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Chairman Huffman, Vice Chair Antani, Ranking Member Antonio and members of the Health Committee:

First let me thank you for taking the time to read this letter.

PANDAS, PANS, PITANDS, these are all a variation on names, for the same disease. It was originally described by Dr. Swedo from the National Institutes of Health in 1998. Despite being recognized over 20 years ago, 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 recently there was no code for this disease, however that has changed as of October 1, 2020 with the new ICD-10 revisions; the code D89.89 now not only reflects disorders involving the immune mechanism, but also describes the disease PANDAS.

PANDAS 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. Insurance companies clearly state in their preauthorization approvals "that this is not a guarantee of payment."

Insurance companies including Medicaid make it very difficult to approve a preauthorization for treatments of PANDAS. Even if they preauthorize a treatment, Medical Mutual in particular, may take almost one year to pay the claim. They leave the family with a cloud over their heads worrying about the tens of thousands of dollars of bills left unpaid by their insurance. I also believe Medical Mutual terminated my contract after almost 40 years because now they will have no one in the state of Ohio to request IVIG for these children.

PANDAS 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 and EMS 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.

I remember when the chicken pox vaccine was first marketed more than 25 years ago. It was not marketed as saving lives, but saving billions of dollars in lost revenue. 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, just to mention a few of the consequences.

The first patient I ever treated with PANDAS was more than 15 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 at a very renowned institution. He was a normal child by all standards, until one day, when he essentially woke up very 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, numerous lab tests, 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 received. One treatment and this child was cured. Five years later, this child still remains a happy, thriving, and now 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 self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and 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 unalienable right that our forefathers believed in.

Please feel free to reach out to me if there is any further information or expert medical opinion that I could provide.

Sincerely,  
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