

Letter to the Editor Journal of Pediatrics,

SAMPLE #1

I am a parent of a boy who at age 8 was diagnosed with PANDAS after an associated streptococcus infection. He received immunomodulating treatment and is doing very well.

When he was 4 years old he had a severe whole body tics. I only wish someone would have told me to get him checked for infection. I had no idea. And neither did his doctors. And THIS should be first line treatment.

From a parent's point of view: They have a child that comes in with sudden onset behavioral or neurologic change. They don't know what to do. Doctors won't know what to do. Based on this paper, it is unclear what they should do. The only thing that is clear is that they should be prescribed psych drugs and CBT. The first paragraph they state that psychiatric drugs will prevent "worsening or permanent sequelae" -- but I am not certain how this would be possible?

This paper will further delay appropriate care. From an ethical standpoint, this is just wrong. There is no one advocating for these children - and sometimes advocating could be as simple as doing a strep culture.

These children will once again be given inadequate and often inappropriate care that will serve to delay and worsen the situation. These families will be forced to seek outside care, often travel long distances and to spend enormous amount of pocket expenses (IF they have the means).

Doctors need to understand that there are simple things they can and should do. These children and families, as people, are really suffering and are in desperate need of care. This paper does not do us justice, and as a resourceful parent who has gone through hell to help their child, it is maddening.

Maytali Novak from New York

OR IT CAN BE SIMPLY THIS!

Letter to the Editor Journal of Pediatrics

SAMPLE #2

I have two children who developed PANDAS both at age 7. A simple swab for my first child showed active strep and a round of antibiotics improved him. He went on to get more strep infections and got worse and worse with life-threatening levels of OCD and neurological symptoms. He suffered for 3 years. Finally, immunomodulating treatment, IVIG, was given and it saved his life together with ongoing antibiotics while he healed.

My second child, several years later, developed PANS (or PANDAS) after playing with a friend that had mycoplasma. She was 7 years old as was my first child. She never developed strep titers and the swab was not done properly. We had a pediatrician willing to give a round of antibiotics which clearly lessened symptoms. She had become anorexic and developed extreme fears that all lessened over a two-week period of antibiotics. We never had to do IVIG and she remains healthy today.

Had it not been for the diagnosis and treatment using PANDAS-PANS guidelines I may not have either one of my children healthy today and the devastation to our family --- I cannot imagine. Have Compassion. Listen to our Stories.

Marie Miller, California