February 5, 2020

Amy Corselius
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Delegate Alfred Carr
House Office Building, Room 222
6 Bladen Street
Annapolis, MD 21401

Dear Delegate Carr:

What were you doing at the age of 22? Finishing college? Working? Traveling? Saving money for your first new car? Perhaps you were going to grad school or making plans to get married.

On August 9th, 2019 my son turned 22. A week prior to his birthday, he asked me not to celebrate the day. Never a lover of cake, each August he would request a rhubarb pie since he could spell the word rhubarb. But not this past year. He asked that there be no pie, no special dinner, no gifts. I held back the tears as he explained that his birthday is just another reminder that he's not where he wants to be or thinks he should be in life. His dreams are small – learn to drive, get a job, have his own apartment, adopt a Pembroke Welsh Corgi. Instead, he spends his days alone in his bedroom, as neuropsychiatric and neurological symptoms dictate his brain function and his ability to engage in meaningful activities.

In 2001 at the age of 4 when my son most likely had his first onset of PANDAS, emerging research from the National Institute of Mental Health hadn't yet made it to the front line of most pediatric practices. Following a strep infection and impetigo and, 4 weeks later, a ruptured appendix and peritonitis, my son's behavior became strange, with symptoms of separation anxiety, sensitivity to touch and sound, inappropriate social behaviors and abrupt mood changes. His pediatrician and a psychologist attributed his symptoms to immaturity.

The symptoms came and went over the next few years, but following a brief illness in third grade, he became debilitated with obsessive compulsive behaviors, restrictive eating leading to weight loss, memory issues, handwriting difficulties, severe separation anxiety, school refusal, and emotional outbursts. He expressed fear of losing molecules from his body and he compulsively touched furniture and walls and retraced steps to "collect his lost molecules." He would growl at teachers and elope from the school building when he became frustrated. His confusing and concerning decline culminated in thoughts of committing suicide. He was only 9 at the time.

A psychiatrist prescribed anti-anxiety and antipsychotic medications, which only worsened his symptoms. His father and I were dumbfounded by his seemingly overnight academic, social and behavioral regression.

Following repeated elopements from the school building in 4th grade, my son was removed from the local elementary school and placed at the Kennedy Krieger School with a one-to-one aide to assist him throughout the day. As medications, psychotherapy, behavioral management, occupational therapy and supportive school programs failed to remediate his symptoms, he was eventually evaluated for immune dysfunction, as we learned that some children with similar symptoms have immune-mediated encephalitis. At the age of 13, over 9 years after the onset of his symptoms, my son was diagnosed with P.A.N.D.A.S. and Common Variable Immune Deficiency. Too sick and immune compromised to attend school, my son was placed on home and hospital instruction where he was taught at home by a teacher assigned by the school system. Isolated from peers, he remained on home and hospital instruction for 5 years through his graduation

from high school. Eventually, doctors determined that my son's symptoms were better explained by PANS, as his symptoms are exacerbated by exposure to many antigens, not just streptococcal bacteria.

In the following months, 4 board-certified doctors concurred with these diagnoses and determined that my son would require immediate treatment with antibiotics for chronic infections and immunoglobulin replacement therapy (IVIg) to address his immune dysfunction and severe and chronic symptoms. However, our health insurer's medical policy listed the treatment of PANDAS with IVIg as "not medically necessary," and a request for a prior-authorization for IVIg to address the immune deficiency resulted in repeated denials and appeals. Following a voluntary corporate appeal by me, a prior authorization for IVIg was eventually approved for the treatment of the primary immune deficiency, almost two and half years after IVIg was first recommended.

Monthly IVIg stabilized immune function and restored antibody levels, and within months my son's PANDAS symptoms also improved. Doctors were amazed by his progress, teachers reported improvements in academic and behavioral functioning and he was weaned from anti-anxiety and antipsychotic medications.

He continued to struggle with cognitive deficits including memory issues and executive function deficits, but he could focus better, his handwriting improved and he returned to a healthy weight. Residual OCD symptoms were addressed with cognitive behavioral therapy. Old symptoms flared from time to time, but flares were mild and short. I was optimistic that my son's health would be restored.

A year and half later, my optimism was replaced with fear when severe symptoms returned. Anxiety and OCD symptoms raged full-force, along with aggression, cognitive decline, insomnia and anorexia, resulting in a 40 lb. weight-loss. At 6'3" he weighed 114 lbs. He developed autonomic dysfunction, with symptoms of tachycardia, dizziness and fatigue. His doctor recommended a tonsillectomy and adenoidectomy, as he was still testing positive for strep despite aggressive treatment with antibiotics, and he had to be fed intravenously through a central catheter in his chest to avoid more weight loss. Anorexia resulted in loss of muscle mass, requiring physical therapy for almost a year. Medications were adjusted and the symptoms eventually became less severe.

Once he graduated from high school, my son attended a community college part-time, volunteered at a local nature-center, and, for the first time in many years, he had a friend. He learned to play the accordion and got his learner's permit. In 2017, with his symptoms seemingly well-managed, he moved to an academically and socially supportive college in Vermont, with hopes of earning a degree in fish and wildlife studies. But a few months later, following exposure to the flu, old symptoms of anxiety, OCD, and suicidal ideation returned. He had to withdraw from college and return home. In the months following, he again developed anorexia with dramatic weight loss, requiring IV nutrition. Autonomic dysfunction, panic attacks, insomnia, a phobia of leaving the house, OCD symptoms and cognitive decline, resulted in days spent lying in bed, pale and fatigued.

Following an evaluation last fall by an expert in the field of neuro-immunology, we were told that my son will most likely continue to experience flares in his symptoms indefinitely due to his delayed diagnosis and treatment. He asserted that the goal of treatment at this point is to prevent the progression of disease, offering no hope of a full remission. My son has also been diagnosed with bone marrow failure, which doctors attribute to the progression of autoimmune disease. His psychiatric symptoms are now managed with anti-anxiety drugs, his cognitive deficits are being addressed with a drug used for dementia. His symptoms of tachycardia and dizziness are managed with daily intravenous medications, administered through a central catheter in his chest. He continues to receive IVIg to manage his immune deficiency, IV antibiotics to address infections, and other helpful therapies not covered by our health insurance.

He spends his days at home, too physically and mentally debilitated to do much outside of medical appointments and physical therapy. His medical care is multidisciplinary, involving hematology, neurology, neuroimmunology, psychiatry, psychology, physical therapy and dietetics. To support him as a disabled adult unable to live independently or be

employed, he receives social security income and disability support services, costing the state and federal government more than $50,000 annually.

Anecdotal evidence suggests that early diagnosis and aggressive treatment of PANDAS/PANS is necessary for best outcomes. If my son had received aggressive treatment with IVIg earlier in the disease process, it is likely that he would have had a better outcome. Instead, he is permanently debilitated with no hope of a full recovery.

Not only is my son suffering, but the impact to our family has been great in terms of emotional trauma, loss of our home in 2014 because of large medical bills, and an uncertain financial future as we continue to pay for out-of-network physicians, large copays for costly medical treatments, and helpful therapies not covered by our insurance. As his main caregiver, I am unable to work, as my son requires support throughout his day.

I am providing this testimony not for my son, as he is beyond the point of benefitting from mandated insurance coverage for the treatment of PANDAS/PANS. Instead, I am boring you with details of his unfortunate case, on behalf of those children who are currently suffering as they wait for their health insurers to approve treatments that could restore their health and quality of life. I urge you to stop the discussion and start mandating the insurance coverage in Maryland for PANDAS/PANS, so that children with this devastating disease can get the help they need to move on with their lives.

Thank you in advance for taking the time from your busy schedule to read this. Please let me know if I can provide more information if you determine this would be helpful.

Sincerely,

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