



Baby's First Test- What's Newborn Screening?

Newborn screening is a special blood test that can find serious conditions that cause mental and physical impairment or death if not treated early. When a baby is 24 - 48 hours old, a few drops of blood are taken from his heel and put onto a special paper. The test is repeated when the baby is 10 -15 days old. Oregon babies are tested for more than 30 disorders, including Cystic Fibrosis. The good news is that most babies who are identified with a serious condition at birth get treatment early and grow up healthy.



[Read more here](#), and [see a demonstration](#) of newborn screening here. Or, contact the Or F2F HIC if you need information mailed to you.

FAST FACT:

56% of children with special health care needs in Oregon have adequate private and/or public insurance to pay for the services they need.

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!](#)

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

Getting You to the Conference!

Many parents of children with special needs will say that attending conferences and seminars is one of the best investments of time, money, and energy. Although it can be hard to get away to a conference or training, we encourage you to give it a try!

At a conference you can:



- Meet other families who share your experience
- Meet experts who can help you get the information you need
- Learn about the most recent treatments or interventions available to your child
- Get re-energized with new ideas

See page two for a list of just some of the conference opportunities in Oregon . There are many, many more, and some scholarships are available to help you get there!

The Oregon F2F HIC has a tip sheet called *"Getting You to the Conference: Funding Tips for Families."* Call 1-855-323-6744 if you would like a copy.

— Your Child's Medical Home — Tips for a Successful Office Visit

If your child has a disability or a chronic condition, a visit to the doctor may be stressful for you both. The doctor's office can work with you to make sure the visit is successful.

Here are some tips from the Oregon Center for Children and Youth with Special Health Needs:

- When you schedule your child's appointment, mention any special needs he or she has. You know what will work best, so feel free to suggest it. For example, maybe your child could benefit from a longer appointment; or perhaps he would do better if the appointment was at a special time of day.
- If your child has difficulty with long waits, the receptionist may be able to call you in the car when the doctor is ready to see you and your child.
- If your child is sensitive to light or sound, suggest lowering the lights or scheduling the visit when few children and parents are present.



For [more tips](#) on how to set up your child's visit to the doctor for success, call us at 855-323-6744 and ask to speak with a Family Liaison.



Keeping Children Safe

—Wandering—

Those of us who have children who are prone to wandering know how frightening it is when our child wanders away. According to the AWAARE Collaboration, a child might wander away from you to get something of interest, like water or train tracks, or to get away from something that is disturbing him, like loud noise or people.

Make sure your family has a [plan](#) in case of a wandering emergency. Before an emergency happens, sit down together and decide how you will get in contact with each other, where you will go and what you will do in an emergency. Keep a copy of this plan in your emergency supply kit or another safe place where you can access it in the event your child is missing.

Many excellent resources about wandering are available from AWAARE. If you would like copies of their information, call us at 1-855-323-6744.



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.

Your Child's Health Records are Confidential

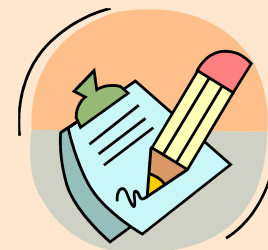
—What to Consider when Signing a Medical Release Form—



As parents of children with special health needs, we are frequently asked to sign medical release forms that allow doctors to give our kids' records to schools or other organizations. Here are some things to keep in mind about medical release forms:

- *Always check to see if the medical release has an expiration date.* If there isn't an expiration date that means the organization could have full access to your child's health records, forever, until you revoke it in writing.
- *You can control what information is included.* If you only want some records to be released, you will need to indicate that on the form.
- *You may want to contact the doctor directly* for the required information rather than signing a release form. You can always take the form to the doctor's office yourself and deliver the records yourself. That way you know exactly what is being shared.
- *You can ask the doctor's office to contact you* any time they receive a request for information. This way you will keep aware of who requested it, what is being released, and when it was released.
- *If you have any concerns* regarding how your child's records have been shared, you should contact the doctor immediately.

This information is based on the article "[To Sign or Not to Sign](#)" by Karen Scallan and printed in [Complex Child E-Magazine](#). If you would like a reprint of the entire article, call us at 855-323-6744.



Getting You to the Conference, continued

Below are just some of the conferences and events for families and professionals coming up in Oregon:

[A Gift of Time – September 7 - 9, 2012](#)

A state-wide weekend break for family caregivers and grandparents.

[Oregon Disability MegaConference – October 25-27, 2012](#)

The Mega Conference is three days of outstanding sessions, nationally acclaimed speakers, and exhibitors/vendors from across the county and this year features the Employment Extravaganza.

[UCP Family Conference – November 2-3, 2012 \(UCP\)](#)

15th UCP Family Conference on Cerebral Palsy and Other Developmental Disabilities. Please contact Susan Cushman for more information: scushman@ucpaorwa.org or 503-777-4166 ext 332 or 1-800-473-4581