

## Our Battle to get Insurance to pay for my son's IVIG to treat his PANDAS

by [REDACTED]

Obstacles to insurance paying for PANDAS:

1. There is no billing code for PANDAS/PANS.
2. Cannot find an in-network provider to treat my child for PANDAS so I was forced to go out of network and pay high fees.
3. Under my policy, the list of "diagnoses for which IVIG is considered medically necessary" does not include "PANDAS" (and there is no code for it anyway).
4. You can try to get IVIG covered by getting a diagnosis which IS on the list (like CVID), but then you must have labs with numbers that prove you qualify for that diagnosis, but PANDAS is a clinical diagnosis that does not require a lab test result.
5. CareFirst gave us (me and the staff at the pediatric neurologist's office at Sinai Hospital in Baltimore) confusing and conflicting instructions as to HOW to apply for pre-approval of IVIG. First, we were told to seek pre-approval of IVIG under medical policy. Then we were told that was not correct and we must seek pre-approval of IVIG through Caremark which is my prescription policy. Then we were told, no we should seek pre-approval through CareFirst Blue Choice under my medical Policy. Neither CareFirst Blue Choice nor CareMark has approved the IVIG prescribed for my son by 2 different PANDAS experts. My son has been sick for almost 7 years now and suffers daily.

I tried to find an in-network provider to evaluate my son to see if he truly did have PANDAS. I did not know who to go see, so I called insurance and they said they do not have access to a list of doctors in their network who are experts in the treatment of PANDAS. I was told that I needed to find a specialty field and they could give me names of doctors in that field. It would then fall to me to call each one, ask if they treated PANDAS, and ask if they were accepting new patients. I could not find anyone in-network who would treat PANDAS. Many offices did not know what PANDAS was and had to ask the doctors if they treated PANDAS and call me back. I called and emailed with Children's National Medical Center in DC and the email response I got from them said that Children's does not treat PANDAS and that I should contact Dr. Susan Swedo at NIMH.

My son, [REDACTED], is now 8 and a half years old. He regressed beginning around age 20 months. His pediatrician and the neurodevelopmental pediatrician at Kennedy Krieger Institute diagnosed him with autism. I knew he was very sick, and so I continued to seek doctors who were willing to look past the diagnosis of ASD to seek the underlying cause of these intense and scary psychiatric symptoms. I suspected PANDAS, Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep, but I wasn't sure. Using the PPN (PANDAS Physician Network), I found Dr. Elizabeth Latimer, a neurologist with a private practice located in Georgetown. She was out of network, so I was stuck paying out of pocket for the intake appointment (\$1,200). She did diagnose [REDACTED] with PANDAS and prescribed IVIG for him (6/27/2017).

I called my insurance and they said they would not cover the cost of the IVIG because Dr. Latimer was out of network. I was told I could pay out of pocket then submit a bill and hope for reimbursement, which may only be a partial reimbursement or nothing. [REDACTED] received a 5-hour infusion of IVIG on August 22<sup>nd</sup> and a second IVIG infusion on August 23<sup>rd</sup>, 2017. Gammunex-C was the specific name of the IVIG he received. His most notable gain was that for the first time in his life he eliminated his bowels on the toilet like a typical healthy child. For two days he regained all toileting skills, then he unfortunately

lost that skill. (I am still changing my 8 and a half year old son's dirty diapers.) The good news is that we know this medicine works for my son. He had significant gains across the board that continued to emerge throughout the entire school year, especially in the areas of language and social skills. The heart break was that he needs more, and insurance refuses to pay for this necessary medicine. I submitted the bill for IVIG to my insurance and they refused to reimburse any amount of the roughly \$9,800 bill on the grounds that the doctor was out of network.

After we paid for [REDACTED]'s IVIG out of pocket, I tried again to find an in-network provider in hopes that the doctor would know how to get IVIG covered for my son. My son's nurse case manager tried to help me, told me that Children's has a PANDAS Clinic, gave me a name and number to call. I told her that I didn't believe so, but I called in hopes that things had changed. The PANDAS Clinic at Children's Hospital in DC offers palliative care to children who are dying. It is hospice. They do not treat children who suffer from PANDAS.

I finally found Dr. Yuval Shafrir, pediatric neurologist at Sinai Hospital of Baltimore. After a detailed review of [REDACTED]'s medical records and taking a thorough medical history of my son, Dr. Shafrir agreed with the Diagnosis of PANDAS and prescribed IVIG for [REDACTED]. We began seeking pre-approval of Gammunex-C (IVIG).

***We received a printed "Notice of Adverse Determination" from CVS Caremark dated 9/21/2018.***

***Plan Member name:*** [REDACTED]

***Plan Member ID:*** [REDACTED]

***Plan Name: Montgomery County Public Schools***

***Prescriber Name: Dr. Yuval Shafrir ,etc.***

***... "We needed additional clinical information from your prescriber in order to make a decision to either approve or deny the request. We did not receive additional clinical information in the time allowed... therefore the request was denied because:***

***Standard IVIG Policy does not allow coverage of Gammunex-C if there is missing clinical information including but not limited to: A copy of the laboratory report with a recent immunoglobulin G trough level."***

[PANDAS is a clinical diagnosis which does not require any labs to support the diagnosis. Insurance wanted my son's immunoglobulin G trough level to see if he qualified for IVIG under a different diagnosis already on the list of conditions for which IVIG is covered.](#)

Dr. Shafrir appealed the decision.

***On 9/30/18, we received a "Second Level Appeal-Notice of Final Adverse Determination"***

***The reasons for your denial of your appeal was:***

***Your appeal for Gammunex-C for autoimmune encephalitis has been determined as not medically necessary. Per physician review, current standard intravenous immune Globulin plan criteria and current medical literature do not support the use of Gammunex-C in this case. Intravenous immune globulin is prescribed for an autoimmune encephalitis; however, additional clinical information***

*regarding diagnosis is lacking. Supporting clinical information includes mycoplasma antibody levels and a 24-hour electroencephalogram report, which is normal. Additional clinical information is needed to support the use of intravenous immune globulin for treatment of autoimmune encephalitis. As such, intravenous immune globulin is not medically necessary for the patient at this time. The diagnosis is too general, and supporting literature is not available. Your request was reviewed by an MD Board Certified in Neurology. 09/29/2018*

**PA# Montgomery County Public Schools** [REDACTED]

**Plan Approved Criteria: IVIG SGM**

**Service date: 9/30/2018**

**ICD diagnosis code: G04.81**

**Associated Diagnosis: Other encephalitis and encephalomyelitis**

Dr. Shafir even had a peer to peer phone call with someone at my insurance to try to get the IVIG approved. It was denied again.

Under Dr. Shafir, my son has received antibiotics, oral steroids, and a 24-hour EEG, all of which were covered by our insurance.

My son had his tonsils and adenoids taken out by Dr. Earle Harley at Georgetown University Hospital. Dr. Harley is in-network for us. That was covered by our insurance.

[REDACTED] was on two antibiotics for 15 consecutive months. He swabbed positive for strep while actively taking 2 antibiotics. His immune system is definitely not functioning properly. I knew he was sick because of his increased aggression (biting me, kicking holes in the walls, throwing objects at family members, etc.). He does not get fevers, sore throats, or a cough when he has strep. When sick with strep, [REDACTED] will sometimes have a fine sandpaper rash, or no physical symptoms of illness other than increased aggression and a worsening of his sleep disturbances. He continues to have a sickly pallor and to struggle with intense OCD and crippling anxiety. He has significant sleep disturbances, struggling to fall asleep and or waking for several hours in the middle of the night.

Thank you for trying to help us access this life-changing and very healing medicine for our son. Recovery is possible, with the proper treatment and medications like IVIG, Rituximab and Plasmapheresis. I pray that it is not too late for my son; he has suffered too long already. The consequences of not healing our children when they are young is dire. Children will be sentenced to a lifetime of suffering debilitating psychiatric symptoms unnecessarily. Our children deserve better.

Sincerely,

[REDACTED]

[REDACTED] mom, PANDAS Advocate, Teacher of Students Who are Deaf and Hard of Hearing

[REDACTED]