

PANDAS Community- Raise Awareness this Oct. 9

Submit a letter to the editor or op-ed piece to your local newspaper/ media outlet!

Feel inspired to share your experience with PANDAS or PANS? Interested in raising awareness so other families don't have the same stress in the future that many of us have faced?

Take a few minutes of your time to draft a letter or opinion column and send to your local media outlet or paper. This is a great way to share your own experience and spread information to others that they can easily share as well!

The following tips may help you organize your letter. You can also use the talking points below. Try to keep your letter around 200 words (600-700 for an op-ed), and be direct and straightforward. Our goal is to have as many letters as possible around the nation running on or near Oct. 9—so try to get a letter in to your local paper by Oct. 4-5.

Tips

1. Check out the requirements from your local paper before you begin. Google the name of the paper and "letter to the editor" or "op-ed" to read the guidelines.
2. Several tips are available at <https://www.theopedproject.org/oped-basics> to help you get started. The structure suggested is
 - Lede: Start the letter with something that will grab the readers' attention- This could be a statement or two about your own story and the overnight changes, information on children with PANS as a whole, or even a description of some of the cases in My Kid is Not Crazy.
 - Thesis – State your argument or main point. Ex: Children with sudden onset mental illness should be evaluated for infection – or – We need more health care providers to be aware of PANDAS – or – whatever you want your theme to be.
 - Argument – Base this on evidence. You can site credible sources such as those listed below.
 - Circle back to the lede – end strong with your theme restated and tied to the opening lede.

Talking points to consider

(feel free to share your own story/ experience here as personal stories often make a big impact):

- PANDAS and PANS are real and challenging disorders that have been studied by the medical community in numerous peer-reviewed studies. In PANDAS and PANS, an autoimmune reaction, triggered by strep or another illness or factor, causes inflammation of the brain and leads to neurological and psychiatric difficulties.
- Timely diagnosis and treatment is critical for children with PANDAS and PANS
- Families dealing with PANDAS/PANS often struggle with paying for care (insurance may not cover diagnosis or treatment, particularly immunotherapy) (This is a great place to share your experience with treatment or insurance—especially if your state is one of the ones where insurance bills are pending.
- Families often experience significant emotional stress in caring for a child with PANDAS or PANS.
- Families and children desperately need more awareness, more treatment options, more support in the mental health system, better options for school. Research is moving ahead but not fast enough—too many of our children remain at risk, so there is a desperate need for more research!
- There are hundreds of evidence-based articles researching PANDAS and PANS.
- Information is available on several very credible web sites including. Pandas Physicians Network <https://www.pandasppn.org>; Pandas Network <http://www.pandasnetwork.org>; National Institute of Health (<https://www.nimh.nih.gov/labs-at-nimh/research-areas/clinics-and-labs/pdnb/web.shtml>); the International Obsessive Compulsive Foundation <https://www.nimh.nih.gov/labs-at-nimh/research-areas/clinics-and-labs/pdnb/web.shtml> ; and the American Psychiatric Association <https://www.psychiatry.org/news-room/apa-blogs/apa-blog/2017/09/what-are-pans-pandas>).