



Parent Newsletters

Parents who cannot get out to meetings or events can still feel connected by reading materials written by parents, for parents. Here are some of our favorites:



[Hands and Voices](#)
[Deafblind](#)
[Complex Child](#)
[Family Voices Friday's Child](#)
[Catalyst Center Quarterly](#)
[My Child Without Limits](#)
[FACT Oregon](#)
[Disability is Natural](#)
[NAMI Beginnings](#)

No internet? Call us for a sample copy.

Upcoming Conference!



Shoulder to Shoulder 2012

Standing Together for Families
November 12, 2012

This state-wide conference is for families of children in the foster care system, both with and without special needs. Parent scholarships applications due by September 28.

FAST FACT:

Roughly 27% of Oregon children with special health care needs age 2-17 have ADD or ADHD (an estimated 29,893 children).

Learn More:

www.childhealthdata.org



CONTACT US!

E-Mail

1-855-323-6744

Spanish: 503-931-8930

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Could it be Genetic?

Anyone can have a birth defect or genetic disorder. Many families want to know if their child's condition was inherited or has a genetic basis. A genetic evaluation and genetic counseling may be helpful, especially if your child or someone in the family has:

- More than one birth defect
- Developmental delay/intellectual disability
- Growth problems

Genetic Consultation Services may help answer the following questions:

- Why did this happen?
- What can we expect in the future?
- Will this happen again?
- Where can we go for help?

How do families obtain a genetic evaluation and consultation?

Start by talking with your primary care provider or specialist and ask if they recommend a test. You may also call an [Oregon genetic clinic](#) directly and ask how to get a referral through your health plan.

What about home testing kits?

You may have seen an ad or website offering at-home genetic testing. Before buying a home genetics kit, [read more about their risks and limitations](#). If you would like a copy of the fact sheets on home genetic testing, contact the Or F2F HIC and we will mail it to you.



For more information, see:

[Western States Genetic Services Collaborative](#); [Genetics Home Reference](#)

— Your Child's Medical Home —

Developing a Care Notebook: Organizing your child's health information

If your child has special health needs, you know that medical appointments, lab tests, and visits to specialists and therapists generate a lot of new information. A care notebook is a good tool for organizing health information. It's a place to keep all of your child's healthcare information. It should include:

- A copy of your child's care plan and action plan
- Information about current services
- Allergies and immunizations
- What to do for your child in an emergency
- Reports from professionals who provide services to your child
- Information on hospitalizations and emergency room visits
- Results of tests and procedures
- Other forms, for example a medication log or seizure log
- Family information



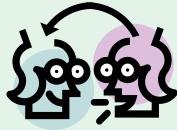
Make sure to update information in the care notebook regularly. Share the information with your child's doctor, specialists, teachers, and therapists at each visit. Having the information handy can help you manage your child's care better. What's a care plan? A care plan contains information on your child's past medical care such as hospitalizations, immunizations and allergies. It also tells what needs to be done for your child, who will do it, and when. An action plan identifies two or three goals for you and your child and the steps needed to address them over the next few months. We will discuss care plans and action plans in more detail next month.

The Oregon Center for Children and Youth with Special Health Needs has tips for organizing healthcare information and links to forms you can use. Go to http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/What_is_a_Care_Notebook.pdf or call us for a copy.



Parents' Wisdom— Communicating with Your Child's Physician

Families
share their
advice:



"Be open minded about suggestions from the health care provider but share your experience and biases about suggestions or treatment philosophy so that treatment options can be explored together." DD, Gearhart

"Don't be afraid to ask questions of your doctor or other health care providers. Make sure the terminology and vocabulary they are using make sense to you and others. Knowledge is power, but only if you understand it." AB, The Dalles

"There is a great binder at Swindell's center that is free and offers families a fantastic way to make sure that physicians are kept up to date. Come (to appointment) ready with questions you would like answered as well as important facts about your child." LW, Portland

"Try your best to be early, prepared with a list of questions and if at all possible, not frazzled. Express appreciation for their expertise and care for your child." SS, Troutdale

Next month's question is:
"What is your best advice when working with your child's insurance company? What tips do you have to get children the treatment they need?" [Send us your advice!](#)

Should your Child Participate in a Clinical Trial?

Parents of children with special health conditions are sometimes asked to participate in research studies (also called "clinical trials") of new drugs or treatments. Clinical trials are the best way for doctors to decide whether a new treatment is effective and safe. The Food and Drug Administration (FDA) requires thorough research before making new drugs available to everyone. Here is some information that can help you decide whether or not to have your child take part in a research study:



- Always discuss the study with your child's doctor. Bring him or her the information about the trial in case he or she has questions you are unable to answer.
- If you enroll your child in a study, you can always decide to withdraw from it later if you are not comfortable.
- Most studies offer the study drug and/or treatments for free and may pay you money for time and travel.
- All research studies will require you to sign an "informed consent form" which will tell you the purpose of the study, what is involved, and any potential risks that are known about the treatment.

[The Center for Information on Clinical Research Participation](#) has more excellent information on this topic. To see if there are any research studies on your child's condition, visit: <http://clinicaltrials.gov>. If you do not have internet access, and need this information sent by mail, call us at 855-323-6744.

Mental Health Resource for Oregon Youth Experiencing Early Signs of Psychosis: Early Assessment and Support Alliance (EASA)



Psychosis is a common brain condition which, if untreated, prevents one from knowing what is real and what is not. Most people who develop psychosis do so between the ages of 15 and 25. Some of the signs and symptoms may include:

- reduced performance (such as having trouble with activities that used to be easy)
- behavior changes (such as new or extreme fears or saying things that make no sense)
- perceptual changes (such as hearing voices or sounds that others do not.)

With the right early identification, support, and treatment, young people can manage and even prevent psychosis and get on with their lives.

EASA programs are in most Oregon counties. The [EASA website](#) is a wealth of information for parents and siblings of youth experiencing psychosis, as well as some inspiring [success stories](#).