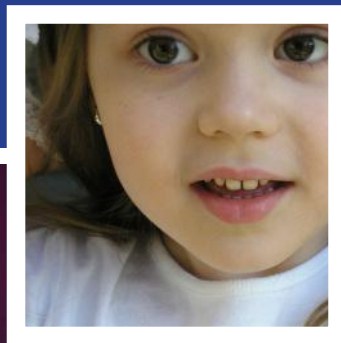


Your Child Has Changed

Should You Consider PANDAS?



Let's Talk



ASSOCIATION FOR
COMPREHENSIVE NEUROThERAPY
www.latitudes.org

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Should You Consider PANDAS?

Let's Talk

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11. So how do I know if it's PANDAS?
12. Well, if a throat swab isn't reliable, what about a blood test for strep?
13. Are any other tests available to help figure out if it's PANDAS?
14. Is there a good chance the Moleculera's Cunningham panel is covered by my insurance?
15. How do I find a doctor? I've heard that's a real challenge.
16. Is there anything I can do by myself to help figure out what's going on with my child?

Dealing with PANDAS Symptoms

17. OK, so it is looking like PANDAS. Now what?
18. You talk about repeat episodes. What is the pattern of symptoms? How long do they last, and how long are they in remission?

Your Child Has Changed

19. We had a positive strep culture, but treating for PANDAS hasn't worked. Now my doctor is saying the symptoms could be from Lyme or another kind of infection or trigger. Help!

Prevention, Treatments, and Therapies

20. After the strep is treated, what other treatments should we consider?

21. You mention anti-inflammatory medications. What are they, and do I need a doctor to prescribe them?

22. I have so many questions about IVIG that I barely know where to start! What is it? Is it painful? Will insurance cover treatments?

23. What about plasmapheresis? Is it better than IVIG for PANDAS?

24. Will we really need to do major treatments? Might my child just outgrow this condition?

25. We won't be doing IVIG or plasmapheresis. No one local does them, I can't afford them (\$!), plus I'm reluctant to do something so intrusive. What else can we do?

Getting Support

26. What should I tell my child? I know she's scared, too.

27. I'm having trouble explaining PANDAS to my family and my child's teachers.

28. I try not to cry in front of my child, but I'm so worried. Then I find myself overcompensating as I try to make everything right.

Resources

Websites

Articles

Books



What the heck is happening to my kid?

I spend my day walking on eggshells.

She's afraid to leave my side.

Since this hit, I'm always braced for a tantrum or meltdown.

My doctor doesn't know what's wrong. What should I do?

He keeps repeating things over and over

It's so strange... Handwriting has gotten much worse.

I swear, she went to bed and woke up a different child!

Where did my happy child go? He looks so sad.

Seems like he's gone BERSERK!

Where did these tics and noises come from?

Our family life has been turned upside down.

Why won't he sleep alone anymore?

She is suddenly impossible to parent!

I feel like I've lost the child I knew.

He seems paralyzed by fears.

My son won't eat and is losing weight.

Preface

If you suspect your child has PANDAS, chances are that some of the comments on the previous page hit home. They reflect what you've seen in your child or have been feeling yourself. Perhaps you have a few to add.

We all know that no two children are completely alike in their needs and behaviors. Similarly, when we talk about PANDAS, no "exact" set of symptoms and treatments applies to everyone. However, with this booklet, we hope to give you enough information that you can

- Better understand what PANDAS is and how to recognize it
- Know where to turn for a diagnosis and medical help
- Have knowledge of different treatments that may be considered
- Find the support you need

While more research is needed on PANDAS, new insights are constantly being discovered. Full recovery is the goal, and families have every reason to keep that goal before them.

It's normal to feel lost or panicked when symptoms of PANDAS strike. Parents have shed buckets of tears, acquired worry wrinkles, and cursed at whatever seems to have taken hold of their child. In the midst of these feelings, parents are faced with the daunting tasks of finding help, providing support through something their child doesn't understand, and often supporting siblings and a spouse who may be confused, angry, or in denial. The demands of a career, family, and academics don't stop just because PANDAS has entered their lives. They suddenly can't remember to do laundry, let alone comprehend a research paper about antibodies and neurology.

That feeling of being overwhelmed is universal. In fact, it has been repeated on the ACN [PANDAS forum](#) so many times, we felt there was a real need for this book. We aren't experts on every aspect of PANDAS, but we are pretty experienced in helping parents work through the nightmarish web of feelings that hit them when they first look into PANDAS. If you're still confused at the end of the book, other parents on the [PANDAS forum](#) can support you and answer your questions.

As adults, we desperately want to help our kids through difficult, distressing times, and we also want to make sense out of what's happening. Let's begin our talk with questions we often hear from parents who are concerned about their child's sudden change in behavior. In other words, let's try to make sense out of a situation that appears far from sensible.

A disclaimer and an invitation

The team at ACN Latitudes has been learning about and dealing with PANDAS for over a decade. Our [forum](#) was among the first of its kind, launched at a time when only two or three doctors in the country were willing to treat the illness. Since then, our members have advocated, educated, launched nonprofits, organized rallies and conferences, lobbied for legislative action, and changed the landscape for those who have come after them. We are truly grateful for the warrior parents who stopped at nothing to get their children well again and generously shared their wisdom as they forged ahead.

Based on the research we've done, the knowledge we've acquired, and the experiences that have shaped us, the team at Latitudes has worked to develop this PANDAS primer. Our goal is to help those who are new to the world of PANDAS gain an overview of the disease and an understanding of treatment options. Most important, we want you to know you're not alone, that others share your questions and confusion.

To the best of our knowledge, the information in this book is accurate and supported by scientific research. But we realize scientific discovery is an evolving process and that what seems true today may be only partially true tomorrow, as the tip of the iceberg is better studied and reveals more of its secrets.

To make this book a living document that can offer the most current knowledge, we welcome feedback on what we could/should include in future editions. If we've written something that's been disproved through research or runs contrary to personal experiences, please contact us at pansproject@latitudes.org, so we can discuss the information and keep this book as meaningful and accurate as possible.

Thank you for your support!

Symptoms and Criteria for a Diagnosis

1. What is PANDAS?



PANDAS is an acronym for a childhood condition known as pediatric autoimmune neuropsychiatric disorder associated with streptococcus. It's a big name for a basic concept: a child is having an autoimmune response that's affecting the brain, and this response is thought to be triggered by a strep infection. *Autoimmune* means that the reaction taking place involves cells in the body going awry and attacking one another instead of a foreign invader. This is the same response that occurs in rheumatic fever: an autoimmune reaction to a strep infection that affects the heart.