

**STATEMENT ON CHILDHOOD POST-INFECTIOUS NEUROIMMUNE DISORDERS**

**AMANDA PEEL CROWLEY  
FOUNDING MEMBER  
NATIONAL ALLIANCE FOR PANS/PANDAS ACTION (NAPPA)**

**U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION  
AND RELATED AGENCIES**

**MARCH 23, 2023**

Mr. Chairman,

It is an honor to provide testimony to the Subcommittee on behalf of children and young adults across the country who have had their lives turned upside down by Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus (PANDAS). PANS and PANDAS are Childhood Post-Infectious Neuroimmune Disorders (CPINDs). We are requesting support for report language with \$5,000,000 in program funding through the Department of Health and Human Services for PANS and PANDAS in the fiscal year 2024 Labor, Health and Human Services, Education and Related Agencies bill.

First, I would like to thank the Committee for the strong language included in past Committee reports. This has brought attention to PANS and PANDAS, helping to stimulate the award of a few research grants. However, it is now time to take decisive action to direct NIH and other federal agencies to increase funding for investigations into these conditions.

I am the parent of three children with PANDAS, a founding member of the National Alliance for PANS/PANDAS Action, or NAPPA, and co-founder of the Mending Minds Foundation. I started these organizations with other parent advocates to drive much-needed

research and awareness and, in the past five years, I have met hundreds of families impacted by these horrific illnesses.

I would like to share several devastating stories that are all too common for families affected by PANS/PANDAS.

Imagine that your happy, playful seven-year-old boy goes to bed one night and wakes up a completely different child, terrified to be alone, unable to leave his room, and exploding into uncontrollable rages. He writhes in pain on the floor, sometimes for hours, and pleads with you to “make it stop!” Normal life becomes a nightmare. Leaving the house is so traumatic that he cannot attend school or play with friends. As you desperately seek help over the next few weeks, the pediatrician refers you to mental health services and a psychiatric evaluation, but the medications prescribed for anxiety and agitation only seem to escalate his symptoms. Agonizing months pass as he cries and tells you he wants to die and attempts to jump off a third floor balcony.

Now imagine finding out the cause of this unbearable and sustained crisis. You meet with a new provider who asks if he has been checked for infection. After tests are run, you discover that these months of horrific symptoms were actually the result of strep throat. Yes, that is correct: strep throat and other common infections including flu, and now Covid-19, can lead to behavioral and neurological symptoms that leave a child unrecognizable and destroy families’ lives in the process.

NAPPA and the many families across the US impacted by PANS/PANDAS urge Congress to help. NIH must take action to further study how to identify and treat PANS and PANDAS, conditions where the immune system “goes rogue” and sets off a devastating post-

infectious inflammatory process. The time is now to help parents like us who have watched helplessly for months, sometimes years, as our children lose everything they once loved.

PANDAS, a neuropsychiatric disorder associated with streptococcus, is similar to rheumatic fever in that it can develop if strep infections are not treated quickly or adequately. The infection-fighting immune system becomes misguided, instead attacking normal cells in the body. PANS is an umbrella term for a neuropsychiatric syndrome that follows any infection, including flu, pneumonia, and Covid-19. If identified early, PANS and PANDAS are treatable with immune modulating therapies and anti-inflammatories. With the right screening and diagnostic tools, children can respond to treatment quickly.

But sadly, many children are missed. In PANS and PANDAS, mood and behavior changes are so prominent that they often overshadow debilitating physical and neurological symptoms. For these young people, ruling out a medical condition as the cause of psychiatric symptoms is especially critical. Undiagnosed and untreated kids lose months or years of learning and critical stages of development. They are especially vulnerable to chronic mental illness and disability that can follow them into adulthood. Psychiatric hospitals do not currently test for or treat medical illnesses, so children can remain in limbo without care appropriate for their condition, resulting in further deterioration. In contrast, when the underlying process is recognized and treated, they can better respond to all therapies, medical and psychological.

I have heard hundreds of tragic stories from families impacted by PANS and PANDAS, of children who experience neurological symptoms such as loss of the ability to walk and bedwetting, physical symptoms such as debilitating joint pain and gastrointestinal issues, and agonizing compulsions like pulling out every hair on their head. Some children have such an irrational fear of eating food and contamination that they become severely anorexic and have to

be placed on feeding tubes. Families often have to travel out of state to find providers, pay out of pocket for treatments, and find specialized schools for their children. The social, emotional, and financial costs for families are enormous.

There is one story that is very difficult to tell, but that lawmakers need to hear to truly comprehend the horrors of these illnesses and understand that lives are on the line.

Louisa thrived academically and socially until age 11 when her life deteriorated abruptly and severely overnight. Prior to her dramatic and horrific onset of PANDAS, she was a straight A student with much promise who aspired to become a doctor. The day that Louisa became ill was her last day at school, and she suffered terribly for two and a half years until her untimely death. Upon Louisa's initial hospitalization at a major children's hospital, her strep infection and OCD symptoms went unrecognized for weeks; until she was finally swabbed for strep after discharge by her pediatrician.

As a result, Louisa developed a severe and complex case of PANDAS. She was later hospitalized multiple times and developed other conditions triggered by her initial strep infection. She suffered from extreme mood swings and aggression. For over a year, she had terrible insomnia with an inverted sleep cycle. Her night-time waking hours were spent on obsessive and compulsive disorder rituals accompanied by intrusive fears. She sometimes did not sleep for days. Louisa's severe illness could have been treated far more easily had her original strep infection and OCD symptoms been recognized.

Her parents want young people to have access to early diagnosis and treatment. They donated Louisa's brain to Georgetown University's PANS/PANDAS and Other Neuroimmune Disorders (POND) brain bank. With the support of NAPPA, they have fought tirelessly to share

the message that educating and training the medical community, increasing vital research, and ensuring that all children are routinely screened for PANS and PANDAS will save lives.

We are at a critical point in history. We are in the midst of a staggering youth mental health crisis that has worsened since the pandemic began. Suicide is a leading cause of death in young people beginning at age ten. Children and adolescents with PANS and PANDAS are especially at risk due to their high degree of impulsivity and intrusive thoughts of self-harm. Many young people have lost their lives from PANS and PANDAS as a result of impulsive acts.

Research has shown the indisputable link between infections and neuropsychiatric symptoms in susceptible individuals. Recent major breakthroughs have transformed our understanding of the effects of infection on the body and brain by showing that a segment of people with psychiatric symptoms have an underlying infectious, immune, and/or inflammatory process. Ruling out medical conditions and identifying highly treatable illnesses such as PANS and PANDAS can change and even save lives. Across the US, dedicated scientists and clinicians are doing groundbreaking work to find biomarkers and new treatments, but they need your support.

A \$5 million commitment from Congress and NIH to dedicate funding to PANS and PANDAS will contribute to a paradigm shift in research, medicine, and mental health care. America's youth deserve the best that our healthcare system has to offer—not a lifetime of pain and symptom management. Your support will help PANS and PANDAS families achieve a dream that we know is in reach—a healthy, happy future for all.