

April 21, 2023

Re: PANS/PANDAS Family Experience Statement

To Whom It May Concern:

I am a 37 year old queer white woman with an advanced degree, and I have two young children who have Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)/Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)/Autoimmune Encephalitis (AE). This disease has turned my family and my life upside down, and repeated unlawful insurance denials for treatment have simply added to an already strained existence.

It has taken me an inexplicable amount of energy to manage and address insurance denials from multiple insurance companies in relation to PANS/PANDAS/AE... the emotional impact of these denials cannot be overstated. Repeatedly, we've been issued denial letters that include justification that is not only incorrect, but blatantly misleading, from Blue Shield's insistence that they can't authorize Rituximab because it's not approved by the FDA for the treatment of Autoimmune Encephalitis (which is not required in California), to Kaiser's refusal to approve Intravenous Immunglobulin because it is 'experimental' for the management of AE (in spite of a plethora of research backing its use). Imagine the number of providers and families who receive these denials and don't know how to navigate external appeal processes? Imagine how many patients don't get the care they need because the insurance companies issue misleading denial letters to families like mine, letters that make it seem like it's 'game over' even though it's not?

I have spent my entire career doing Utilization Review (UR) in both medical and behavioral healthcare; I am a national trainer on the topic, and have even presented for the PANS Physician Network about UR processes and denial relating to PANS/PANDAS treatments. With each denial that has rolled in for my own family, I have taken a deep-dive into the PANS treatment research, and spent literally hundreds of hours preparing both internal and external appeals... hours I don't have, particularly when our lives are overrun with doctor appointments and treatments. Hours of additional missed work, hours of lost time that could be used so much more meaningfully. The emotional impact of a child's PANS/PANDAS diagnosis on parents and families is well-documented, and the added stress of having to fight tooth-and-nail at every turn

with multiple insurance companies has created the most stressful years of my life.

It has occurred to me on many occasions that it should not take an advanced degree and years of direct insurance advocacy experience in order for PANS/PANDAS/AE patients to receive research-backed medical treatment for their conditions... the system is inherently stacked against PANS/PANDAS/AE providers and families, and these flaws only magnify existing inequities within society. My own children are mixed-race, and I know all too well the realities marginalized people of all types face in the medical system. I have experienced direct sexism myself as I've advocated for my own children. As I navigate this hellish system, I keep thinking to myself, "And ***I'm*** having trouble with this... someone who has nearly every advantage possible to secure this care for my child, and I'm failing. Imagine what it's like for those of lower socioeconomic status, for those without the formal education opportunities I have been afforded, for those who have more 'marginalized identity cards' in their wallets than we do?"

We PANS/PANDAS/AE families are grateful for all the support we can get... we're exhausted, heartbroken, and constantly teetering on the edge of hopelessness. I beg of you, please put an end to these additional trials by supporting legislation that will make it more difficult for insurers to deny care for PANS/PANDAS/AE patients.

Thank you for your time and consideration.

Sincerely,

Elizabeth 'Beth' Irias