



Child Safety Information & Low Cost Safety Products

The Tom Sargent Safety Center offers low cost home safety products, sport helmets and information to help you keep your children safe. Their staff includes Certified Child Passenger Technicians with special needs training and they offer car seat checks at the hospital, for families in the Portland Metro area and can help you find a clinic in your area too. They are happy to mail products within Oregon and SW Washington and can be reached Monday – Friday from 10:00-4:00 by phone at (503) 418-5666 or anytime at safety@ohsu.edu.



To learn more about their products, programs and community partners or to download seasonal safety tips, please visit our website at www.ohsu.edu/childsafety. They look forward to working with you and your family!

FAST FACT:

38% of Oregon children with special health care needs age 3-17 (or roughly 42,000) have difficulty making and keeping friends.
Learn more: www.childhealthdata.org



CONTACT US!

E-Mail

1-855-323-6744

Spanish: 503-931-8930

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The Power of Parents Helping Parents

When you are seeking reliable information about your child's diagnosis, an excellent source of up-to-date information can be a national, parent-driven organization. Many parent-led foundations fund research, sponsor conferences, and offer on-line parent-matching programs. These are just a few of the many well-known organizations that were founded BY parents FOR parents.

Prader-Willi Association: Founded in 1975 by Seattle parents Gene and Fausta Deterling. Originally called "Prader-Willi Parents and Friends," the group had 140 members in just one year.

CHADD: Founded in 1987 by a handful of parents in response to the "frustration and isolation" that Attention Deficit Disorder caused their children and families.

National Down Syndrome Society: Founded in 1978 by new mom Betsy Goodwin and her good friend, Arden Moulten, after Betsy found there was a lack of current information about Down syndrome available to her.

United Cerebral Palsy: Founded in 1948 by two sets of parents in Long Island, New York, who placed an ad in the newspaper recruiting other parents to help "improve the quality of life for their children with cerebral palsy and for others like them."

Autism Society of America: Founded in 1965 by Dr. Bernard Rimland, ground-breaking autism researcher and father of a young man with autism who would inspire the story of "Rainman."

There are many other parent-led foundations for conditions such as Fragile X Syndrome, Epilepsy, Apraxia, and even one for rare disorders. For help finding a parent-led group that is specific to your child's unique health needs, call us at 1-855-323-6744.

Celebrating Caregivers Like You

If you are caring for a child with complex, chronic health care needs, we urge you to speak up for respect, support, information, and to get the help you need. Here are some tips and suggestions provided by the National Family Caregivers Association, the nation's leading organization for family caregivers. For more information, and a wealth of other resources for caregivers, call 1-800-896-3650 or visit www.thefamilycaregiver.org

Believe in Yourself. You have the right to make choices that are in your own best interests, such as:

- Recognizing your strengths and acknowledging your limitations
- Learning to say "no"
- Commanding respect from healthcare providers



Protect Your Health. You have the right to:

- A good night's sleep
- Time to exercise
- Regular checkups to ensure that if something is wrong you catch it early
- A life of your own apart from caregiving

Reach Out for Help. You have the right to ask for:

- Recognition that family caregiving is more than a one-person job
- Care coordination services to help you navigate the health care system
- Financial assistance so you can purchase help in the marketplace
- Adequate education and training in the skills you need

Want to share your caregiving story or reach out to other caregivers? [Visit the Caregiver Story Project.](#)

Parents' Wisdom: Keeping Up With it All

We asked parents, "How do you keep track of all of the meetings, doctor's appointments, therapy appointments, prescriptions, reminders, insurance paperwork, school, etc.?" and here is their advice:

"Google Calendar. You can color code appointment types and link them to your phone. Also, getting one big binder and organizing it to fit your needs. Swindell's has a great binder that will lead you through the process."
LW, Portland



Keeping a binder has kept all of our paperwork organized. IN the front we

keep a page with insurance phone number numbers/policy numbers, doctor phone numbers/professional phone numbers. HC, Salem

I love Google Calendar for tracking appointments, and I keep all the contact numbers and addresses in my phone for quick access on the road! I ask for text reminders when that's available. CC, Portland

I use a full size planner with a calendar large enough that I can write all of my appointments and make a list of things I need to do. It is more like a client appointment book, that way I have lots of room to write the things down that I need to do or remember. I carry it with me where ever I go. TS, Coos Bay



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.

After a Hospitalization: Helping Assure a Smooth Transition Home

The transition from hospital to home for children and youth with special healthcare needs can be a complicated process if you don't have a plan in place. Some things for your family to consider include:

Parents' readiness: Once your child is medically stable for home care, are you prepared? Are all of your questions answered? Do you know when and who to call in case of emergency? Do you know what changes or symptoms you should be watching for? If you live far from the hospital, what steps will you take?

Your house: Do you have everything you need to make sure your house is safe and accessible? If you aren't sure, who can help you take a look around to help you accommodate any special equipment you will be bringing home?

Siblings and family: Is there someone close to your family who can help you coordinate meals, school, transportation, appointments, etc? Is there another family member of a child with a similar condition available for you to talk to?

Medications, equipment and supplies: Who is responsible for arranging for medications, equipment, and disposable supplies? If it is you, do you have all of the contact information at hand? How long will the supplies you go home with last?

Communication: How will you and your child's physicians communicate? Are the phone numbers in your phone and where others can find them? When will you see the pediatrician next? Do you have a place to write down your questions and concerns between visits?

Training: Do you feel you are adequately trained to care for your child and that all of your questions are answered? Speak up if you feel you need more supervision or help you while you are learning to manage new procedures, equipment, routines, etc.

The American Academy of Pediatrics recently [published an article](#) about this topic in more detail. If you would like to receive a copy of it by mail, contact the OR F2F HIC 855-323-76744.

Are you the parent of a child with special health needs in *Rural Oregon*?

- Would you like to increase your knowledge about the services and programs that might be available to your child?



- Would you like to learn more about how to be your child's health advocate?

- Would you like to meet other parents who share your experiences?

The Oregon Family to Family Health Information Center is now scheduling Regional Family Gatherings for winter and spring, 2013.

Call 1-855-323-6744 to find out about one in your community!

We want your advice!

Answer one or more of these questions with your best advice for other parents! We will include it in our "Parents' Wisdom" columns.

School and Health:

Does your child miss school or other activities because of his or her special health care needs? If so, how do you manage absences? How do you work with teachers, coaches, etc.,

Working with Case Managers:

What are your tips for working with your child's case manager or care coordinator? How do you assure that they know your family's needs, goals, and strengths?

Conferences and Trainings:

What conferences, workshops, or trainings have you found helpful that you would like to recommend to others?

Send your responses to:

contact@oregonfamilytofamily.org