

## News & Resources

October 2023

For parents of children with special health care needs

### October 2023 Table Talk: Talking to your child about their diagnosis: Families share tips, ideas, and worries

When, where, and how do you talk with your child about their diagnosis? Is it a one time talk, or an ongoing conversation? How do you know when they are ready? What about siblings or extended family members?

Join parents of children with special health needs to explore:

- Information: What information should be shared?
- Timing: Should parents wait for questions or start the conversation?
- Wording: How to start the conversation and when is it time to stop?
- Strengths: Finding your child role models, peers, and s/heroes

You will hear from other parents, learn what happened for their family, and share ideas. Resources provided.

Thurs, Oct 19, 2023 | 12:00-1:00pm | [Register here](#)  
<https://tinyurl.com/TT-101923>

You will receive a zoom link via email.

Cost: FREE

The first 10 Oregon families to register and participate will receive a \$10.00 Amazon or Starbucks gift card.



Visit our [Facebook](#) page and [website](#). [Speak with a Parent Partner: 855-323-6744](#) or [Refer a parent](#) to Speak with one of our Parent Partners. For more information, to schedule a free training, or to be added to our mailing list: [contact@oregonfamilytofamily.org](mailto:contact@oregonfamilytofamily.org)

### Parent Spotlight: Kloth Lim



#### Q: What do you want others to know about your child?

A: My child is human with imperfect and perfect qualities like everyone else. He is resilient and has overcome many obstacles to be the spunky happy boy he is today. I know my child pretty well but there is much more to learn about and his developmental issues. He's not talking yet but he is communicating in his own way... he has his creative ways to call attention to himself.

#### Q: How do you advocate for your child?

A: The first part is self-care; I need to take care of myself, whether it be managing my stress levels or going outside to exercise, so that I am healthy enough to take care of my son for years to come. The second part is staying actively involved in my son's life despite having to share custody. By spending time with my child... I have come to realize that my view of what is best for my child may differ from that of the other parents. And that's not necessarily a bad thing.

#### Q: What is one thing you have learned that you would share with a new parent?

A: Time goes by so fast when you are having fun. It feels like it was just yesterday when my baby was barely 6 pounds crying for milk and now he's a big boy (4.5 years old) riding his bike with training wheels so fast laughing with joy. Being a parent is tough but fortunately I don't have to be perfect. Your child is only young once and what matters most is you being there to love and care for them.

## Organization Spotlight: Northwest PANDAS/PANS Network

NORTHWEST  
PANDAS/PANS  
NETWORK

NWPPN



This month is PANDAS/PANS awareness month! We are happy to feature the Northwest PANDAS/PANS Network, a 501c3 nonprofit started by parents who are dedicated to educating families, physicians and the general community about this often-devastating condition.

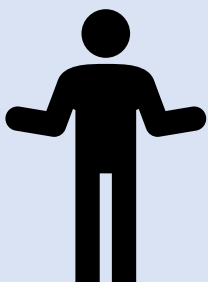
**What is PANDAS/PANS?** Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) are post-infectious neuroinflammatory disorders that can cause some children and adults to experience a sudden onset of psychiatric and neurological symptoms. Common symptoms include obsessive-compulsive disorder, severe anxiety, eating restrictions, tics, sensory sensitivities, deterioration in math and handwriting, urinary issues, rage and more. PANDAS is triggered specifically by a strep infection while PANS includes all other infectious triggers.

**Why did you create a regional nonprofit here in the Northwest?** We saw the need within our local communities and wanted to help. Our mission is to:

- Raise awareness
- Help children get appropriate and thorough care
- Ensure that PANDAS/PANS treatment is covered by insurers.

**What can your organization do for families?** The most important thing we can do for families is provide support as they explore the possibility of this diagnosis. The most vital piece of helping a child with suspected PANDAS/PANS is connecting them with a knowledgeable provider who is willing to diagnose and treat. Our nonprofit maintains a list of treating providers in the Northwest. We also offer online support forums for parents and caregivers.

For more information about NWPPN, visit their [website](#), and for more information about PANDAS/PANS, visit the National Institute of Mental Health's [overview](#). To get on the NWPPN mailing list, or ask a question, [connect here](#).



- Oct 10 Swindells: [Practical Emergency Preparation for Busy Families](#)  
6:00pm-7:00pm | Online Training
- Oct 18 [NorthWest Senior and Disability Service Office](#)  
Salem, OR | 10:00am-11:30am
- Oct 23 Swindells: [Transición de la atención médica pediátrica a la atención médica para adultos](#) | 6:00pm-7:00pm | Online training in Spanish
- Oct 25 Swindells: [Transition to Adult Healthcare](#)  
6:30pm-7:30pm | Online Training
- Oct 26 CODSN: [Grupo Mensual de Padres y Cuidadores De Habla Hispana](#)  
6:00pm-8:00pm | Bend | in person event in Spanish
- Nov 3 [United Cerebral Palsy Family Support Conference](#)  
9:00am-3:30pm | Holiday Inn Portland | Wilsonville

*The Oregon Family to Family Health Information Center is affiliated with the Oregon Center for Children and Youth with Special Health Needs, Oregon Health & Science University, and supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS). (Grant #H84MC21658/Family Professional Partnership/\$95,700). This information, content and conclusions are those of the author(s) and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS, the US Government, or OHSU.*