HELP CIRCLE · PARENT CHEAT SHEET · PART 1

Getting a *Diagnosis*

How to recognize the pattern, and how to build the record a doctor needs to see it.

1 The key sign: a sudden change

PANS and PANDAS usually start abruptly, often overnight or within a few days. The hallmark is a dramatic onset of **OCD** or **restricted eating**, plus at least two of these, appearing just as suddenly:

- Anxiety or separation fear
- Mood swings or depression
- Irritability, rage or defiance
- Regression, baby-talk
- Handwriting or math decline
- Tics or sensory sensitivity
- Sleep problems
- Bedwetting or urinary urgency

2 PANDAS or PANS?

PANDAS

- Linked to a strep (Group A) infection
- Sudden OCD and/or tics
- Usually starts before puberty

PANS

- The broader diagnosis: any trigger, such as flu, mycoplasma or other infections
- Sudden OCD or restricted eating, plus two or more symptoms above

You don't need to know which one. Your job is to describe the change; the doctor sorts out the rest.

3 Build your record

1. **Pin down the date.** When did you first notice the change? How fast did it come on? The suddenness is the most important clue.
2. **List recent illness.** Strep, flu, colds or fevers in your child, siblings, class or camp in the weeks before.
3. **Capture it.** Short phone videos of rituals, tics or rages, with dates.
4. **Compare handwriting.** Save school work from before and after the change.
5. **Collect school notes.** Teacher emails, nurse visits, report cards.
6. **Note family health history,** including autoimmune conditions.

4 Symptom timeline — bring this to every appointment

Date	What changed	Recent illness / exposure	Notes, videos, school

HELP CIRCLE · PARENT CHEAT SHEET · PART 2

Finding a Doctor *Who Listens*

What to bring, what to ask, and what to do if you're not being heard.

1 What to bring

- Your symptom timeline (Part 1)
- Dated videos of symptoms
- Handwriting samples, before and after
- Teacher or nurse notes
- Recent illnesses and any test results
- Current medications and allergies
- Insurance card and your written questions

LEAD WITH THIS

"My child changed suddenly on [date]. Could this be PANS or PANDAS?"

2 Questions to ask

1. Could an infection or immune response be causing this?
2. Should we test for strep? Ask about a throat culture and strep blood tests (ASO and anti-DNase B).
3. Should we check for other infections, such as flu or mycoplasma?
4. Do the PANS consensus criteria fit what we're seeing?
5. If it isn't PANS or PANDAS, what else could explain it, and how do we rule it in or out?
6. Who should we see next, and how soon?

3 If you're not being heard

1. **Ask for a referral** to a specialist who treats PANS, such as a pediatric neurologist, immunologist, rheumatologist, psychiatrist or infectious disease doctor.
2. **Get a second opinion.** It's normal and you don't need permission.
3. **Use the practitioner directory** at pandasppn.org to find experienced providers.
4. **Ask for it in writing.** Request visit notes, and the reason if a test or referral is declined.

4 Insurance in California

Since January 1, 2025, **AB 2105** requires state-regulated California health plans to cover diagnosis and treatment of PANS and PANDAS, including IVIG.

Self-funded employer (ERISA) plans don't have to follow it. Call your plan and ask which kind you have.

Trust what you saw. You know your child best. A sudden, dramatic change is worth a real workup, even after one episode. If your child is in danger or in crisis, call **911**, or call or text **988**.