



PANDAS NETWORK
ADVOCACY, SUPPORT & RESEARCH FOR PANDAS, PANS, AE



**NEW ENGLAND
PANS/PANDAS
ASSOCIATION**



FINDING ANSWERS FOR CHILDREN WITH NEUROIMMUNE DISORDERS



**Northwestern
PANDAS/PANS
Network**

Southeastern PANS/PANDAS Association

840 Essie Ave SE
Atlanta, GA 30316

May 9, 2018

Stephen Burke

Chief Executive Officer, NBCUniversal

Pam Golum

Executive VP, Lippin Group

Michael Brandt & Derek Haas

*Producers, Chicago Med
Brandt & Haas*

Gary Mednick

Director, NBC Entertainment Publicity

Jeff Drayer

Writer, Chicago Med

Oren Gottfried, M.D.

Medical Advisor

**Dear Mr. Burke, Mr. Brandt, Mr. Haas, Mr. Drayer,
Dr. Gottfried, Mr. Mednick and Ms. Golum:**

As leaders of a coalition of U.S. nonprofit organizations, we share a common mission of raising awareness about post-infectious autoimmune encephalopathies such as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Disorder (PANS). Additionally, we work to increase access to treatment through provider education and expanded insurance coverage, as well as supporting research into the cutting-edge field of neuroimmunology.

The longest standing group among us is PANDAS Network, a national non-profit with 501(c)3 status, which the National Institute of Mental Health (NIMH) has designated a national partner. In this role, PANDAS Network helps disseminate information about PANDAS to diverse populations and, important to the circumstances which led to this letter, “helps to assure that science-based information about mental illness and mental health have broad reach throughout states and local communities.”¹

Chicago Med: The Parent Trap

Hundreds – if not thousands – of families have written to or contacted you via social media in response to the episode (S3017 “The Parent Trap”) of *Chicago Med* written by Jeff Drayer and aired on April 26, 2018. In addition, a Change.org petition responding to the episode has collected nearly 6,000 signatures and is attached [here](#).²

The episode depicted and poorly characterized a PANDAS case. The storyline cast parents as histrionic and fabricators of truth. For the thousands of families who have been affected by these disorders, this story was a damaging affront that perpetuates the myth that mental illness is a character weakness. Parents who saw the episode were horrified, especially those who watched with their older children who have PANS/PANDAS or have siblings with PANS/PANDAS.

In addition to insulting a segment of your viewers, this episode was a disservice to the public. We understand this is a dramatic television series, but in this case, your writers missed a key opportunity to reflect current science regarding this disorder and to educate your millions of viewers about a disorder that – if it has not already – WILL touch their families or their communities.

1. <https://www.nimh.nih.gov/outreach/partnership-program/national-partners.shtml>

2. <https://www.change.org/p/pam-golum-demand-nbc-s-chicago-med-issue-formal-apology-to-pandas-pans-kids-parents-and-providers>

Background on PANDAS

PANDAS/PANS and related autoimmune encephalitides (AE) are infection-triggered brain diseases that affect hundreds of thousands of children in the U.S., with an average acute onset age between ages 4 and 7.

PANDAS-PANS Symptom Criteria are the following:

1. Sudden and acute onset of OCD or severe restrictive eating; and
2. Two or more of the following symptom criteria:
 - Anxiety
 - Developmental regression
 - Deterioration in school performance
 - Emotional lability and/or depression
 - Oppositional behaviors
 - Sensory/motor abnormalities
 - Sleep disturbances
 - Enuresis

Based on the CDC's 2013 Mental Health Surveillance Report ³, we estimate the incidence of this illness is at least 1 in 200 children in any given year.

Without early recognition and treatment, children face dire and potentially life-long consequences. In fact, some children die from these disorders, as they can lead to suicide and starvation related to avoidant-restrictive food intake disorder.

In addition to the children who suffer from this disorder – the majority of whom go undiagnosed and untreated – these disorders negatively impact the entire family unit, leading to trauma for parents⁴ and siblings alike. The lack of knowledgeable providers and insurance coverage for care means these disorders can derail careers and bankrupt families.

Appropriate PANS/PANDAS treatment depends on the severity of the illness, but it is always a triad of three interventions: ⁵ (1) antimicrobial therapies to treat the inciting infection (e.g., antibiotics and/or antivirals); (2) immune-modulating therapies, which can range from something as simple as ibuprofen to aggressive immunomodulation like intravenous immunoglobulin (IVIG), plasmapheresis, and cancer treatment medications like Rituximab; and (3) psychological supports (e.g., Cognitive-Behavioral Therapy) and/or psychiatric medications.

State of the Science

Because PANS/PANDAS can have severe mental and neurologic consequences if left untreated, we hope you will consider learning more about this illness and sharing appropriate, up-to-date information with your viewers. Many children have overcome the illness with proper treatment, and the outcome and prognosis is an exciting story unto itself. Many children affected early in life are now going on to universities and a life free of physical or mental illness.

A great deal of exhaustive research on PANS/ PANDAS has been done, and continues to be done by a consortium of researchers in the U.S. from universities including Stanford, Harvard, Columbia, Georgetown, and the University of Arizona, amongst others. These researchers have focused on the characterization of this illness and development of treatment methodologies.

In March 2018, PANDAS Network, with the support of the other regional and national nonprofits who have co-signed this letter, hosted a groundbreaking conference at Columbia University featuring the work of leading researchers and clinicians from around the world. ⁶ More than 800 people, including a production crew from ABC's Nightline and 20/20 news programs, attended this two-day event. Nightline and 20/20 will feature their stories about these disorders this month.

Requested Actions from Chicago Med and NBC

We are certain that NBC and Chicago Med are interested in providing viewers scientifically sound information. We also know that there is ample drama in an accurate depiction of what children and families affected by this disorder face as they attempt to access treatment in emergency departments and hospitals around the country. The 2017 documentary, "My Kid is Not Crazy," produced by Emmy award winner Tim Sorel, followed the stories of six families impacted by these disorders. You can view an extended clip [here](#). ⁷

3. <https://www.cdc.gov/mmwr/preview/mmwrhtml/su6202a1.htm>

4. <https://www.ncbi.nlm.nih.gov/pubmed/29547961>

5. <https://www.pandasppn.org/jcap2017/>

6. Slides from the conference are available online at <http://www.pandasnetwork.org/common-threads-conference-2018/>

7. <https://vimeo.com/235642253/13123cc5e4>

We can connect you with families who can offer both the horrors of the illness and barriers to appropriate care AND the incredible, hopeful stories of healing that happen when children DO get the medical care they deserve. We are happy to provide you with any resource you might require to remedy this issue, including a team of our consortium professionals who can testify not only to the impact of this illness but also to the wonderful positive effects of timely, accurate diagnosis and proper treatment.

Please consider a written apology to our community and an assurance that you will learn about PANS/PANDAS and its consequences. An acknowledgement of the misrepresentation of these disorders would not only be meaningful to parents and children, but would also be beneficial to the NBC brand. We also respectfully request that this episode be taken out of reruns, so this damage to our community can be avoided in the future. At the very least, we suggest you include an educational message at the end of the episode that directs viewers to appropriate resources such as the National Institute of Mental Health for more information.

Sincerely,



Diana Pohlman, *Executive Director*
PANDAS Network
diana@pandasnetwork.org



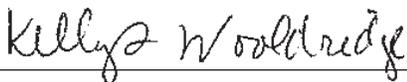
Wendy Nawara, *President & Executive Director*
PANDAS/PANS Advocacy and Support
wendy@pas.care



Gabriella True, *Executive Director*
New England PANS/PANDAS Association
gaztrue@yahoo.com



Jessica Gowen, *President*
Southeastern PANS/PANDAS Association
jessica@sepans.org



Kelly Wooldrige, *Co-President*
Midwest PANDAS/PANS Parent Association
kelly.woolridge@mercy.net



Lisa Hardy, *President & Executive Director*
Children's Autoimmune Brain Disorder Association
lisa.hardy@cabdatexas.org



Jessica Gavin, *Executive Director*
Pediatric Research and Advocacy Initiative
jessica.gavin@praikids



Sarah Lemley
Northwestern PANDAS/PANS Network
sarahsignelemley@gmail.com



PANDAS NETWORK
ADVOCACY, SUPPORT & RESEARCH FOR PANDAS, PANS, AE



FINDING ANSWERS FOR CHILDREN WITH NEUROIMMUNE DISORDERS



**NEW ENGLAND
PANS/PANDAS
ASSOCIATION**



**Northwestern
PANDAS/PANS Network**