

News & Resources

July 2023

For parents of children with special health care needs

Table Talk

Gearing up for a healthy school year: putting all of the pieces in place

Does your child attend a school in Oregon and experience complex health needs? Do they have an Individualized Health Plan (sometimes called a nursing plan) along with an IFSP, 504, or IEP?

Join parents of children with special health-care needs to explore:

- **Ideas** you can use to organize yourself before the start of the school year.
- **Strategies** for connecting and communicating your questions/ doubts with school staff
- **Resources** available in your community and online

You will hear from other parents, learn what works for them, and share ideas. Resources provided.

Wed, July 19, 2023 | 11:00-12:00pm | [Register here](#)
<https://tinyurl.com/TableTalk-July23>

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.



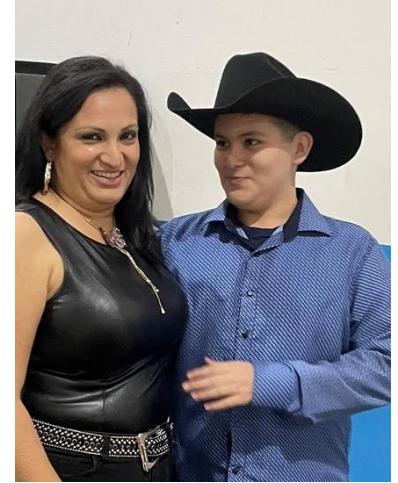
Visit our [Facebook](#) page and [website](#).

[Speak with a Parent Partner](#): 855-323-6744

For more information, to schedule a free training, or to be added to our mailing

list: contact@oregonfamilytofamily.org

Parent Spotlight: Dora



Q: What is a lesson you learned from your child?

A: My son has taught me many things but one that has always stayed in my mind and in my heart is that he always tells me to smile even if the day is not easy. He is very skilled at noticing when someone feels different than other days (reading emotions). When he notices a change in my face he comes and puts his hand over my mouth and tries to make the shape of a smile and also puts his fingers over his mouth to show me that he is smiling and tells me to repeat after him.

Q: What does your family do for fun?

A: We try to get out as much as we can together as a family, whether it's a walk in the park or getting to know somewhere new where my kids can enjoy. Always focusing on having quality time to create new memories that they can remember when they grow up.

Q: What's one thing you've learned that you would share with a new parent?

A: The importance of always having the hope that things will change for the better, most of the difficult things will be momentary and sooner or later everything will get better. Also do not put limits on children or say you can't/should not do this because of your condition, as long as it's safe and make sure you don't exclude them from participating in social events.

Dora Tinoco lives in Yamhill County

Genetic Journey Resource

Last Month our Table Talk topic was around the genetic testing journey. Here is a helpful information guide explaining more about genetic testing referrals for children created by [The Western States Regional Genetics Network](#). Please be sure to reach out to one of our Parent Partners if you have any additional questions.

Call 855-323-6744

Email: contact@oregonfamilytofamily.org

[Self referral form \(English\)](#)

[Self referral form \(Español\)](#)

[Referral form for professionals](#)



GUIDE TO GENETICS REFERRALS FOR CHILDREN



WHO SHOULD BE REFERRED?

Children with:

- Physical differences from birth or growth problems
- Intellectual disability or developmental delay
- Autism Spectrum Disorder
- A known genetic diagnosis without follow-up for several years

WHY A GENETICS REFERRAL?

Benefits of a genetics appointment:

- Understand a child's condition and how it may change over time
- Avoid unnecessary tests or treatments
- Give access to services, possible treatments, or research studies

WHEN SHOULD SOMEONE BE REFERRED?

- If any concerns show up
- If someone was seen by genetics 2-3+ years ago and no diagnosis was made
 - New tests may exist
 - More tests may now be covered by insurance

HOW TO GET REFERRED?

- Referral from child doctor (pediatrician) or family doctor
- Contact a genetics clinic directly to request a referral

WHERE TO BE REFERRED TO?

- Genetics clinics
- Developmental or behavioral clinics
- Multidisciplinary specialty clinics (where a child sees more than one type of specialist in the same visit)

TALKING TO YOUR PROVIDER

Primary doctors may have different levels of understanding with genetics. If your doctor does not want to refer your child, try to:

- Have a specific appointment to discuss a genetics referral. This gives the doctor more time to hear and focus on what you have to say, compared to during a routine visit
- Make a list of the concerns you have and show this poster
- Bring previous doctor's notes where a genetic evaluation was done or recommended
- Contact any previous genetics clinics where your child was seen to ask if an updated evaluation is recommended, and if so, bring this to your doctor



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