



OR F2F HIC

Continues the Work

We are happy to announce that the funding for the Oregon Family to Family Health Information Center has been extended through May, 2014. This means we will still be here to help families navigate the health system, offer trainings and workshops related to our kids' special health needs, and reach out to more families in rural Oregon.

Because *Every Child Deserves a Medical Home*, in 2013 –14 we will work to help families understand Oregon's new Patient Centered Primary Care Home program and what it means to their children, how the Affordable Care Act will impact their lives, and how they can get the most from their health care dollars. And, of course, continue to publish the newsletter and tip sheets, and represent families in policy-making efforts.

Contact our Family Liaisons at 855-323-6744, or email them directly!

- Clatsop County: [Diane Dieni](#)
- Wasco County: [Aaron Bowman](#)
- Hood River County: [Marisa Marquez](#)
- Marion/Linn/Benton: [Tami Montemayor](#)
- Portland Metro: [Shauna Signorini](#)
- Coos County: [Tracie Skinner](#)
- Malheur County: [Shelly Gilman](#)
- Statewide, Spanish: [Teresa Gomez](#)

FAST FACT:

Similar to the nation, CSHCN in Oregon are most likely to be adolescents, ages 12 to 17 years, and male.

Learn more: www.childhealthdata.org



Contact the

**Oregon Family to Family
Health Information Center** at
1-855-323-6744

**Stay in touch by joining
our mailing list!**

We Love Our Kids and Dogs!

Can a service or companion animal help your child?

The Americans With Disabilities Act of 2011 defines service dogs as those trained to do work *directly related* to a person's disability. A service dog accompanies a person with a disability at all times and must receive specialized training in one of the following areas:

Mobility Assistance (open/close doors, help with dressing/undressing, etc.)

Medical Response (retrieve medication, call 911, bark for help, or identify medical symptoms, etc.)

Signaling (alert handler to presence of people or sounds, warn of cars approaching from behind, etc.)

Guiding (avoid obstacles or moving vehicles, locate object or person on command, retrieve objects)

Autism Assistance (find and retrieve wandering handler to a safe place, interrupt self-harming behaviors, provide deep pressure in event of panic attack or meltdown, etc.)

Psychiatric Assistance (guide handler away from stressful situations, remind handler to take medication, etc.)

An **Emotional Support or Companion Dog**, on the other hand, does not usually have such specialized training. These animals are chosen for their gentle, calming temperament, and may be of any size or breed. While service dogs work outside the home and around groups of people, emotional support animals primarily provide comfort at home for one or two people. Federal law in the USA allows people with disabilities and psychiatric conditions to live with their emotional support animals even in housing that prohibits dogs.

Pet Partners (formerly the Delta Society of Portland) has much more information about service and companion animals, a directory of trainers and a list of minimum standards for service dogs. Visit their [webpage](#) or call the OR F2F HIC if you would like a copy of these resources. Commonly asked questions about service dogs and the law may be found [here](#).



Share your advocacy story!

Have you taken steps to get a service or item for your child? Have you ever spoken out on behalf of your child or other children?

Genetic Alliance is partnering with Parent to Parent USA (P2P) and Family Voices (FV) to collect resources that will help families advocate for their children, themselves, and others. They are



building an **online Advocacy Toolkit** which parents can use to build strong leadership and communication skills.

Do you have a story to share about a time you advocated for your child in one of the following areas?

- Transition to Adulthood
- Insurance and Financial Assistance
- Communicating with your Child's Doctor
- Getting Access to Health Care

To have your story considered for the **advocacy toolkit** please send a 1-3 paragraph summary to Sharon Romelczyk, Program Manager at sromelczyk@geneticalliance.org. Include only information you wish to be shared, including any and all names or other identifying information. Genetic Alliance staff will contact you to let you know if your story has been selected.

Questions? Contact sromelczyk@geneticalliance.org.

Program Spotlight: Community Connections Network

Do you have concerns about your child's health or development? Does your child have medical, emotional, learning, or behavioral needs that aren't being met? **Community Connections Network**, or CCN, may be able to help put the pieces together. CCN takes a team approach. A CCN meeting brings your family together with a doctor and people from school and community services. Your team works with you to figure out what's going on for your child. The team finds and coordinates the right services. You and your team will write a care plan with information, resources and referrals. You'll also be offered support with the plan, for as long as it's helpful to you. Any family is eligible, and there is no cost to meet with a CCN team.

CCN is available in these counties:

- Clatsop (Astoria and Seaside)
- Coos County
- Hood River
- Lincoln (Newport and Lincoln City)
- Linn County (Albany)
- Malheur (Ontario)
- Marion-Polk-Yamhill (Salem)
- Tillamook
- Wasco-Sherman-Gilliam (The Dalles)

CCN is a program of the Oregon Center for Children and Youth with Special Health Needs.

For more information, call 1-877-307-7070 or visit their webpage [here](#).

Alternate Newsletter Formats Available Upon Request



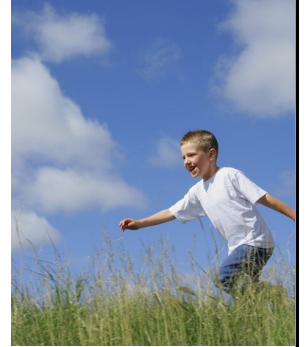
Families of children with special needs who do not have internet access may receive this newsletter by mail by calling

Is Your Child a "Wanderer?" Let Your Local Law Enforcement Know

Finding and safely recovering a missing child with special needs often presents a challenge for families, law enforcement, first responders, and search teams. The behaviors and actions of a missing child with special needs may be seen as non-compliant or confrontational. This can result in mistakes, misunderstandings, and sometimes the unnecessary use of force. Law enforcement agencies around the state have been receiving training on working with persons with Autism, however parents need to take steps as well.

If your child is a wanderer or prone to become lost in public or open spaces, contact your county and city law enforcement agency to ask about registering your child's information in their database. You can find your county's Public Safety Answering Point (PSAP) [here](#). If more than one PSAP is listed in your county, or if you live near a county line, contact all that might apply. Give the law enforcement agency the following information and ask what you can do to help your child stay safe in the event of wandering.

- Physical description such as height, weight, eye and hair color, any scars or other identifying marks
- Ways your child can be calmed down
- Sensory, medical, or critical dietary issues
- Behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Methods of communication, if non-verbal-sign language, picture boards, written word



More excellent tips can be found by visiting the programs below. Contact us if you need copies of their information.

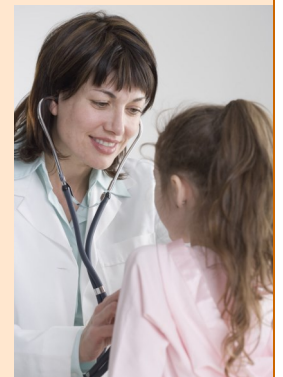
- [National Autism Association: Autism Safety](#)
- [Autism Society of Oregon](#)
- [Autism Risk & Safety Management](#)

Don't Forget Well-Child Visits for Your Child with Special Needs

Parents of children with complex medical conditions, especially those who visit one or more specialists, frequently tell us that they spend so much time with specialty care that they forget about making appointments for well-child checks! The Oregon Family to Family Health Information Center, as part of our Bright Futures for Families activity, reminds you that our kids with special needs should see a health care provider on the same schedule as their siblings who have no special health needs. (And remember that starting in 2014, under the Patient Protection and Affordable Care Act, well-child checks are a covered benefit on public insurance plans and most private plans. If you are worried about your child's weight or cholesterol, for example, you will be able to ask your health care provider for preventive care.)

We also hear from families that once their children reach middle childhood and adolescence, that they only visit the doctor if their child is sick, injured, or needs an exam for sports or camp. We urge families to get the most from their health plans, and schedule a well-check for their older children, too! Bright Futures reminds parents to take their children for well-checks between 5 and 6, 7 and 8, and 9 and 10 years of age. Once children become adolescents, you should schedule an appointment between 11 and 14, 15 and 17, and finally at 18 to 21 years of age.

See [Bright Futures for Families](#) for a great checklist of other reminders and guidelines.



The resources on this page are not comprehensive nor does inclusion imply endorsement by the Oregon F2F HIC or the Oregon Health & Science University (OHSU). These resources are intended to be a starting point for further research. The Oregon F2F HIC is a family-led effort, funded by a grant from the Health Resources and Services Administration/Maternal and Child Health Bureau. The F2F is closely affiliated with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), located at the Institute on Development & Disability (IDD) at OHSU.