



Did Insurance Deny Medical Equipment for Your Child?

Wheel to Walk is a nonprofit foundation that assists families of children and young adults (21 years or younger) with special needs to obtain medical equipment that is not provided by their insurance company. They purchase equipment such as wheelchairs, therapy bikes, special beds, and communication devices. You must have been denied by insurance, and you must demonstrate a financial need. If your application is selected, the funds will be sent directly to the company where the equipment is being purchased.

Please note that they do not pay for iPads, iPhones, iPods, or computers.

For more information, visit www.wheeltowalk.com. To request an application, you can email them at info@wheeltowalk.com or call 503-257-1401.

FAST FACT:

22% of Oregon children with special health care needs (around 26,335 children) have difficulty with coordination or moving around.

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!**

Speech Therapy On the Computer?

Our guest writer Sharon Soliday, Speech Therapist with The Hello Foundation, answers typical questions about receiving speech therapy online. Rural families who have difficulty finding speech therapists in their communities may wish to look into this unique approach. For more information, call the OR F2F HIC at 855-323-6744.

Q: Is it true that individuals needing speech therapy can now access direct service online?

A: Absolutely. Many different therapists are using the internet to bring high quality service to clients. Online service is flexible and convenient.

Q: Can anyone benefit from online speech therapy?

A: Most clients needing help from a specialist can benefit. A professional speech therapist will be able to determine if you are a good candidate.

Q: What communication challenges can a speech therapist address online?

A: Many! Articulation, Language, Cognitive Thinking Skills, Organization, Consultation for medically fragile individuals. Whether a person is 8 months or 80 years old, a qualified speech therapist can help.

Resources:

Teletherapy Technical Report: www.asha.org/docs/html/TR2005-00152.html

Private Online Therapy: www.thehellofoundation.com/PrivateOnlineTraining

Visual Speech Therapy: www.visualspeechtherapy.com/blog/view/what-is-visual-speech-therapy-like

Parent Group Spotlight

Parents of Children with Eosinophilic Disorders

You are not alone— neither is your child

Meet with other parents of children with Eosinophilic Disorders to:

- Educate one another about the latest resources and research on your child's condition
- Share coping and feeding strategies for your child and the family as a whole
- Problem solve and strategize to face the complications parents have dealing with a child's continuous care
- Plan for your child and family's future

Please contact, Darlene Pagán at
dmpagan@frontier.com
or call 503-591-1536

(Darlene and her husband are parents of a son with Eosinophilic Esophagitis)

MD 4KIDS Free Smart Phone App Available Now!

What should you do if your child develops a fever, cough, vomiting, rash, sore throat, or head injury?

Get answers quickly using the Doernbecher Children's Hospital app called **MD 4KIDS**. This app is available for iPhones or Androids.

MD 4KIDS can help you make smart decisions on what level of care (if any) is needed and how to **provide symptom relief for minor illnesses or injuries you can manage at home.**

To download the free app, search "MD 4KIDS" on iTunes or Android Market.

Don't have a Smartphone? You can still access all of the information online at:

www.ohsdoernbecher.com/md4kids





What is your Story? Seeking Submissions from Mothers of Children with Special Needs

Mothers of children with special needs are invited to submit their creative thoughts, poems, or stories to a new anthology. The editors of the anthology are Lyn Jones and Liz Whiteacre from Ball State University in Indianapolis and they have asked our Family to Family Health Information Center to encourage Oregon families to add their voices.

Mothers of children with special needs, please consider submitting an essay or poem, with photos or illustrations if you wish. Your work must address one of these themes:

- Challenges: Sometimes it sucks
- Purpose: I learned my own power; I get "it"
- Providence: Why was I chosen?
- Joy: It is the simple things

Guidelines: You may submit more than one piece. Essays should be fewer than 6,000 words and typed in 12 point, double-spaced font. For more information on guidelines, contact lizwhiteacre@gmail.com.

The deadline to submit is **Monday, April 22, 2013.**

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.**

Summer is Just Around the Corner: Does Your Child With Special Needs Require Extra Safety Precautions?

All parents worry about safety. But families of children with special physical, developmental, or behavioral health needs have more to consider. When a child is impulsive, has a sensory impairment, or doesn't understand your instructions, he or she may be at a greater risk for injury. If you worry about your child and feel you need help to keep him or her safe, speak to your child's doctors, nurses, teachers, therapists or other providers. Below are some resources specifically aimed at families of children with a variety of special needs.

- Safekids USA has a series of videos created to help parents and caregivers organize the home to prevent injuries. Other video topics include children with cognitive disorders, wheel chairs, autism, and blindness. The videos highlight how to prevent injuries to children with physical, cognitive, and developmental disabilities. For more information: www.safekids.org/safety-basics/special-needs
- Dennis Debbaud's excellent guide entitled "[Are You Prepared for an Autism Emergency?](#)" Also available by calling us at 855-323-6744.
- [Child Passenger Safety Clinics](#) are held all around the state. If you would like a consultation about acquiring a special needs car seat or restraint system, call the ACTS Oregon Help Line at 877-793-2608.
- There are [Safe Kids Coalitions](#) in all corners of Oregon that can help parents with a variety of safety topics and products. Call 971-673-1001 to find a group near you.



Do You Have a Child with a Rare Illness or Condition?

Madisons Foundation believes that information is support. This website links families with children who have rare illnesses with other families fighting the same disease or condition from around the world. Using their "connecting parents" program, parents can create a personal network of support. Also, parents and caregivers can search a database of over 550 rare diseases.

Visit their website to sign up for free: www.madisonsfoundation.org

If you don't have the internet, call the F2F HIC at 1-855-323-6744 and a Family Liaison will be able to help you access the information.

MOMS AND DADS
IN SEARCH OF
NEEDED SUPPORT



madisons
FOUNDATION

"Rare diseases are very common."

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.