

My name is [REDACTED], and my son [REDACTED] is 10 years old. He has suffered from PANDAS (Autoimmune encephalitis) for many years. He takes many medications/supplements daily, including two full strength antibiotics. He also takes anti-psychotics and other psych drugs to manage symptoms. He is often too sick to attend school, and goes partial days when he is able. He suffers from terrible OCD, anxiety, eating issues, immune system deficiency, and psychiatric symptoms. We began IVIG infusions in the fall of 2017, and are currently going for monthly infusions. We were denied insurance coverage for these necessary infusions. We paid a medical advocate to fight the insurance company for us and she was able to obtain PARTIAL coverage. We still pay thousands every month because they help him. Additionally, there are NO pediatric neurologists that specialize in PANDAS that accept insurance. So we have to pay out of pocket for each appointment, as well as for the treatments.

Although IVIG is helping [REDACTED], he continues to suffer greatly and we need to pursue additional treatments. The recommended treatment is Rituximab infusions which cost \$32,000 and up per infusion. We are already deep in debt from paying out of pocket for the IVIG and other necessary treatments. The disease (and insurance company's refusal to accept/pay) has ruined us financially. I am currently battling the insurance company to cover the rituximab expense, since there is no way for us to pay for it otherwise.

These children suffer greatly and often do not get the care they need. One of the main reasons is that the insurance companies won't recognize the disease and/or treatments are considered experimental despite being well documented to help--and are the current standard of care.

These children and families are not only suffering with the disease, but are often costing the insurance companies even more money by delaying appropriate care. Many end up hospitalized and in long term facilities. They become a drain on society because they are never properly treated, so they never heal. If we can get the insurance companies and Medicare to provide appropriate and quick care, these children have a much better chance of healing and becoming productive members of society. It will also save money in the long run.

Please push for HB15 - we need IVIG, Rituximab, and other necessary drugs covered to help.

Please do what you can.

In addition, please realize that because Pandas is not properly recognized, these children and families get NO help or support. No SSI, no free programming, no respite care, no financial assistance for medical bills, NOTHING. We are completely on our own to come up with large sums of money for treatments, while caring for 24/7 for these sick children . We need help. We need this to be recognized so we can get the help these kids need including medical coverage and services.

We have Carefirst BCBS BluePreferred PPO Silver

Member ID- [REDACTED] Group 99EE [REDACTED]

Thank you so much for your consideration and assistance. I would be happy to speak with you further.

[REDACTED]

[REDACTED]

[REDACTED]