

News and Resources

May 2021

for Families of Children and Youth with Special Health Needs

The OR F2F HIC helps families of children, youth, and young adults with special health needs navigate health care and other systems. This newsletter highlights up-to-date, practical information and resources for families and is published a few times per year. [Contact us](#) to be added to the mailing list.

What do you need for a successful hospital stay?

Hospital stays. Nobody likes them, but of course sometimes they are a necessity. As a parent or guardian, they can sometimes feel even more trying because of your "visitor" status. But there are systems to help. Try these tips:

- It's usually OK to change the thermostat in your room, bring your own bedding, or anything else that makes your stay more comfortable — just remember to be mindful of medical staff and their needs.
- Hospitals are full of secret pleasures you might not think to look for or ask about. Scout out the vending machines, courtyards, playgrounds and viewpoints.
- Ask for a Child Life volunteer. They have access to toys, games, video games and other things to help your child pass the time in the hospital.
- If you have an issue that isn't resolved by talking to your team, you may wish to contact the hospital's patient advocate or patient relations office. Your insurance company may also have a patient advocate you can speak with.
- Make a [One-Page Profile](#) to give to hospital staff. It's a handy way to introduce them to your child's personality preferences, and unique needs in the medical setting.

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

[Speak with a Parent Partner:](#)

For more information, to schedule a free training, or to be added to our mailing list: contact@oregonfamilytofamily.org



Sibling spotlight: Mimi

Q: What is something that people say to you about your siblings that bugs you?

A: Hearing: "I'M SORRY." Sorry for what? Many people think that it is a tragedy having siblings or a family member with a duo diagnosis of autism and Down syndrome. It's not something I love to hear, but I understand they have no idea the joy and warmth my siblings bring to our home. Yes, it is hard at times, but what isn't? They are the pride and joy to our family! They make a difference in our lives and the people that come into our lives.

Q: How has being their big sister changed your life?

A: It has made me the person I am. It has made me a learner and advocate, passionate for change in systems, and able to see people for who they are and not their disability or appearances. I am able to show love and patience to those who aren't welcoming and inclusive. They have taught me to see situations in a different way. They inspire me to be a more caring, loving, valuable, outgoing person, no matter the barriers.

Join a Table Talk!

Small gatherings for sharing ideas and learning from one another

Table Talks are a great way for parents and caregivers to explore topics related to raising children who experience special health needs. They are informal, informative, and supportive. OR F2F HIC Parent Partners facilitate the conversations and you will receive useful resources afterwards. Each Table Talk is limited to 10 parents or guardians and you can receive a \$25 Amazon or Walmart gift card as a thank you for your time and expertise! The next Table Talk will be:

Dealing with a child's health emergency: Saturday, May 15, 11 am - noon

[Request a spot](#) or more information by May 14

We'll discuss: Has your child with special health needs required an ambulance or emergency room at least once? What worked or didn't work? What suggestions do you have for EMS professionals for working with families and kids with unique health needs?

Get involved with your I/DD state council

Did you know that every state and territory in the United States has a federally funded Developmental Disabilities Council?

It started out of the movement in the 1960s for alternatives to institutionalization. The 56 councils in every state and territory exist to raise awareness and advocate for change.

In our state, the [Oregon Council on Developmental Disabilities](#) has a board of more than two dozen members, 60 percent of whom are people experiencing intellectual or physical disabilities or their immediate family members. OCDD also operates the [Go! Project](#), which offers advocacy events and a news bulletin.



Check's in the mail: Are you eligible for help with insurance premiums?

If your child is a Medicaid recipient **and** you also buy insurance through your job or privately, you may be entitled to reimbursement for those premiums.

Oregon offers the [Oregon Health Insurance Premium Payment](#) program. Recipients must apply and are required to resubmit paystubs or other proof of payment annually or whenever premiums change. Checks come in the mail once a month to offset the cost of the premium.

Not all families will qualify for this program, but you can read more about it at the link above or click here to apply:

<https://apps.oregon.gov/dhs/opar>

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