

Advocacy Groups Issue Urgent Call to Action on Life-Changing Disorders Affecting Kids after Common Infections

Neuroimmune disorders, triggered by common viral/bacterial infections cause the body's immune system to attack healthy brain tissue, are extremely underfunded.

WASHINGTON DC, WASHINGTON, USA, May 25, 2023 /EINPresswire.com/ -- [The Alex Manfull Fund](#) (TAMF) and the National Alliance for PANS/PANDAS Action (NAPPA) are convening in Washington, DC, on June 2-3, 2023, with an urgent call for critically needed funding to jumpstart research on traumatic and under-funded neuroimmune disorders that upend thousands of lives across the US each year.

These disorders, referred to as PANS/PANDAS, autoimmune encephalitis, and post-infectious immune-mediated neuropsychiatric disorders, are triggered by common viral and bacterial infections, such as strep throat and the flu, which cause the body's immune system to attack healthy brain tissue.

This leads to physical and behavioral changes in children and young adults so dramatic that they are almost unrecognizable, and families' lives are turned upside down. A recent study from Stanford University found that the caregiver burden in PANS and PANDAS was greater than that of Alzheimer's.

"These disorders may present as mental illness but have a different cause and require different



Alexandra "Alex" Coulter Manfull died August 7, 2018 in Washington, D.C. As a graduate of Phillips Exeter Academy and Princeton University, she had a successful start on Wall Street, had just started an exciting job in finance in Washington, D.C., and was

types of treatment to provide lasting recovery,” says Susan Manfull, Executive Director of The Alex Manfull Fund, a nonprofit created to honor the memory of her only child, Alex, who lost her life to the disease.

“They are easily misdiagnosed because many medical professionals are simply not familiar with the role of infection and the immune system. If only one of Alex’s doctors had recognized PANDAS earlier, Alex would be alive today. Our vision is to ensure that no life will ever again be cut short — or interrupted — by PANS/PANDAS.”

The Alex Manfull Fund is teaming up with NAPPA and other regional and national advocacy groups and families from around the country on a series of events to raise awareness, educate local medical professionals and demand federal funding for research and insurance coverage of these devastating illnesses.

Kicking off the activities is the first-ever PANS/PANDAS Advocacy Day on Capitol Hill, taking place on Friday, June 2, at 10 am. Advocates and family members will share remarks at a press event

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on the steps of the US Capitol and spend the day advocating in congressional offices. The advocacy comes on the heels of recent testimony by Amanda Peel Crowley, Executive Director of NAPPA, to the US House Appropriations Committee on Labor, Health and Human Services.

“Advocacy efforts are paying off with the support of

Congress. Two scientists have been successfully awarded grant funding from NIH in the past 5 years for studies of PANS/PANDAS, but significantly more is needed,” Crowley says. “The time is now to provide transformative funding specifically for PANS/PANDAS to develop treatment breakthroughs and improved diagnostic tools that will save lives.”

The June 2 advocacy will culminate in a dinner that brings together researchers, advocates, and health professionals to foster alliances and strengthen efforts to advance awareness, research,



The Alex Manfull Fund supports awareness, education, and research to further understand the incidence, etiology, and best treatment of post-infectious neuroimmune disorders (aka PANDAS, PANS, and Autoimmune Encephalitis) with an emphasis on their manifest



Alex told her parents, William and Susan Manfull, that as soon as she was well, she intended to educate everyone about PANDAS. To deliver on Alex’s wishes and to ensure no other person loses his or her life, or lose the years it can take to treat this dis

legislation, and treatment. Headlining the event are pianist Shelby Lock, a three-time Finalist for the American Prize in Composition and disability rights advocate, and Kayla Caulfield, actress of the three-time Academy Award-winning movie CODA – both of whom have been diagnosed with and treated for PANS/PANDAS. The event will also include remarks by Susan Manfull, co-founder of The Alex Manfull Fund; Amanda Peel Crowley, co-founder of NAPPA; Dr. Beth Latimer and Dr. Gary Kaplan, DC-area physicians who treat PANS/PANDAS; and Dr. Brent T. Harris, Director of the PANDAS/PANS and Other Neuroimmune Disorders (POND) Brain Bank at Georgetown University University Medical Center.

Capping the weekend events is the [June 3 Inaugural Alex Manfull 5K Run in Georgetown](#). “Alex loved running along the Potomac, and we know this race would have been very meaningful to her,” Manfull says. She adds: “We are past the time when we can overlook the growing prevalence of PANS/PANDAS. Empirical research and peer-reviewed articles—from Harvard, Yale, Georgetown, Dartmouth, University of Arizona, Columbia, Stanford, and other accredited researchers and health professionals—recognize the incidence of post-infectious neuroimmune disorders and the importance of early diagnosis and treatment in determining a favorable outcome for the progression of the illness. The time to act is now.”

ABOUT THE ALEX MANFULL FUND

When Susan and William Manfull lost their only child to this disorder, they established The Alex Manfull 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 assembled specifically for leading federal PANS/PANDAS legislative efforts. Their 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 2020-23. This congressional language directs NIH to shine a spotlight on PANS/PANDAS by expanding research funding and clinical care. Contact NAPPA at info@panspandasaction.org for more information.

BACKGROUND INFORMATION ON PANS/PANDAS

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) occur after an infection, such as strep infection and other bacterial, viral, or environmental irritants. The immune system misdirects its response, attacking healthy brain tissue and setting the stage for inflammation in the brain. The symptoms can vary from child to child, but the onset is usually sudden and

dramatic. Symptoms range from profound cognitive and behavioral regressions to debilitating fatigue that can render patients unable to walk and can even lead to death. While symptoms of PANS/PANDAS mimic other illnesses, there is a distinct pattern of symptoms and lab tests that exist to facilitate diagnosis. Despite the prevalence of these disorders and their debilitating impact on a child/young adult's functioning, few doctors are trained to identify and treat PANS/PANDAS. There's grossly insufficient federal research on PANS/PANDAS and insurance companies often deny treatments as experimental.

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