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# Advocates Raise Alarm on Debilitating Post-Infectious Illness that Targets Young People

*Research on PANS/PANDAS, disorders in which the immune system attacks the brain after common infections, is extremely underfunded. Young people pay the price.*

PORTSMOUTH, NH, USA, April 9, 2024 /EINPresswire.com/ -- The Alex Manfull Fund (TAMF) and the National Alliance for PANS/PANDAS Action (NAPPA) today issued a joint call for urgent government action on underdiagnosed, underresearched, and undertreated neuroimmune brain disorders afflicting children and young adults across the US.

> There is no other disease like PANS and PANDAS. The shocking reality demands urgent action. The brains of young people cannot wait for the cogs of government and outdated thinking to catch up.”
>
> *Susan Manfull, Executive Director of The Alex Manfull Fund*

Known as PANS and PANDAS, these disorders strike after common viral and bacterial infections, such as strep throat and Covid. They occur when the immune system mistakenly attacks the brain, resulting in life-altering brain inflammation and an array of disabling physical and mental ailments. When identified and treated early, the prognosis is very good. Left untreated, PANS and PANDAS can result in progressive brain damage and lifelong disability–and can even lead to loss of life.

“It hardly seems possible that kids and young adults in this country could succumb to a severely debilitating illness that literally turns their lives upside down overnight and that few, even in the medical community, have ever heard of,” says Susan Manfull, Executive Director of The Alex Manfull Fund.

“That’s why we’re calling for an urgent increase in awareness, research, and training on PANDAS/PANS. Our goal is to ensure that no life ever again be cut short or interrupted by these infection-triggered neuroimmune disorders.”

The call-to-action sets the stage for an array of advocacy activities taking place later this week in Washington, DC. On April 12, NAPPA will join other national and state PANS/PANDAS organizations, as well as parents, patients and members of the medical community, for a Capitol Hill Advocacy Day. Advocates from over 15 states will meet with Members of Congress to share their stories and emphasize the dire need for greater awareness and research.

Amanda Peel Crowley, co-founder of NAPPA, adds: “The alarming lack of awareness surrounding these conditions is perpetuated by one thing: the gross underfunding of critically needed research. That’s why we’re requesting that PANS/PANDAS receive urgent prioritization for research funding in the 2025 Appropriations bill.”


Alex Manfull was in the prime of her life when diagnosed with PANDAS. She died shortly before beginning treatment. Her parents established The Alex Manfull Fund in her honor, with the goal of ensuring that never again would another life be cut short due to PANDAS.

Advocates will take their call-to-action to the streets of DC on April 13, where they’ll be joined by hundreds of runners and walkers taking part in the 2nd Annual Alex Manfull Fund 5K. Funds raised will contribute to cutting-edge research at top-tier academic institutions, including Georgetown University Medical Center.

“There is no other disease like PANS and PANDAS,” Manfull adds. “The shocking reality of the illness’s trajectory and impact demands urgent action at the highest levels. The brains of kids and young adults simply cannot wait for the cogs of government and outdated thinking to catch up. Nor should they have to.”

To learn more about the NAPPA Capitol Hill Advocacy Day, visit [https://thealexmanfullfund.org/advocacy-day-on-capitol-hill-2024/](https://thealexmanfullfund.org/advocacy-day-on-capitol-hill-2024/). To learn more about The Alex Manfull Fund 5K, visit [https://thealexmanfullfund.org/the-alex-manfull-fund-2024-5k-run-walk/](https://thealexmanfullfund.org/the-alex-manfull-fund-2024-5k-run-walk/)

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ABOUT THE ALEX MANFULL FUND

When Susan and William Manfull lost their only child, Alex Manfull, 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 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 to lead 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. This congressional language directs NIH to shine a spotlight on PANS/PANDAS by expanding research funding and clinical care.

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 throat 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. Symptoms vary and typically include obsessive compulsive behaviors, restrictive eating or tics. Other symptoms may include cognitive decline, learning difficulties, headache, nerve, muscle and joint pain, behavioral issues, anxiety, insomnia, loss of motor control, and urinary frequency and incontinence. For many, the onset is sudden and dramatic. Untreated, these disorders impact and compromise the quality of life of adults suffering from PANS/PANDAS. Yet few doctors are trained to identify and treat PANS/PANDAS. There's grossly insufficient federal research on the disorder, and insurance companies often deny prescribed treatments, despite the critical need for early intervention.

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