

News and Resources

June 2022

for Families of Children and Youth with Special Health Needs

Study: Paid family caregiving works in CO

In a recent issue of *Family Connections with Pediatrics*, author Cara Coleman [summarizes a study](#) on the success of Colorado's paid family caregiving program.

The issue has become a hot topic in Oregon as the coming end of the public health emergency signals the end of a temporary program that allowed qualifying parents to become paid Personal Support Workers or Direct Support Professionals to their own minor children.

Since 2001, Colorado's program has trained family members as Certified Nursing Assistants and pays them the same wage as other caregivers. The program, open to children with medical complexity like cerebral palsy, has been successful at stabilizing children's health and family finances.

To learn about efforts to create a similar system in Oregon, view videos of legislative hearings held on [June 2](#) and [June 3](#). The June 2nd discussion starts at 1:47 and the June 3rd discussion starts at 1:06. You can also read more at [Oregon Advocates for Equitable Disability Services](#).

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.

Visit our [Facebook page](#) and [website](#). Get more information, talk to a [Parent Partner](#) or schedule a free training: contact@oregonfamilytofamily.org



Parent spotlight: Ana

Q: What does your family like to do on weekends?

A: We take this time to not concentrate on schedules and reconnect. Usually by having a family movie or game night.

Q: What is your fondest hope for your child(ren)?

Both of my children are encouraged to live their life without others judging, or limiting their true abilities.

Q: Finish this sentence: The biggest myth about this lifestyle is...

A: ...that it is all work and no fun. It is the exact opposite: we constantly find joy and happiness in just about every activity we do.

Ana Brooks is the newest staff member at OR F2F HIC, supporting families in both English and Spanish.

Surprise medical bills are now illegal in many cases

Medical billing surprises beg many questions:

How could the anesthesiologist be out-of-network when the surgical suite he was working in is in-network? How are you supposed to plan for an in-network LifeFlight helicopter when an emergency happens in Idaho?

Well, a new law is designed to make eye-popping medical bills a relic of the past.

The law, which applies to most health insurers, states that in emergency care situations, out-of-network billers may not charge more than in-network providers.

Also, for nonemergency procedures, out-of-network providers can't bill more than in-network providers if the procedure is at an in-network facility.

Called the No Surprises Act, the bill doesn't protect you from the need to pay co-pays, co-insurance, or deductibles, so you'll still need to pay those.

Do you have a surprise medical bill from a health care provider that you think might qualify? If so, contact the U.S. Department of Health and Human Services to file a complaint by calling 800-985-3059 (toll-free) or <https://www.cms.gov/nosurprises/consumers>.

Financial freedom classes for all learners

A nonprofit in Oregon is teaching young people with intellectual and other disabilities how to manage their own finances.



Financial Beginnings Oregon, creates personal finance classes and downloads for learners at all levels: K-12 to college. Topics include how to understand bills and have strategies for managing cash flow. They can also talk about managing debt, savings and investments.

Learn more, request materials or presentations at: <https://www.financialbeginnings.org/>

Study seeks parents of kids with seizures

When paramedics treat active seizures, one-third of children arrive at the hospital still seizing. As part of the Pediatric Dose Optimization for Seizures in Emergency Medical Services (PediDOSE) study, Dr. Matt Hansen is trying to improve these outcomes by helping paramedics to quickly give the right anti-seizure medication dose. Because it is a time-sensitive condition when a child is transported by ambulance to Oregon Health & Science University (OHSU), children will

get enrolled before parent/guardian permission can be sought.

To learn more about PediDOSE, and to participate in a 15-20 minute survey, visit <https://www.Texaschildrens.org/pedidose-study>. For more information, contact: cprem@ohsu.edu

This is an approved study: OHSU IRB #23026

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.