

NEW ENGLAND PANS/PANDAS ASSOCIATION

PANS/PANDAS Stories – Every Family Has A Story

www.nepans.org

Hello NEPANS Friends!

We want you to be involved in the NEPANS' project, PANS/PANDAS Stories ... Every Family Has a Story. We aim to continually add to this collection of PANS/PANDAS Stories. Many of our personal stories are different but we are all united in our struggles, triumphs and search for answers for our children. No one can tell the stories of what it is like to live with PANS/PANDAS like those that have experienced it. The list of symptoms and descriptions of various treatment protocols does not bring the condition to life. The family telling their individual story is what illuminates the day-to-day struggles and triumphs our children and families experience. For families living with PANS/PANDAS, the aim of sharing these stories is to help you not feel so alone in your struggles, to let you know there is a family out there just like you, and ultimately to let you know that there is hope. For those who are just beginning to learn about this autoimmune disease, we hope the stories will help them to understand PANS PANDAS with greater depth. These stories will bring to life the wide range of experiences families encounter.

Below are some guidelines and additional information:

1. Length: 500-1500 Words
2. Photographs: You may include a family photograph or a photograph of your child. Or you may include photographs that are relevant to your story like before and after drawings/handwriting samples.
3. Last names will not be included. First names will be kept private also if you wish to remain anonymous.
4. Content:
 - a. The story should focus on specific details and not include every detail of your family's experience.
 - b. Include most pressing issues (3 to 5 symptoms, varying triggers) and most effective treatments. Relevant data from labs can be included.
 - c. Was diagnosis difficult and why? Was finding the right doctor/s difficult?
 - d. Examples of before, during, and hopefully after PANS/PANDAS.
 - e. Examples of hope and recovery.
 - f. Doctor's names will not be published so please write what kind of doctor you saw i.e. Neurologist, Immunologist, Integrative, CBT Therapist, etc.
 - g. Please remember: This is not a platform to bash or praise a specific doctor/institution. This is also not a venue to purport that the treatment/s that did or did not work for your child are the going to yield the same results in another child.
5. Publication of submitted stories is at the discretion of NEPANS. Submitted stories will be edited for grammar and basic typos by NEPANS. If NEPANS has questions and/or would like you to expand on certain sections we will request that information.

We are excited to continue this program with you and other members of the PANS/PANDAS Community. If you are interested in sharing your story or have questions, please email us.

Best,

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