

I will never forget the day when I knew something was wrong with Parker. It was the day before his first PFAPA (periodic fever, aphthous stomatitis, pharyngitis, cervical adenitis) episode. It was a bright, warm, sunny afternoon in late August 2011. We were getting out of my husband's 1969 Chevelle convertible. I had leaned into the back seat to unstrap Parker from his car seat and he was laughing. The kind of laugh where his mouth was wide open and you could see the scattered teeth in his mouth, and that's when I saw *it!* A mouth sore that looked identical to the ones I got from lupus.

There it was, staring me right in the face. My heart jumped into my throat and my stomach dropped. I took my laughing 8-month old son out of his car seat and felt his head. No fever and I didn't think babies got mouth sores. I was nervous then. I mentioned it to my husband. He said it's probably nothing. The next day was the beginning of Parker's first PFAPA episode.

Our Reactions

I tell you this story because our reactions can guide us, or hinder us, in our search for the answer to what is wrong with our child. Some of our reactions are spot on, and those reactions are what should guide us. But sometimes we are led astray by outside "forces." I am going to focus on what reactions to trust, and how to properly filter in or *out information!*

The Gut Feeling

The feeling I had, the instant recognition of "something wrong," was a gut feeling. I *knew* as a mother, and an individual with an autoimmune disorder, something didn't look right. You had the same thought, right? You felt that same heart in your throat, stomach falling out of your feet type of feeling about your child. You may have even picked up your phone right that second and called your child's pediatrician. I think most people do that when they see something "unidentified."

I learned from people I helped with unknown medical conditions, nine times out of ten their initial thought was they had something "out of the ordinary" wrong with them. And you know what? They were **RIGHT!**

Rushing to the Pediatrician or Doctor's Office

Although we didn't immediately grab that phone and call the doctor, most people do. My husband and I are a "give it a few days" before you call type. There is nothing wrong with calling the doctor immediately if it makes you most comfortable. But here is what I can offer you about that approach. Until we got a correct diagnosis, calling the doctor immediately led to more frustration and irritation, and no more answers than we already had. I will share with you, later in this book (chapter 2), some dead set rules we follow to call the doctor immediately.

You may be wondering if we took Parker to a doctor during the first episode. We did. His fever was over 102 during the five days of the episode and we were clueless what it was at that time. He was misdiagnosed with coxsackievirus. Children with coxsackievirus have high fevers and sores in the back of their mouth. He had no other symptoms of this virus (rashes on the hands,

legs, and buttocks that blister and are blatantly obvious), but that was the **quickest, easiest, most seen** virus at the doctor's office.

There are over [80 autoimmune disorders](#) seen in children, and most of them are relatively unknown to pediatricians and have no cure. This is just the classification of autoimmune disorders, and your child may have something other than that. Just because I discuss autoimmune disorders here doesn't mean your child has one, or these resources won't help you. These resources are built to help anyone searching for answers, no matter what that answer is.

Mental illnesses in children are often misdiagnosed. Children with no mental illness receive an incorrect diagnosis of mental illness or children with mental illness are dismissed altogether. They are often treated for other illnesses unrelated. The over-diagnosed ADD/ADHD is all over headlines today. It's a perfect example of the approach taken today - which is to make a diagnosis fit behaviors seen when it just isn't correct.

And that leads me to the point I was making above.

Your pediatrician sees children with coxsackievirus, standard viruses, ear infections, and the stomach bug on a regular basis. They are not used to seeing children with symptoms that don't add up to those things.

It's pushing the limits, or far beyond the limits, for some pediatricians.

Reading on the Internet

Although the Internet has brought you to this site, and you purchased this book, the endless hours, days, and sleepless nights scouring webmd.com and other medical sites will only make you exhausted and frustrated. You need the right tools and background to determine what information is important and what information is **not important**. And the reason I bold text "not important" is because that is what will help you, and your doctors stay on track. We are overloaded with information today via all types of media, and it's hard to filter out unimportant information.

Let's not forget to talk about [the nocebo effect](#). The nocebo effect is the opposite of what you have heard of before - the placebo effect. The placebo effect is a healing effect. And it's true. But the nocebo effect is the opposite. It's when you read about illnesses, for yourself or for your child, and you start to believe that is what is wrong with you, or them. You can actually manifest symptoms you are believing to be true. There are actually reports of people who believed they were dying and then actually dying in that timeframe. After the autopsy, they found, there was no cause for what happened to them. This is something to keep in mind while you are in pursuit of an answer. You want a **real answer, a legitimate answer**. You don't want a misdiagnosis by a doctor, but you **do not want** a nocebo self-diagnosis.

On this journey, I will help you learn to filter out what is not important. That way you can focus on the important signs and symptoms.

There are useful information, studies and forums, support and more on the Internet. On this site, I have compiled a hub to help you sort through information, and determine what is useful. But everyone needs a set of skills to help them understand what is good information and what is not. That's what I am here for, to get you those skills.

Talking to Other Parents

Talking to others is incredibly important as a parent. We found it helpful to talk to our friends and family with children to establish our own "norm" of health conditions in children. Because we were up against the wall with the pediatrician (more about that later), we needed to start to determine what was standard and what was not.

I started by talking to people about teething. That was my initial hope of the cause of what was going on with our son. Parker was our first child, and I didn't know what went along with teething. I think we were in the second episode when I went out for a girls night and quizzed my friends about how their children teethed. Did they have fevers over 102 (my online reading said no, but was online right??) Did their children get mouth sores? Did their children appear to be very healthy yet still have a high fever? Has their child ever had a fever over 102? My questions were answered and quickly. No, no, no, no. Gut feeling confirmed.

BUT this is where parental conversations go awry. You need to remember, you are asking, ***not for an answer (and don't expect one), but for reference.***

You are asking to develop a baseline for yourself to help sort through symptoms and narrow down a path.

What happens after you ask these questions? The other parents start thinking about why you are asking them. Then comes a load of this "I am sure it's just teething... I am sure it's just a virus... I am sure it's just a bug... I am sure it's nothing at all. Maybe he's not getting enough sleep... Maybe he ate something bad and it gave him sores..." You can fill in the blanks about your own child's symptoms. Don't let the other parents belittle your situation. You have to remember you are ***asking for your reference, not for their diagnosis of your child.***

You might get lucky one of those times. Don't give up, even if you are tired of listening to people's simple diagnosis of your child's complicated condition. One time, you might stumble into another parent with a child with a difficult condition or the same condition as yours. So keep on talking, just keep your frame of reference in mind.

What We Are Here to Do

The next few pages are diary/entry sheets you should keep in a binder. It will be the beginning of a tracker journal you take with you for every doctor appointment and continue to maintain

over time. It's something you can present at the appointment to help your physician. You can also provide it to your child's school nurse, babysitter or family member who might need information about your child's condition.

Most importantly these first pages are the initial tool you need to start to **filter out information and focus on key symptoms** and aspects of your child's condition. These are keys to opening the door to the diagnosis and helping your child. Over time, as you begin to keep track of your child's condition, you may have more to add to this notebook. You can keep this as a record and complete it again at a later date (add the later date to show the change). Or you can keep it dated, and then use your tracking sheets to show change.

A note: In the following resource sheet I did not reference any online research you have done. That is intentional. Later in this book, and on our Website, I will teach you how to use the Internet to make progress in learning about your child's condition. Don't search ALONE. Let us help you get a direction.

All of the tools are in this book in each section they correspond with. If you would prefer to print them all together, instead of piece by piece, you can purchase the complete journal as one document on our Website. Feel free to type your own document, using the questions I provide. It can be an electronic journal so you can add additional information and thoughts.

This FREE guide is Chapter 1 of [How to Get a Diagnosis](#) - an ebook that walks you through a step-by-step process. The book is filled with helpful tools to manage your child's records and symptoms for their unknown medical condition. The book will help you get on a path to get a diagnosis.

A History

Date of Journal Completion: _____

Date first symptoms noticed: _____

Your Gut Feelings

• Where are your feelings coming from? Do you or the child's father have a similar disorder? Another family member? Another child of yours? List any family history you might find relevant.

EXAMPLE: My gut feelings came from a place of fear that my child would have an autoimmune condition like my own and would suffer. I noticed an identical symptom to my own and was afraid for him. I didn't want him to be in pain or be unhealthy. My husband's family has a strong family history of autoimmune disease as well. I was afraid for all those reasons. Our family history included: Mother - SLE, Father Family - direct Aunt and Grandmother - Rheumatoid Arthritis that led to their deaths.

• What makes you feel this is different than other children, and different than a standard illness? Summarize below.

EXAMPLE: The first month I wasn't sure, just had a feeling, but after the second episode exactly one month later, to the exact weekend, of a high fever lasting exactly 5 days in a row, with no signs of germ-related illness, I was certain something was wrong. My own lupus symptoms included a fever (although low grade). I had never had any of my nieces or nephews have a recurrent fever that was the same exact weekend with no illness signs, lasting for the same exact number of days. I asked other parents if their children had such things, perhaps related to teething or other things going on in life. I had nobody say that their children had this, and, in fact, most parents seemed worried and shocked the more of Parker's story I told. I could not find one parent with a similar story.

Things for A Doctor to Know

- What were the very first symptoms you saw, the ones before you started reading the Internet, talking and listening to other parents? List them below.

EXAMPLE: Mouth sores, high fever lasting 5 days in a row, that came back the exact weekend the next month. The fever was always above 102 or higher. Parker never seemed germ-sick. He would do a lot of screaming as an infant right before, during and especially AFTER the fever broke. As he aged we noticed he seemed to limp and would scream uncontrollably in pain on the floor out of nowhere. As he began to talk he complained about extreme joint pain in his lower extremities.

Let's look at a few key things:

- How long do the key symptoms you listed above last? Do they last longer than 3 days at a time? Give a description below.

EXAMPLE: Fever lasts 5 days in a row, sometimes only 4 days, but rarely. Fever is always above 102. The week before an episode there is noticeable changes that lead us to notice a fever is coming. The mouth sores last a few days before an episode and continue throughout and about a week following. His tonsils are swollen during the fever and subside by the day after it breaks. Joint pain lasts only during the episode and waxes and wanes during the episode.

- How frequently do these symptoms return? Be very specific. If you are not sure do your best to summarize the past, and take this opportunity to use a tracking sheet (later in the book) to start to keep track of the frequency of symptoms.

EXAMPLE: The symptoms return every 17-24 days. Occasionally, we get a bit of a longer break between episodes, but 95% are 17-24 days apart and fall nearly on an identical day the following month (day of the week, and date of the month).

- Do these symptoms seem to correspond with anything else in your life? Events? Timing? Busy schedules? Foods eaten? Medications consumed? Sleep habits? Explain any and all that apply.

EXAMPLE: At first we thought they were associated with busy times, but, in fact, they were just solely associated with dates and length of episodes, as we noticed by following a detailed tracking sheet. There were no associations with food eaten, but his appetite was diminished during an episode. And as he aged we figured out that was due to the mouth sores and size of his tonsils making it uncomfortable to eat. He barely slept overnight - was awake 11 pm -4 a.m. As an infant, and continues to be awake for 3 hours overnight (or more) during an episode. We also noticed that he seemed to be having a type of night terror the week before, and at the end of an episode. Screaming and flailing but not awake and unresponsive to our presence. He took no medications.

- Are there noticeable changes in your child's mood? If so explain below.

EXAMPLE: The child would become wild at home, mean, and sometimes out of it. He became very difficult to get to sleep, and would frequently skip a very scheduled nap the few days before the episode began.

- Are there noticeable changes in your child's sleep patterns? If so explain below.

EXAMPLE: Child exhibits night terrors before and during episodes. He doesn't sleep overnight during the episode and takes about a week to recover sleep patterns following an episode.

- Are there noticeable changes in your child’s diet, and drinking patterns? If so explain.

EXAMPLE: Parker would eat nearly nothing at all for 5 days. He would drink water in gallons and gallons but no food. We learned as we went the mouth sores were painful and his tonsils were so swollen it was hard to swallow. Appetite and patterns returned immediately after an episode was complete.

- Are there noticeable skin changes, complaints about aches and/or pains? Explain what changes, and what your child describes or what you observe during the change. Be specific.

EXAMPLE: No skin changes noticed. He would flail on the floor screaming like he was in pain before he could speak, and screamed as an infant nonstop during an episode. As he learned to walk, he would limp and then cry in pain. As he talked, he complains about severe joint pain in his legs and feet, to the point where he needs to be carried to even use the bathroom. It waxes and wanes with each episode.

- Did your initial visit to the pediatrician’s office for these symptoms lead to a diagnosis? What was that diagnosis and why do you believe it was incorrect?

EXAMPLE: He was initially diagnosed with coxsackievirus once. It was incorrect because he had none of the telltale symptoms of rashes and blisters. He was diagnosed several other times with “just a virus” of unknown origin. It is incorrect because it continues to occur monthly and he is obviously not ill.

Have you returned to the pediatrician for the same symptoms/complaints? What has happened on subsequent visits?

• Has your child had any lab work, or other tests done regarding these specific sets of symptoms? What were the results?

Not sure what the results were or how to describe them? Ask the doctor who ran the tests to provide you with the records, or log in to your required patient portal and access the results. Print them and put them in the binder with these papers. We will show you later how to organize all the results that you keep track of in a way that will show patterns.

EXAMPLE: My child had not had any lab work done before a referral to a specialist because nobody believed he had anything other than “just a virus.”

• Has your child had repeat lab work for the same symptoms done at a later date? If so what did those results show?

EXAMPLE: After we were obtained a referral (we will tell you how we did that later in this book), we had blood work done as a baseline, and then done during an episode. The blood work showed a noticeable difference in a very distinct set of components that led to a solid diagnosis. More testing was done at a follow-up to that blood work to rule out a set of other disorders with similar symptoms, and when it showed nothing, the results were solidified.

Were there any pieces of the testing that came back the same way twice? If so describe.

If you are not sure about this section, you might want to check out our bundles and consultation packages and times for help. Also, be sure to check out our other E-books and resources for explanations of blood work, testing and more.

EXAMPLE: Yes the blood work was taken during episodes always showed the same three levels elevated that indicated PFAPA. And yes all blood work done between episodes showed normal levels of everything, repeatedly. No other abnormal test levels were ever found.

What Have You Learned From Others

- When talking to other parents about your child’s condition, and asking them questions, what have you learned about what seems to be “normal” and what seems to be an outlier that your child has that theirs does not?

EXAMPLE: I asked other parents about teething issues, sleep issues, dietary issues and anything else they could think of where their child got high fevers. None of them had ever experienced a fever over 102, and none of them had had a fever longer than 2-3 days maximum.

Other relevant information - or notes about general thoughts related to your child’s condition:

EXAMPLE: We became able to predict to the date (or within 2 days of the date) the date of each episode and started to plan around it. He had noticeable symptoms the days before, and we could tell a week before the episode that it would occur.

If you need more room to write, feel free to copy the questions into your own document, and type in your responses very thoroughly. Feel free to delete my examples and include only your child's story.