and the impact of delayed and inappropriate treatments, and our goal is to make a compelling case for them to prioritize research funding for these disorders in the upcoming year," says Amanda Peel Crowley, co-founder of NAPPA.

On April 12, the 3rd Annual TAMF 5k will kick off along the shores of the Potomac River, with an expected draw of more than 300 participants. Funds raised will go toward PANS/PANDAS research and fellowships at Georgetown and Dartmouth universities.

Support for Georgetown's research and clinical training will build on TAMF's inaugural funding for the establishment of the world's first-ever PANS/PANDAS brain bank at Georgetown University, known as the POND Brain Bank. This research repository is now home to the brains or brain tissue from 9 individuals who had been diagnosed with PANDAS or PANS.

The DC events take place against the backdrop of recent groundbreaking PANS/PANDAS legislative changes in neighboring Virginia. On March 18, Virginia made history with the signing of a new law mandating coverage by state medical assistance services and private health insurers for the diagnosis and treatment of PANS/PANDAS. Virginia became the 13th state to require such coverage.

"Chronic illness is a policy buzzword these days, as national efforts intensify to challenge conventional approaches to some of our most complex and difficult-to-treat diseases," says Manfull. "My deepest hope is that this truly ushers in a new era of awareness, research and treatment for infection-associated chronic illnesses, especially PANS/PANDAS."

ABOUT THE ALEX MANFULL FUND

When Susan and William Manfull lost their only child, Alex Manfull, to this disorder, they established the Fund in their daughter's memory to increase awareness about these disorders, especially in adolescents and young adults, and to advance education for physicians, mental health professionals, and educators, helping them to recognize and treat these disorders. The Alex Manfull Fund was instrumental in establishing the POND Brain Bank at Georgetown University Medical Center—the country's only repository for brains from individuals who have been diagnosed with PANDAS/PANS and Other Neuroimmune Disorders (POND). The facility makes tissue available for research to advance the understanding of these disorders.

ABOUT NAPPA

The National Alliance for PANS/PANDAS Action is a steering committee dedicated to leading federal PANS/PANDAS legislative efforts. NAPPA's mission is to dramatically change the trajectory for patients by unlocking crucial federal funds for breakthroughs in PANS/PANDAS research and treatment. To date, NAPPA has secured language in the federal Appropriations bill for fiscal years 2020-24, directing NIH to shine a spotlight on PANS/PANDAS by expanding research funding and

clinical care.

ABOUT PANS/PANDAS

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) develop after common viral and bacterial infections, triggering the immune system to attack healthy brain tissue. Symptoms typically include obsessive compulsive behaviors, restrictive eating or tics. Other symptoms may include cognitive decline, behavioral issues, anxiety, insomnia, and urinary frequency. Onset may be sudden and dramatic. There's grossly insufficient federal research on the disorder.

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