

PANDAS, PANS, PITANDS are all a variation on names for the same disease. It was originally described by Dr Swedo from the National Institute of Health in 1998. This disease was described over 2 decades ago and the treatment still hits a roadblock with insurance companies. The American Academy of Pediatrics has recognized the disease and the NIH is planning on further studies for the treatment of PANDAS. Up until this year there was no code for this disease, however that has changed as of October 1, 2020 with the code D89.89 now not only reflecting disorders involving the immune mechanism, but also reflecting the disease PANDAS.

This disease affects the most important part of the future of our society-the children. The portion of our population that has no say in the laws that are written or the policies that we as adults institute. And why is that?-They have no money and no voting rights. We the adults should and need to look out for the best interests of one of the most important parts and clearly the future of our society.

What needs to be understood is that generally the longer an illness persists the more difficult it becomes to treat. The longer the delay in treatment the more this negatively influences the final outcome. Pre-authorizations and appeals can take up to 6-12 months while the child and everybody in the family are trying to cope. Even when a pre-authorization is obtained either directly or through the lengthy appeals process the insurance companies still delay or deny the payments. Insurance companies clearly state in their preauthorization approvals "that this is not a guarantee of payment." The parents and family are then left with a significant financial obligation.

By the way, this disease does not just affect the child with the disease but everybody in the child's sphere-parents, siblings, relatives, teachers, friends and on and on. Classrooms are disrupted, families are disrupted, emergency rooms are disrupted and many times even the police are called upon to help.

I do not have statistics but from my own experience-insurance companies are happy to pay for emergency room visits and psychiatric hospitalizations because that is written in the policies as covered expenses. How much would they actually save if they paid for the treatments that actually cured these kids-negating the emergency room and psychiatric hospitalizations.

How much would be saved on the 504 plans and IEP's that the schools would not have to institute and pay for.

You know, I remember when the chicken pox vaccine was first marketed. It was not marketed as saving lives but saving billions of dollars in lost revenue from parents not having to miss work caring for their sick and contagious children. I could make the same argument here-look at all the revenues that are being spent because we are not curing the child because it is not a covered expense per the insurance companies policies and contracts. Consider the nonmedical financial costs of these patients with PANDAS such as the many days of missed work by the parents, the psychological cost on the family the enormous use of the family and medical leave act to mention just a few of the consequences.

The first patient I ever treated with this disease was more than 13 years ago. He is now a productive member of our society. He is in the process of going to medical school. And how did this come about. He was one of the lucky ones. His parents could afford to pay for the treatments and the medical care even when the insurance denied either pre-authorizations or payments. It should not be just the wealthy who get the treatments they need.

Recently I treated another patient. He was 11 years old when he came to me. He had been seen by a very renowned institution. He was a normal child by all standards. He essentially woke up one day different. Different to the point that he was admitted at this large famous institution and had a workup that would make any hospital system proud. He had multiple scans and scopes from both ends. He was seen by over 7 pediatric specialists and no treatment plan seemed to make a dent in his symptoms. I can assure you that his hospital admission alone was much more costly than the one IVIG treatment that this child had. One treatment and 3 years later this child is still a happy, thriving, normal teenager.

In the end it should not be about the money but about the children. Helping these children to become productive members of our society. Allowing these children to get back to their baseline. Not taking away the chance for these children to be happy and productive.

Even the United States Declaration of Independence states and I quote "We hold these truths to be sacred & undeniable; that all men are created

equal & independent, that from that equal creation they derive rights inherent & inalienable, among which are the preservation of life, & liberty, & the pursuit of happiness." " When we deny treatments to allow a child or adult to obtain the preservation of life and the ability to live their life to their greatest potential we are denying the inalienable right that our forefathers believed in.