

## News and Resources

April 2022

for Families of Children and Youth with Special Health Needs

### Visit neurology with this new tool in hand

The Child Neurology Foundation has a new resource for families who need to visit a neurologist.

The 11-page [toolkit](#) is a questionnaire of information your child's neurologist will want to know, as well as places to take notes on recommendations.

"Doctors prefer summaries over specifics," the CNF advises. "If they need more details they will ask, so having your information organized can help make answering those questions easier. Consider putting everything into a binder and group visit summaries, test results, treatment summary and medication history in separate sections. If possible, keep in chronological order, with the most recent information first."

The CNF also recommends that families ask questions when they are confused and provide accurate information about symptoms. Don't forget to ask when test results will be available and schedule return appointments when needed.

The toolkit is available in English or Spanish.

OR F2F HIC helps families of children, youth, and young adults with special health needs navigate health care and other systems. This newsletter offers up-to-date, practical information and resources. [Contact us](#) to be added to the mailing list.

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### Parent spotlight: Les

#### What is the best thing your child taught you?

I was definitely not a nurse and didn't think I had one "nursely" bone in my being before Gloria was born. Glo taught me that when faced with the challenge of leaving my comfort zone I could do it. As many parents in our community know, when you have no other choice but to take on the challenge and grow as a person, most do.

#### What have your other children learned from being a sibling?

Aurora is Gloria's sister and is 11 months older. Also, being a sibling of my adopted brother and sister that experience disabilities I really empathize with her situation and we share that bond. I feel that siblings in the disability community have this perspective that can come from few other experiences that help keep most of us grounded in what really is important: having compassion, patience, a world view of empathy, and not sweating the small stuff.

# Pick the right car seat with help from OHSU

The Tom Sargent Safety Center at Oregon Health & Science University has specialists who can help you pick the right car seat for your child.

Kyndra Lathim is a health educator in the injury prevention program at OHSU. She says adaptive car seats have a wide variety of accessories to fit many different needs. These include incontinence covers, footrests, lateral supports and escape-proof buckles.

Adaptive car seats are for any child for whom store-bought seats aren't meeting their needs, especially kids heavier than 65 pounds who still need postural support and children who "escape" from their seat.

To get started, find a special-needs trained Child Passenger Safety Technician. OHSU Doernbecher Children's Hospital has free special needs car seat assessments. To request an appointment, call 503-494-3735.

A referral is not necessary for an assessment, but the technician will work with your child's physical therapist to write a letter for insurance coverage. Unfortunately, insurance companies often deny



claims for adaptive car seats. If that happens, there are opportunities for appeals or grants or Medicaid funding, such as through the state's K-plan. Reach out to ORF2FHIC if you need help funding an adaptive car seat: 855-323-6744 or 833-990-9930 (Spanish).

If you live outside the Portland Metro area, the Tom Sargent Safety Center can still help with virtual appointments or referrals to local car seat technicians.

## FDA cautions about tube feeding risk

After two children died in 2021, the Food and Drug Administration issued warnings about the potential for strangulation with enteral tube feeding sets. Both cases involved children under the age of two who had the tubing wrapped around their necks for brief periods of time (under 10 minutes) when caregivers were not monitoring them.

The FDA noted that it believes such deaths are rare but that the public should be aware of the possibility. The new recommendations are to be aware of this risk and to keep the plastic tubing away from children and toddlers to the extent possible.

[Read more](#) from the FDA, and learn more about tube feeding from the families at [Tube Feeding Awareness](#).

## Oregon has a 'lemon' law for assistive tech

Have you ever bought or leased a wheelchair or other medical device that was defective? Oregon has a 'lemon' law in place to protect consumers from manufacturer error. This ensures companies guarantee their wheelchairs, scooters, hearing aids and other assistive technology.

Suppliers must repair, replace or refund any devices that are defective. Learn more at [this page through Disability Rights Oregon](#).

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.