



RESOURCE ROUNDUP

*Resources and Information for Families
of Children and Youth with Special Health Care Needs*

**Considering applying for
Supplemental Security Income (SSI)?**

52 New “Compassionate Allowance” Conditions Added

Some medical conditions are so serious that there is no question that they will meet the SSI criteria for eligibility. As of summer 2012, there are 165 adult and pediatric conditions that fall under SSI’s “compassionate allowance” rules. The list involves cancers, neurological disorders, some immune system disorders and more. [View the list here](#), or call 1-855-323-6744 to have the list mailed to you.

Note: even if your child has a condition on the “compassionate allowance” list, you still must meet income guidelines to qualify for SSI.

For a step-by-step guide to applying for SSI for your child, [click here](#). For a list of questions and answers about SSI for children with disabilities, [click here](#). For information by phone, contact your local Social Security Office.

The Oregon Poison Center

Teaching children with intellectual disabilities or impulsive behavior about safety can be challenging. Check out **The Oregon Poison Center**, located at Oregon Health & Science University. Parents can get a wealth of information about poison prevention. The center is staffed 24 hours a day by specially trained physicians and nurses. The OPC can answer your questions about what household products and plants are dangerous for kids, teens, and pets, and can help you in an emergency.



Call the OPC hot line, **1 800-222-1222**, for all poison emergencies and questions or visit the [website](#) for free materials.

FAST FACT:

52% (62,594) of Oregon children and youth with special health care needs age 1-17, have difficulty learning, understanding, or paying attention. Learn more:

www.childhealthdata.org



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

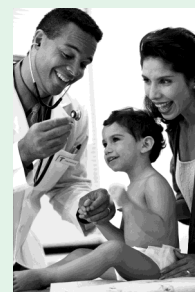


Stay in touch by joining our mailing list!

Parents as Powerful Partners

Here are some dilemmas we have heard from parents calling the Oregon Family to Family Health Information Center:

- *I’m more confused AFTER our appointment than I was BEFORE we came in!*
- *I’m not sure I agree with the plan our doctor has determined, but I’m not sure what to say.*
- *The people answering the phones at our insurance company have no idea what we are facing. I get so angry sometimes.*



Do any of these sound familiar?

The OR F2F HIC is here to help you if you feel overwhelmed by or uncertain about your communication with your child’s physician, their office staff, insurance companies, or health plans. As parents ourselves, we have learned some tips that might help you communicate more effectively, keep your confidence up, and explain your families’ needs and strengths.

We have a great “communication tips” handout from the National Initiative for Children’s Healthcare Quality. If you’d like a copy mailed to you, call us at 1-855-323-6744.

Don’t forget: you are an equal and valuable partner in your children’s health care decisions!



Free Help with Insurance Questions or Complaints

If you have private insurance, the OR F2F



HIC reminds you *that you are not alone* if you need help understanding your coverage or rights, or wish to make a complaint. The Consumer Advocacy Unit of the Oregon Insurance Division resolves thousands of consumer complaints each year and will advocate on your behalf. The quickest way to file a complaint is [online](#), but you can also call an advocate at **888-877-4894** for advice and guidance.

For Healthy Kids families:

If your child has *public insurance* (Healthy Kids) and you have a concern or question, give us a call here at the OR F2F HIC (**1-855-323-6744**) and we can help direct you.

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 1-855-323-6744.

Introducing Our Partners: Swindells Child Disability Centers

The OR F2F HIC is pleased to announce our partnership with the Swindells Child Disability Centers in Hood River, Newport, Medford, Salem, and Portland. Swindells Center helps us extend our reach to these communities and beyond, where services and resources may be harder to find.

In addition to answering questions and giving information to families of children with special needs, the Swindells Centers provide the OR F2F HIC with meeting space for Family Gatherings, distribute our outreach materials and newsletters, and provide training on a variety of special needs-related topics. We encourage you to visit a Swindells Center to:

- Browse the special needs library
- Take a class or workshop
- Join a support group
- Get a free copy of “My Child's Life Care Notebook and Organizer”
- Take a parenting class and more!

If you don't live near a Swindells Center, go on line to:

www.childdisabilityconnection.org and browse the resources there. You can request information be mailed to you!

[More Information about Swindells](#)

How do you Keep your Family Connected During a Health Crisis?

Many families of children with serious health conditions have discovered CaringBridge, a free online program that helps families keep connected with their friends and extended family members during a health crisis. It can help you simplify what is likely to be an emotional time, by providing space for you to post surgery or other updates, photos, requests, etc.,

CaringBridge has a strict privacy policy, and families alone decide what information is shared on their site. The templates are easy to use, and there is an additional “support planner” feature, which allows friends to organize that much-needed help like meal delivery, pet sitting, grocery shopping, etc. To see how other parents of children with special needs have used CaringBridge, visit www.caringbridge.org/story/

