

GUIDE TO PANS/PANDAS



Nancy O'Hara, MD, MPH, FAAP
PEDIATRIC NEUROBEHAVIORAL HEALTH

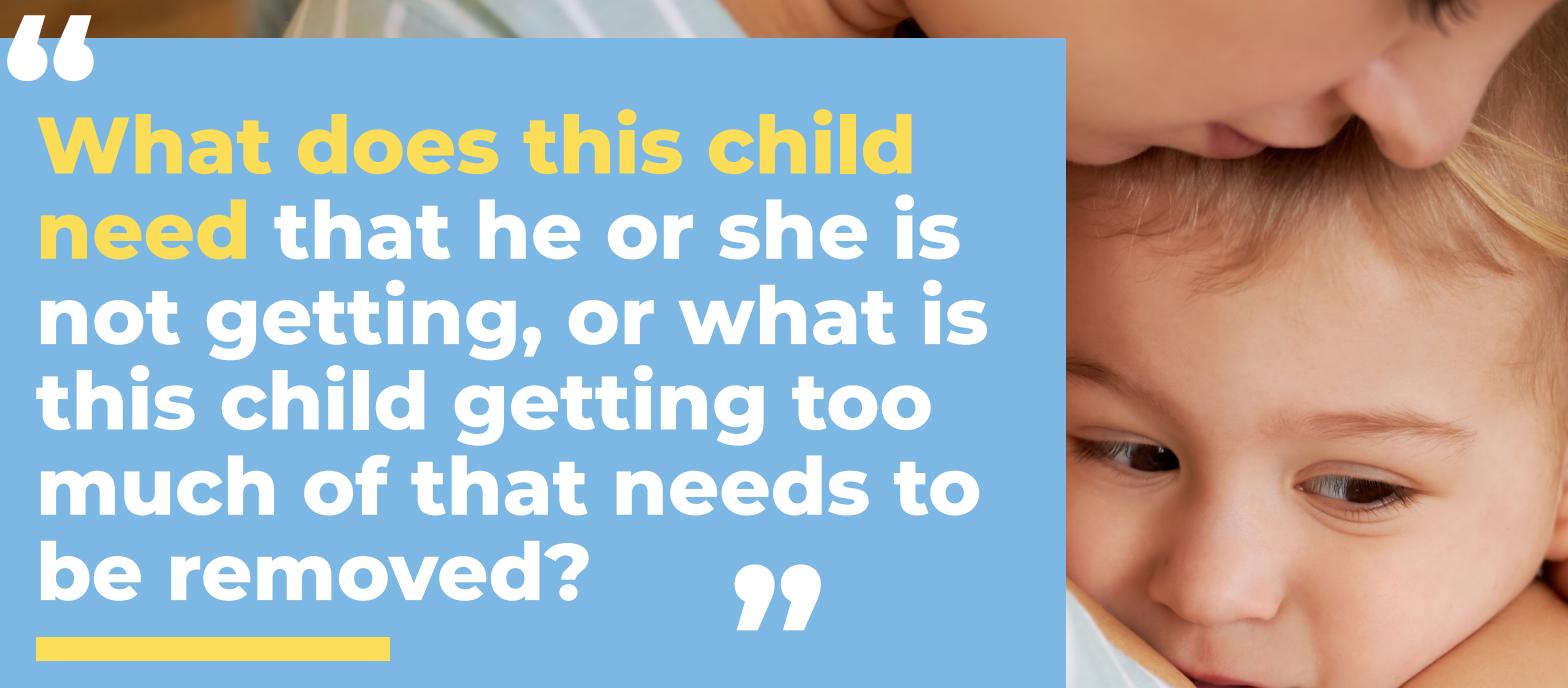
I've been in integrative medicine for well over twenty years. I started my career as a pediatrician, a partner in a primary care pediatric group, but had previously been a teacher of children with autism and had a great affinity for these children. In my first few years of general practice, I met Noah, a four-year-old boy who presented with asthma, allergies, and autism. He was not speaking. He and his family had gone away on vacation, where he contracted a diarrheal illness. His parents called our office and spoke with the nurse, who advised them to stop dairy because the dairy might be making the diarrhea worse.

He stopped dairy and began talking. Once the acute illness passed, his parents incorporated dairy back into his diet and just like that, he was once again not speaking. She started and stopped dairy several times over the next few months, and each time, the same results. His mother called me and urged me to look further into nutrition and behavioral disorders and at that time, I thought,

“Diet change behavior? Diet fix autism? No way!”



Still, the anecdotal evidence was compelling and, ever the investigator, I dug in. I began seeing success in caring for children with Autism Spectrum Disorder by addressing foundational imbalances and insufficiencies, always looking for underlying infectious, immunologic, metabolic, or mitochondrial problems that each child may have. I was always asking,



“What does this child need that he or she is not getting, or what is this child getting too much of that needs to be removed? ”

I was finding my stride by focusing simply on all these aspects of health. Then, I met Matt. Matt presented as a ten-year-old child with a sudden onset of seizure-like tics. His family described his illness saying, “Matt will be quietly sitting and doing homework, then thrown instantly to the ground, appearing as though he was having a seizure, his tics are so violent and progressive.” In addition to these terrifying tics, he developed some mild OCD and anxiety, and his family began to see regression in his thinking and ability to complete assignments at school.

Matt and his family had a healthy lifestyle and although he had a few sensory processing issues, he was otherwise a neurotypical child. Just before presenting to my office, Matt had developed a viral illness with cold/upper respiratory tract infection symptoms. That same week, he developed culture-positive Strep throat, and was bitten by a Lyme-positive tick. All the bloodwork immediately following this infection was normal, but although he initially had negative Strep titres, a few weeks later, these were elevated.

In addition to these eventually positive Strep titres six weeks after the infection, we found an elevated ANA, low vitamin D, low zinc, and a positive Lyme Western blot. He was treated for three months with prescription antibiotics, then was switched to an herbal rotation of antimicrobials. During the entire course of treatment, he was supplemented with zinc, vitamin D, essential fatty acids, and other natural anti inflammatories.

We also chose to incorporate a form of helminth therapy, as an alternative method of managing the autoimmune reaction and promoting immune tolerance. After three months, his tics resolved, but he was still experiencing OCD and anxiety, and required a 504 plan for school. These remaining symptoms were just attributed to “who he was,” and his family learned to live with their new normal.

Years later, at seventeen years old, he presented with a “rash” that appeared as stretch marks that blanched and did not follow a normal dermal line.

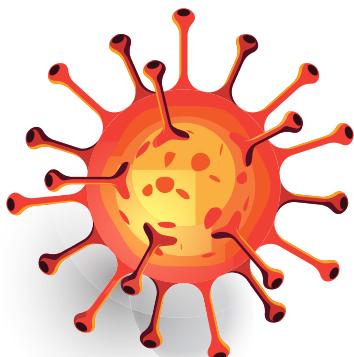
Instantly, I thought Bartonella, and sure enough, Matt tested positive for this Lyme co-infection.

He was immediately started on appropriate antibiotics and antimicrobial herbs. When these were started, his tics became much, much worse, similar to what he had experienced at age ten. Although it seems counterproductive, this abrupt flare in symptoms and even return of old symptoms is what's known as a Herxheimer reaction, and it is quite common when beginning an antibiotic protocol.

The tics continued for about six weeks after the initial onset of treatment, but eventually eased, much to my relief. Interestingly, the resolution of the tics with this antibiotic and herbal protocol brought about another surprising change--the anxiety and OCD he had been experiencing since he first presented at age ten resolved, as did the need for a 504 plan in school.



In retrospect, I assume that he had been living with a Bartonella infection for many years, with symptoms only appearing as OCD, anxiety, and learning deficiencies, but that it had not been properly addressed in the past because, not surprisingly, it had not been identified.



You can read more about Matt in the case study section of our guidebook.

Both Noah and Matt were keys in my learning to correctly and successfully diagnose and manage children with neurobehavioral disorders. With Noah, I learned how to support a child's health by strengthening his ability to fight disease and maintain homeostasis through diet and nutrition, in addition to appropriate therapeutic interventions. With Matt, I learned that infectious disease is multifaceted and complex, and that there can be many culprits playing a role. I learned to always ask,



“Have we done enough for this child?

When caring for susceptible individuals, we need to create a strong foundation for health to build resiliency, and we need to monitor continually for multiple types of infectious or metabolic issues in order to help each child find a healthy and balanced life.

Looking back, it's almost difficult to place myself back in a time when my mind operated completely within the conventional, allopathic model. Particularly when caring for children with neurobehavioral disorders, we need more options than those available to us via the prescription pad. As my mentor, Dr. Sidney Baker, always reminded me: follow those who seek the truth but flee from those who found it. Listen to each family, each child, to help them reach their fullest potential using a holistic and whole child approach. I'm not here to say that every child who goes gluten and dairy free and is given antibiotics or antimicrobials will recover completely from whatever they have been diagnosed with, but it may be a small piece of the puzzle for some children. It may even be a large piece of the puzzle, as it was for these children.

Being entrusted to care for these children and seeing firsthand the difference that integrative, functional medicine makes was the lightning rod that changed my way of thinking about medicine.

We have to treat the person, not the disease, and in treating the person, we have to look at the entire person, including the things that contribute to a strong foundation upon which we can build.

What is it that these children need to get? Perhaps better nutrition, cleaner air, or more potent antioxidants. What is it that these children need to get rid of? Let's consider chemical toxins, allergens, infections, inflammation. We have to investigate how each one of these aspects of health can affect an already compromised system like those of our children, and I fully believe that working with children and families in an integrative, functional way is the solution to this complex puzzle.



Functional Medicine: a New Frontier and Old School Wisdom

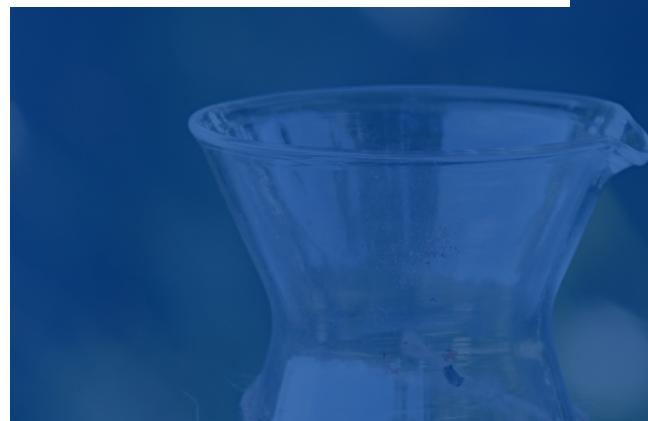
BY DR. JONATHAN PANDA



For many of us in the conventional medical world, words like “integrative,” “holistic,” and “natural,” when linked to healthcare, can be more than a bit taboo. I, myself was trained in the world of evidence-based practice through the example of my own parents, general practitioners in my home state of West Virginia. In my youth, I mistakenly believed that nutrition, herbs, and even homeopathy had no place in modern medicine, because I never saw the research.



The truth is, I never saw the evidence of these modalities having profound and lasting effects on the body because I wasn't looking.



Working with Noah and his family inspired me to look into this world for myself, my own family, and for all the families with whom I work. My world completely opened to a new way of looking at the human body, complete with a new set of tools to complement my own skill set.

Just because I came to a mind-blowing revelation about functional medicine over two decades ago does not mean that this concept is at all new. Naturopathic principles--seeing the body as a whole and perfect system, creating a strong foundation for health through nutrition and lifestyle, utilizing natural substances as much as possible, and teaching the patient to care for himself, to name a few, have been documented as early as the 16th century in Germany.

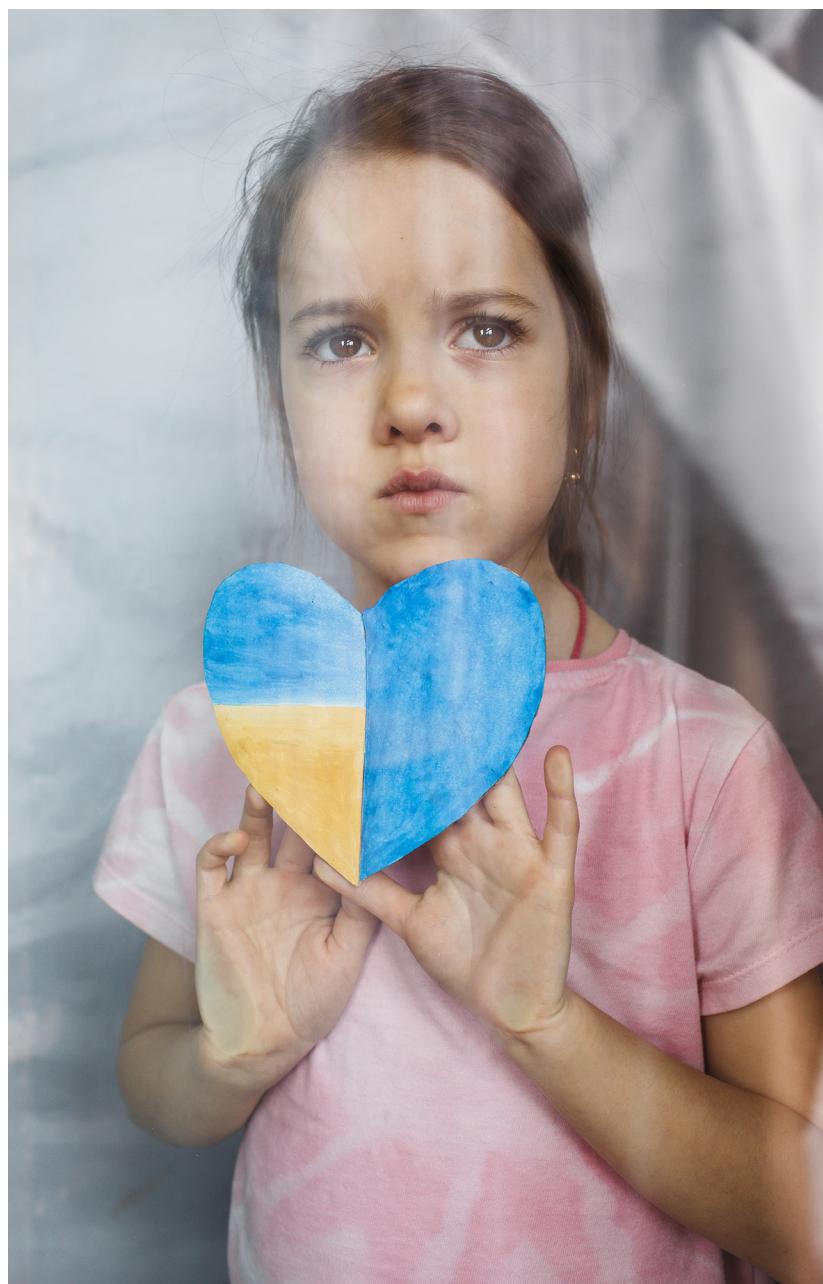
So much of what I practice is rooted in these concepts, and while I am not a naturopathic doctor myself, I am proud to integrate my practice with naturopathic doctors, dietitians/nutritionists, and other allied health professionals, because I know this approach provides the best care possible for my patients.

Many doctors and families see great success with conventional medicine alone, and that is fantastic! Still others go down the conventional route and do not see the same success.

It is for those families and doctors, eager to learn more but unsure of where to turn, that I wrote this guidebook.

I hope our practice and this guidebook brings the best of both of those worlds together to help each child. I want to provide a straightforward framework to diagnose, assess, and treat children with neurodevelopmental disorders, specifically PANS/PANDAS. I also want to bring this debilitating but treatable disease to the forefront, so that families affected by it can find a community where they feel supported and can easily seek excellent care for their children.

In true integrative style, this book is designed to help you approach a case using in-depth history taking, thorough physical examination, and conventional and functional lab testing; analyze your findings both allopathically and naturopathically and develop an individualized treatment plan that takes into account not only the diagnosis, but the unique needs of each child. This is no small task, but I truly believe that once you begin to see a child through an integrative, functional medicine lens, your ability to help more families will skyrocket, and your passion for the medicine you practice will follow suit.





I am under no delusion that as a pediatrician or as a parent/caregiver of a child with neurobehavioral disorders, you have plenty of time to sit and read a textbook all about PANS/PANDAS! That's why I decided to organize this book as a field guide, with straightforward chapters on the most common symptoms of PANS/PANDAS that I see, a breakdown of tests, diagnoses, and treatment options to consider for each, and a solid number of case studies for you to read through (including highlights summarized for each, because this is real life). I want you to be able to reference this book quickly during a busy workday or in small doses after the kids are in bed each night. Although PANS/PANDAS can be an overwhelming illness, with proper diagnosis and appropriate care, it is treatable and manageable, and I can help.

For practitioners, this book should efficiently guide you through an initial assessment, diagnosis, and treatment of a child. It will also help you know how, when, and to whom to refer. We also have a membership program filled with our trademarked Flow Chart, videos of the differential diagnosis, specifics on medications and nutraceuticals, individualized lectures on many related topics and more.

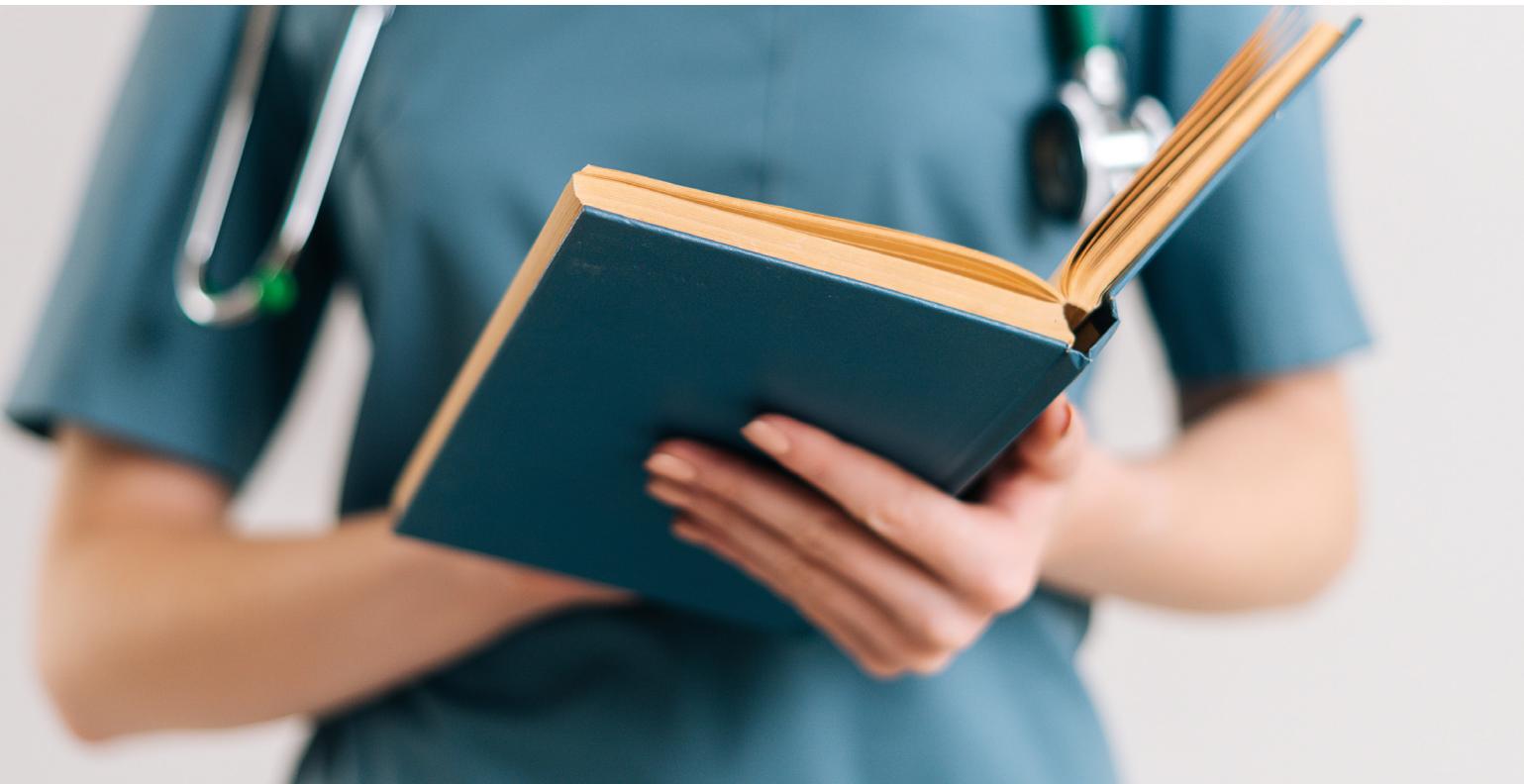
Finally, the guidebook is meant to be the initial foundation for a mentoring relationship between you and our practice. I hope to help you make your practice a place where these children and their families can heal.

Thank you for giving me the opportunity to share my hard-earned wisdom on PANS/PANDAS, Basal Ganglia Encephalitis and more importantly, to connect with you over a topic so near and dear to me. I hope you find this book both practical and empowering, and that it can serve in some way as that lightning rod that unlocks a new chapter of your life.

In health,

Nancy O'Hara, MD, MPH, FAAP
Wilton, CT | March 20, 2022

How to Use the PANS/PANDAS Desktop Reference



While the first two chapters of this book provide an overview of the history and evolution of PANS/PANDAS and autoimmune encephalitis and how to properly investigate these conditions, this book was designed to be a desktop reference instead of an exhaustive resource on the topic. I wanted to give the busy practitioner quick and easily referenced information on what can be an overwhelming topic, because who has time to read a textbook while in practice?

This desktop reference is broken up into several sections--infectious agents, comorbidities and their treatments, and case studies--so that you can identify potential infection(s) at play and match comorbidities/symptoms with effective treatment options during a family's initial visit. Use the case studies to familiarize yourself with the different ways infectious agents can manifest and learn how I would approach cases such as these.



First Steps

It's entirely possible that you're totally new to this topic and assessing a pediatric patient with neurobehavioral challenges is actually overwhelming. I understand! Start with the PANS/PANDAS Diagnosis Flowchart, created by the PANDAS Physicians Network, to orient yourself with how to assess and diagnose PANS/PANDAS.

You can then reference our trademarked Functional Medicine PANS/PANDAS Treatment Flowchart, which we have created to include allopathic and functional medicine interventions in the management of children with PANS/PANDAS and autoimmune encephalitis. Dive into the subsequent chapters to learn the major differences between PANDAS and PANS, as the two diagnoses are quite similar in every aspect except the infectious or metabolic agent triggering them.

Once you've acquainted yourself with these similar disease processes, you can dive into the "Infectious Agents" section, which is chock full of common culprits for autoimmune encephalitis. While they all can cause PANS/PANDAS, each infection has distinct characteristics that can be identified with physical examination or a thorough history taking and may be verified with targeted lab work.

Tailoring a Care Plan

Now, onto the "Comorbidities and their Treatments" section. I'll be honest, this is probably my favorite part of the process. Despite the fact that many cases of PANDAS and PANS can be linked to a particular infectious agent, no two children will present with the exact same symptom pattern, as each child is unique in her susceptibility and response to neuroinflammation.

This section lays out most of the common symptoms that children with PANS/PANDAS and Basal Ganglia Encephalitis experience, along with treatment options from multiple branches of medicine.

Although it may seem easier to follow a treatment algorithm when you have determined a diagnosis, I have found that this does little to inspire trust and confidence from the child's family, and it honestly does not yield much success in treatment.

I would instead encourage you to use a patient's unique signs and symptoms to build a care plan perfectly suited to them at this particular moment in time. It is an opportunity for us to be more creative in our approach, integrating branches of medicine different from our own training, and collaborating with other practitioners just down the street or across the globe.

Just some thoughts as you begin exploring the world of integrative and functional medicine to care for neurodiverse children:

Always address inflammation. The etiology of this disease process involves inflammation in the brain, so inflammation should be addressed from the very first day, no matter the infectious or metabolic agent involved.

Inflammation is an autoimmune component in this disease. Investigate the patient's family history of autoimmune disease to assess risk of autoimmunity and create a game plan to address this as a strategy to reduce inflammation.

Go low and slow. Some children with PANS/PANDAS tolerate aggressive treatment well, but rather than risk sending them into an exacerbation of symptoms, I recommend starting with lowest therapeutic doses and being consistent with the treatment plan for at least one month. Discuss your approach with parents and caregivers so that they can get on board with this, instead of expecting immediate results.

Watch for multiple triggers, not forgetting about Lyme and coinfections, yeast, mold, and other bacterial or parasitic causes.

Basal Ganglia Encephalitis is often an episodic course, with waxing and waning symptoms, so "flares" (aggravations of symptoms) are common and normal. Prepare parents and caregivers for this and arm them with strategies both to reduce flare occurrence and minimize the intensity of flares.

Treat the family, treat the community. If a child has a recurrence of symptoms and you suspect re-infection, look for the source in family members (including the family dog!), caregivers of the child outside the home, and other community members like classmates and friend groups. Encourage those outside of the home to receive effective treatment in order to minimize the child's exposure to infectious triggers in the future.

Your Future with PANS/PANDAS

Read the entire guidebook sequentially or simply peruse individual chapters to help better understand, assess, and treat the children in your practice. It takes a village to care for children and families dealing with autoimmune encephalitis. Thank you for allowing me to be a part of your journey.

In addition to reviewing this guidebook, if you are interested in even further immersion into a functional medicine approach to PANS/PANDAS and Basal Ganglia Encephalitis, I also offer a membership program as well as virtual or in person mentoring. For more details see...

www.drohara.com

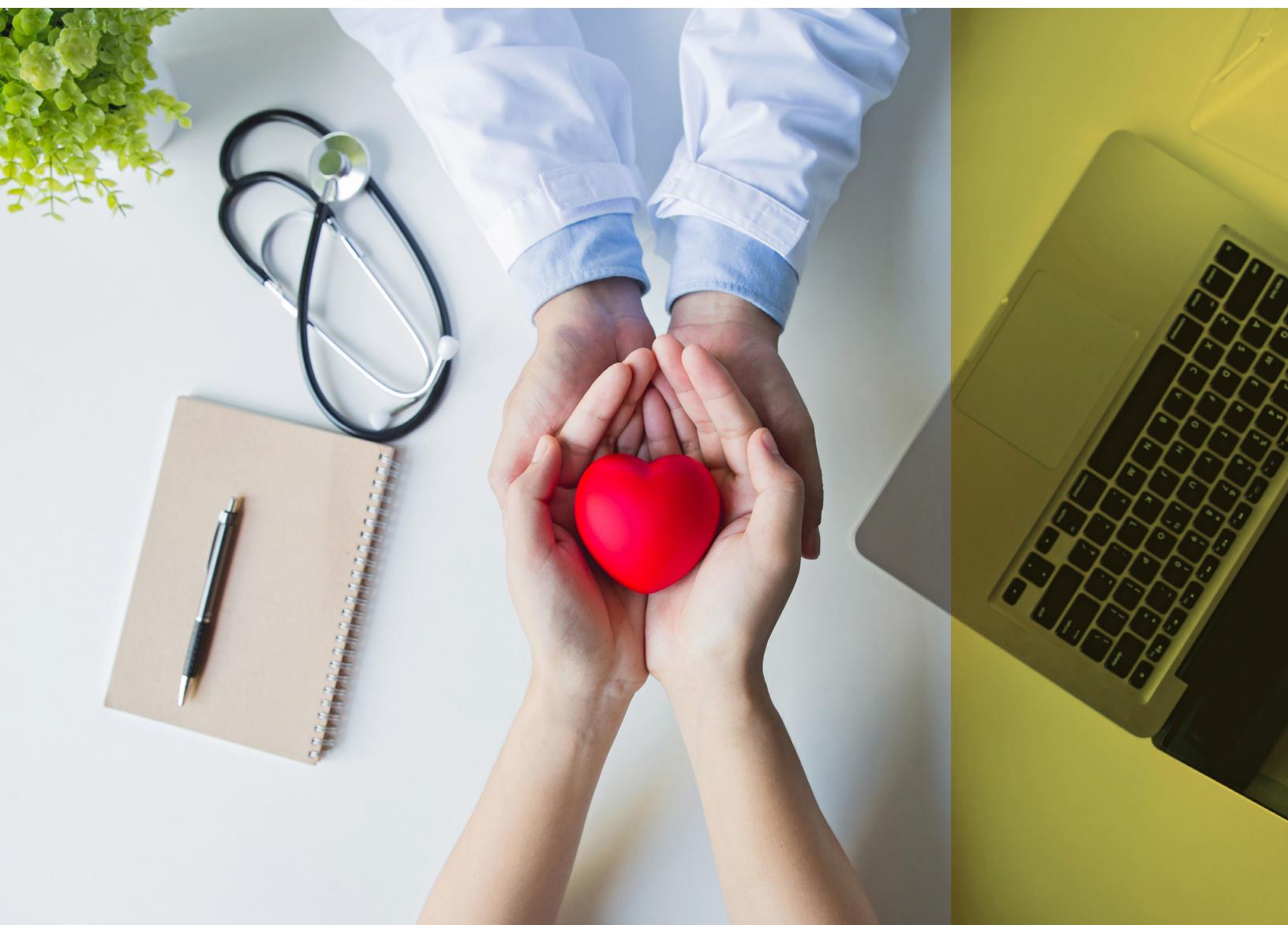


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