Families of CYSHN: Helpful Resources, Family Perspectives

OREGON
Family to Family
Health Information Center

OR F2F HIC is closely affiliated with the Oregon Center for Children and Youth with Special Health Care Needs (OCCYSHN) at OHSU and funded by a grant from the Maternal and Child Health Bureau.

Objectives

- Introduce providers and care coordinators to a family perspective on peer support
- Inviting conversations that enhance the relationship
- Share reliable resources for families post-diagnosis or on a diagnostic journey
  - condition-specific
  - financial
  - legal/educational
  - specialty
  - leisure and recreational
- Introduce Services and support available from the Oregon F2F HIC

Links will be emailed to participants upon request.

The Problem:

“We are overwhelmed, scared, confused, angry, and in the dark. Who will help us?”

Our response:

Eventually, things will become clear.

But for now, there are many people who can help you.

Your providers, teachers, social workers, case managers and other professionals can all be sources of support and information.

But there are some other helpers who are *free* and *available all hours of the day*: OTHER PARENTS.”

Top 5 Reasons to refer to parent to parent peer support

1) Normalizes experiences

Benefit to PCP: once a family starts to share and feel comfortable talking, their stress level goes down and ability to learn goes up

2) Parents get feedback on their experiences. “*That doesn’t seem normal to me…maybe you want to check that out.*”

Benefit to PCP: Parent might bring something to your attention that she otherwise would have just accepted as ‘normal.’ (absence seizures, for example)

3)Parents learn about resources you may not have heard of, (camps, reading programs, play groups, sports programs)

Benefit to PCP: participating in fun activities is good for everyone. Less isolation = better health.

Another benefit to PCP: this parent can keep you informed of good programs in the community

4) Parents learn how to manage the education, insurance, pharmacy, and other systems

Benefit to PCP: A parent who knows how to navigate systems can work more easily with your care coordination staff.

5) Parents can benefit from others' transition experiences. Hearing about others' successes can help ease worries and fears.

Benefit to PCP: families will help you manage their children's transitions

Some clues that a parent may benefit from peer support

- “Oh, we don’t go out too much, its just too hard.”
- “Oh, my child would never let us do that!”
- “Oh, its just easier to keep the (food, pets, etc) locked up so my child doesn’t get into them.
- “Have YOU ever seen a child like this?”
- “None of our other family members understand what its like for us.”

Listen for comments like these and ask for more information!

Sometimes we are *embarrassed* or *reluctant* to tell you everything. We may lack confidence or simply be more reserved. Sometimes, it doesn’t occur to us to tell you more about our family, even though you can help!

Suggested wording for making a parent-to-parent referral

- *"Do you know any other parents who are going through what you are going through? Would you like to?"*

- *"Sometimes my patients find it helpful to talk with other parents whose child has the same condition. I know of a program…"*

- *"If you ever feel like your family and friends aren't "getting it" let me know because I can refer you to a program that might be able to help."*

A Few Peer Programs you can refer to – Spanish and English (Partial List)

Oregon Family to Family Health Information Center

- Clearinghouse for over 100 groups in Oregon plus many other health resources

Swindells Child Disability Resource Center

- Free lending library and current training on many subjects

FACT

- All things education and person-centered thinking

Autism Society of Oregon

- All things autism-related

NW Down Syndrome Association

- All things Down syndrome-related and inclusive education

United Cerebral Palsy

- Also serves families whose children have conditions that mimic CP

These groups have paid staff, will serve families regardless of where they live, phone lines are answered reliably, and can readily respond in Spanish and/or Russian.

RESOURCES AND MORE!

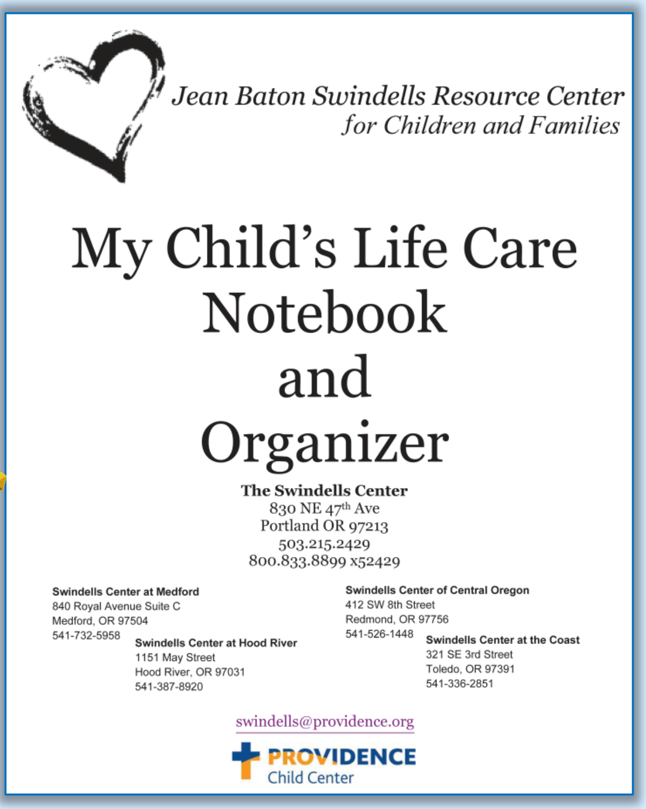
INFORMATION YOU CAN USE NOW TO HELP YOUR CHILD WITH SPECIAL NEEDS

Your County Here Date

OREGON
Family to Family
Health Information Center

Your Child's Life Care Notebook

FREE for Oregon residents, courtesy of Swindells Center



Jean Baton Swindells Resource Center
for Children and Families

My Child's Life Care
Notebook
and
Organizer

The Swindells Center
830 NE 47th Ave
Portland OR 97213
503.215.2429
800.833.8899 x52429

Swindells Center at Medford
840 Royal Avenue Suite C
Medford, OR 97504
541-732-5958

Swindells Center at Hood River
1151 May Street
Hood River, OR 97031
541-387-8920

Swindells Center of Central Oregon
412 SW 8th Street
Redmond, OR 97756
541-526-1448

Swindells Center at the Coast
321 SE 3rd Street
Toledo, OR 97391
541-336-2851

swindells@providence.org

PROVIDENCE
Child Center

Community-Based Programs

CaCoon

- Specially-trained nurses
- Home visits
- Care coordination assistance
- No income requirement
- Can work with your child's physician
- In 35 of 36 Oregon counties (not Wallowa)
- Sometimes work with children up to age 21

Call County Health Department, ask to speak with CaCoon Nurse

Community Connections Network (CCN)

- Family-centered approach
- Multi-disciplinary team
- No income requirement
- Ideas, resources, and guidance
- Family Liaison follow up
- Located in:
  Albany ▪ Clatsop County ▪ Coos Bay ▪ Hood River ▪ Ontario ▪ Salem ▪ Seaside ▪ The Dalles ▪ Tillamook ▪ Newport

Call OCCYSHN at 877-307-7070

Community Developmental Disabilities Programs (“DD Services”)

- Disability must have origin in the brain
- Occurred prior to the age of 18
- Expected to last indefinitely
- Result in significant impairments in two 2+ functional areas: (self care, communication, cognitive, mobility, self direction, ability to work and live independently)
- The impairments must not be primarily related to: mental illness, substance abuse, an emotional disorder, Attention Deficit/Hyperactivity Disorder (ADHD), a learning disability or sensory impairment

If your child has been denied services as ineligible, you may appeal.

✓ It is important that these services are obtained BEFORE age 18.

✓ NEW OPPORTUNITIES ARE AVAILABLE THROUGH THE K PLAN!

Children's Intensive In-Home Services

(for Children who Qualify for DD Services only)

Intensive Behavior Program

Provides support services for children up to age 18 who demonstrate intense behaviors that are dangerous to themselves or others.

Typically, the entire household must make extreme adaptations to keep everyone safe.

Eligibility: Evaluation conducted by CIIS staff and reviewed by the CIIS behavioral team. Family income is not a factor for eligibility.

971-673-2995

If your child does not qualify for the intensive program, he may still be eligible for a behavior consultation through the Oregon Technical Assistance Corporation or a private behavioral consultant.

Ask your Service Coordinator.

Children's Intensive In-Home Services

No DD or income Eligibility Required – Ages 0-18

Medically Fragile Program

Support services for children who have very intense medical needs, are technology dependent and require nursing care.

Eligibility: A clinical criterion as conducted by MFCU nursing staff with input from the families and medical community.

971-673-3000

Medically Involved Program

Support services for children who have a medical condition requiring total assistance with all activities of daily living (ADLs). These children are not technology dependent but due to their size and weight require maximum interventions.

Eligibility: Evaluation conducted by CIIS staff with input from the families and medical community.

971-673-2990

Specialty Clinics at OHSU/CDRC

(partial list)

- Autism
- Genetic Evaluation and Counseling
- Brain Anomolies
- Down Syndrome
- Craniofacial Disorders
- Hemangioma/Birthmarks
- Feeding and Swallowing
- Gastroenterology
- Cystic Fibrosis
- Metabolic/PKU
- Neurodevelopmental Delays
- Rett syndrome
- Cleft Palate
- Craniofacial Disorders
- Spina Bifida
- Sleep Disorders
- Cardiology
- Hemophilia
- Diabetes

Family to Family Support "on the hill"

Carol Criswell and Laura Wilson, Family Navigators

Friendly, supportive parents of children with special health needs will help families navigate appointments, transportation, etc.

Jennifer Horner, March of Dimes Family Navigator in NICU.

Financial RESOURCES (partial list!)

211

A free, information and referral helpline for Oregon. You can get help from a live person with interpreters ready to help in 150 different languages. Housing, food, emergency supports.

800-723-3638 • www.oregonsafenet.org

Oregon HELPS!

Free, confidential, and easy prescreening website to help families determine eligibility for 33 assistance programs. On line only.

www.oregonhelps.org

ZETOSCH FUNDS

Sidney and Lillian Zetosch Fund

Grants for the purchase of adaptive equipment to help Oregon's low-income children 0 – 21 with special health needs. Equipment must help child achieve educational goals. Families must be referred by a service provider or teacher.

503-494-8618 • www.ohsu.edu/xd/outreach/occyshn

Financial RESOURCES

Help Paying for Prescriptions

Huge database of drug companies' discount programs, scholarships, coupons, etc.

www.Needymeds.org

Developmental Disabilities Consumer Involvement Fund

Funds for families of children with developmental disabilities to attend conferences and trainings related to their child's condition.

www.ocdd.org/index.php/ocdd/getinvolved/24/

Supplemental Security Income

Generally awarded to children with significant disabilities whose parents meet the income threshold. Consult the Compassionate Allowance List conditions that qualify for fast approval. Starter application kit available.

http://www.ssa.gov/pubs/EN-05-10026.pdf

A few more excellent resources…

Compassionate Allowances
for Supplemental Security Income

Over 100 Conditions which allow for "fast tracking" to SSI Eligibility

Helping Families with SSI applications:

AAP Publication 2009

Guidelines from the SSA

GEMSS for School Success

Easy to read guidelines for care for 25+ genetic conditions. Suitable for parents and professionals.

Camps and Recreation List
Thank you to Shriner's Transition Program!

Specialty RESOURCES: Statewide

ORPARC (Oregon Post-Adoption Resource Center)

Free support to Oregon DHS Adoptive and Assisted Guardianship families and Oregon Families who have adopted through any state's child welfare system. Counseling, referrals, resources, and more.

800-764-8367 or 503-241-0799 • www.orparc.org

Special Needs Car Seat Consultation and Fitting

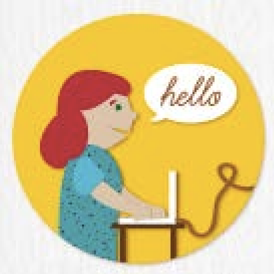
Specially trained safety specialists works with families of children with unique physical or behavioral needs that put them or their families at risk while traveling by car. **http://cert.safekids.org (search "Find a Tech")**

Health Information by Mail

OHSU reference librarians will mail articles and other information to families who do not have internet access. Simply call and ask to speak to a Health Information by Mail Reference Librarian. **503-494-8881**

http://www.ohsu.edu/xd/education/library/research-assistance/health-information-by-mail.cfm?WT_rank=1

Specialty RESOURCES



Hello Foundation Speech and Occupational Tele-therapy

Some scholarships available

503-228-2942 www.thehellofoundation.com

A Gift of Time Retreat

September retreat for caregivers. Pamper Yourself!

www.agiftoftimeoforegon.org

EASA
Early Assessment & Support Alliance

Early Assessment & Support Alliance

Helping families identify and treat early signs of psychosis in teens. Evidence based.

503-361-2796 www.easacommunity.org

Specialty RESOURCES

Inclusive Child Care Program

Inclusive Child Care Program

May help pay for increased costs of care related to a child's special care needs. Coordinates child care subsidies for eligible families. Provides individualized planning to families.

971-673-2286 or 1-866-837-0250 • www.oregoninclusivecc.org

Now, if you can't remember all of this… Call us!

OREGON

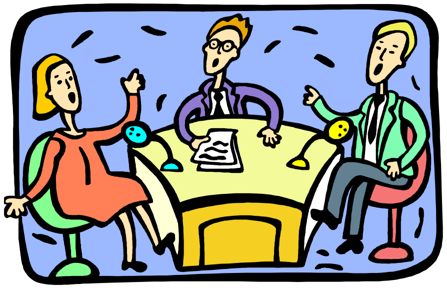
Family to Family

Health Information Center

How we do the work…

One-to-one

Website and list-serve



Family Gatherings

Publications:
newsletters and tip sheets

One-to-one support from an experienced Family Liaison

1-855-323-6744	English/Spanish
503-931-8930	Spanish

All Family Liaisons have their own confidential OHSU email accounts.

Typical Calls

"I just got this notice from my insurance agent. Can you help me before Obamacare kicks in?"

"*My pediatrician told us today that my 26 year old is too old to keep coming there and that this would be her last appointment. How do I find a doctor who understands ___syndrome?*"

"*I'm working with a family whose 9 year old has ___ and they want to get to the ___ conference. Can you tell me what scholarships there are?*"

"The medication costs are killing us. Is there any help out there?"

"I'm moving to Oregon in the fall, can you tell me what kind of services my child with a vent can get?"

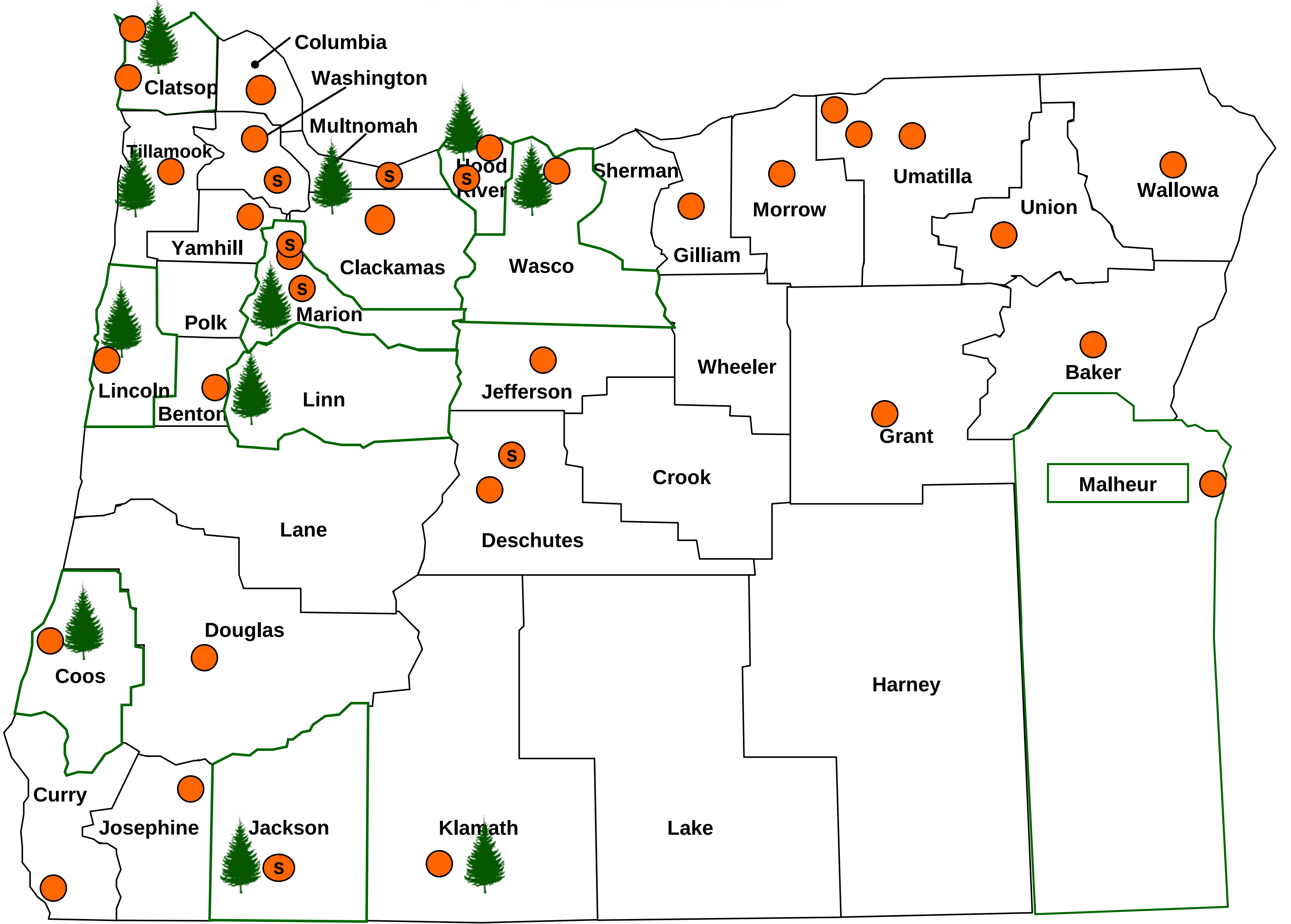
"*My insurance denied a helmet for my child, but my friends' insurance paid for hers. How do I appeal?*"

"My friend has a home visiting nurse. How do I get one?"

"I think my child's condition is genetic, but my doctor doesn't want to authorize the test. Where can I get it done?"


BELIEVE TRUST

OREGON Family to Family Health Information Center

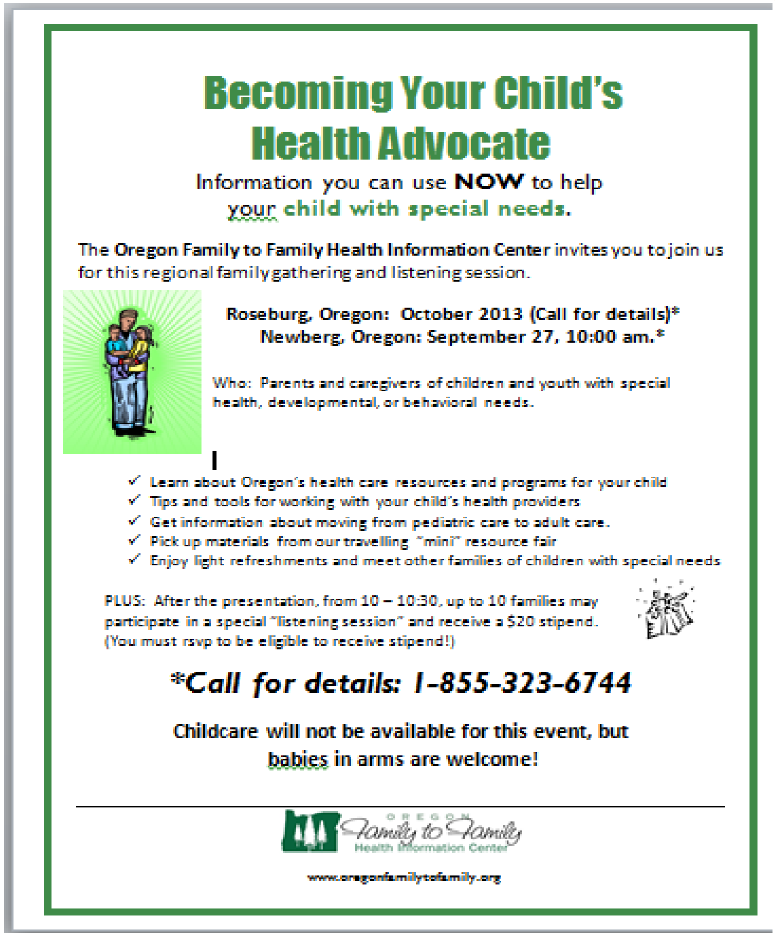


Family Liaisons and Swindells Child Disability Resource Center Sites

● **Listening Session**

● S **Listening Session in Spanish**

Regional Family Gatherings



Becoming Your Child's Health Advocate

Information you can use **NOW** to help your **child with special needs.**

The **Oregon Family to Family Health Information Center** invites you to join us for this regional family gathering and listening session.

Roseburg, Oregon: October 2013 (Call for details)*
Newberg, Oregon: September 27, 10:00 am.*

Who: Parents and caregivers of children and youth with special health, developmental, or behavioral needs.

- ✓ Learn about Oregon's health care resources and programs for your child
- ✓ Tips and tools for working with your child's health providers
- ✓ Get information about moving from pediatric care to adult care.
- ✓ Pick up materials from our travelling "mini" resource fair
- ✓ Enjoy light refreshments and meet other families of children with special needs

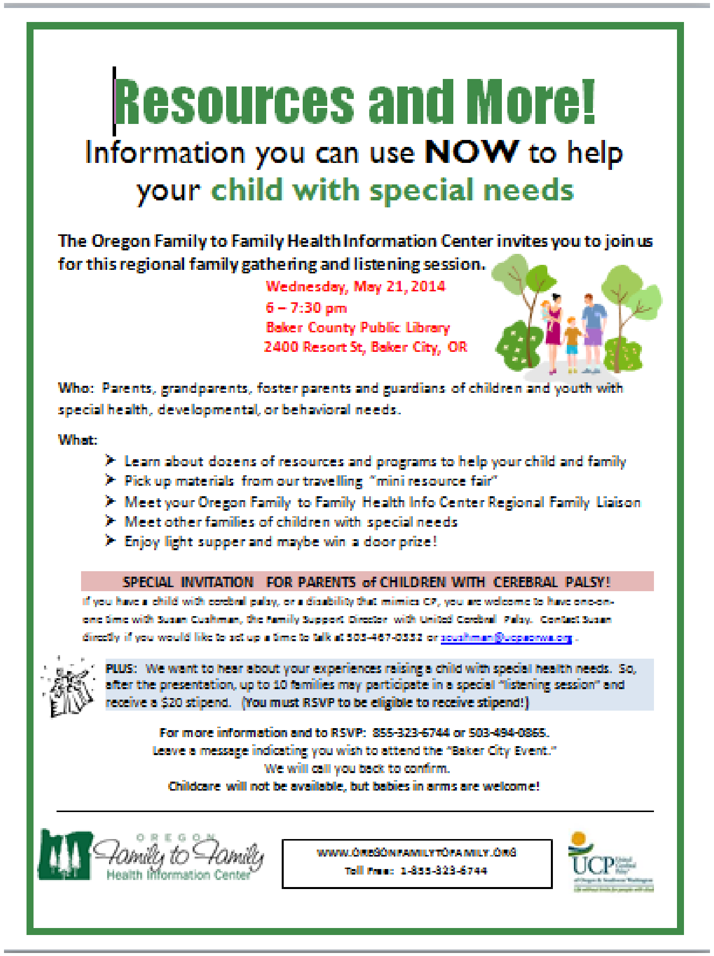
PLUS: After the presentation, from 10 – 10:30, up to 10 families may participate in a special "listening session" and receive a $20 stipend. (You must rsvp to be eligible to receive stipend!)

***Call for details: 1-855-323-6744**

Childcare will not be available for this event, but babies in arms are welcome!

OREGON Family to Family Health Information Center

www.oregonfamilytofamily.org



Resources and More!

Information you can use **NOW** to help your **child with special needs**

The Oregon Family to Family Health Information Center invites you to join us for this regional family gathering and listening session.

Wednesday, May 21, 2014
6 – 7:30 pm
Baker County Public Library
2400 Resort St, Baker City, OR

Who: Parents, grandparents, foster parents and guardians of children and youth with special health, developmental, or behavioral needs.

What:

- ➢ Learn about dozens of resources and programs to help your child and family
- ➢ Pick up materials from our travelling "mini resource fair"
- ➢ Meet your Oregon Family to Family Health Info Center Regional Family Liaison
- ➢ Meet other families of children with special needs
- ➢ Enjoy light supper and maybe win a door prize!

SPECIAL INVITATION FOR PARENTS of CHILDREN WITH CEREBRAL PALSY!

If you have a child with cerebral palsy, or a disability that mimics CP, you are welcome to have one-on-one time with Susan Cushman, the Family Support Director with United Cerebral Palsy. Contact Susan directly if you would like to set up a time to talk at 503-467-0332 or scushman@ucpaorwa.org .

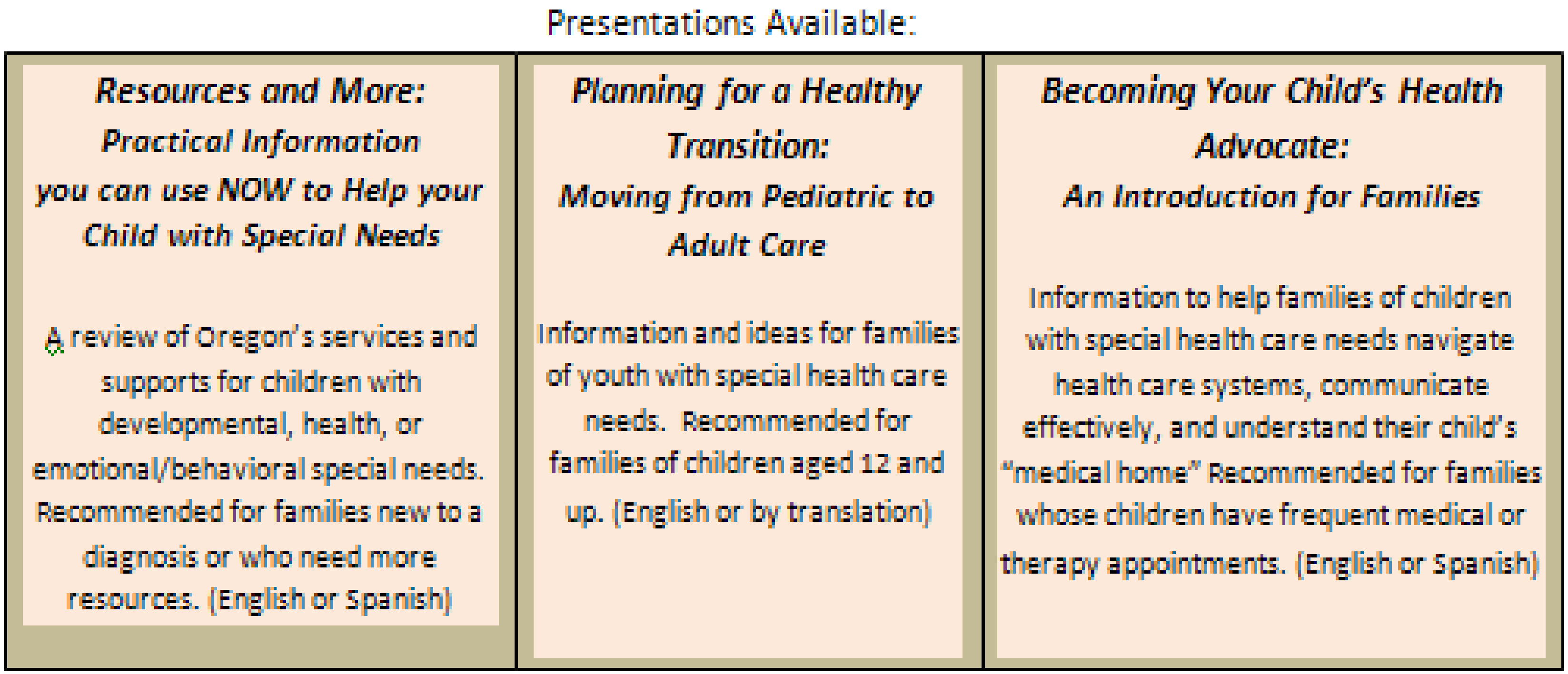
PLUS: We want to hear about your experiences raising a child with special health needs. So, after the presentation, up to 10 families may participate in a special "listening session" and receive a $20 stipend. **(You must RSVP to be eligible to receive stipend!)**

For more information and to RSVP: 855-323-6744 or 503-494-0865.
Leave a message indicating you wish to attend the "Baker City Event."
We will call you back to confirm.
Childcare will not be available, but babies in arms are welcome!

OREGON Family to Family Health Information Center

WWW.OREGONFAMILYTOFAMILY.ORG
Toll Free: 1-855-323-6744

UCP United Cerebral Palsy of Oregon & Southwest Washington



Presentations Available:

Resources and More: *Practical Information you can use NOW to Help your Child with Special Needs*	***Planning for a Healthy Transition:*** *Moving from Pediatric to Adult Care*	***Becoming Your Child's Health Advocate:*** *An Introduction for Families*
A review of Oregon's services and supports for children with developmental, health, or emotional/behavioral special needs. Recommended for families new to a diagnosis or who need more resources. (English or Spanish)	Information and ideas for families of youth with special health care needs. Recommended for families of children aged 12 and up. (English or by translation)	Information to help families of children with special health care needs navigate health care systems, communicate effectively, and understand their child's "medical home" Recommended for families whose children have frequent medical or therapy appointments. (English or Spanish)

Also may include "listening session" of 10 families each, capturing families' impressions on the Oregon Health Care delivery system and their personal experiences.

Website
www.oregonfamilytofamily.org

Velcome

e Oregon Family to Family Health Information Center provides ɔrmation to families who are navigating the complex world of special alth care needs. We are family members ourselves, who have first hand ɔerience raising a child or youth with a chronic health condition, velopmental delay or disability, or emotional/behavioral challenges.

rvices Include:

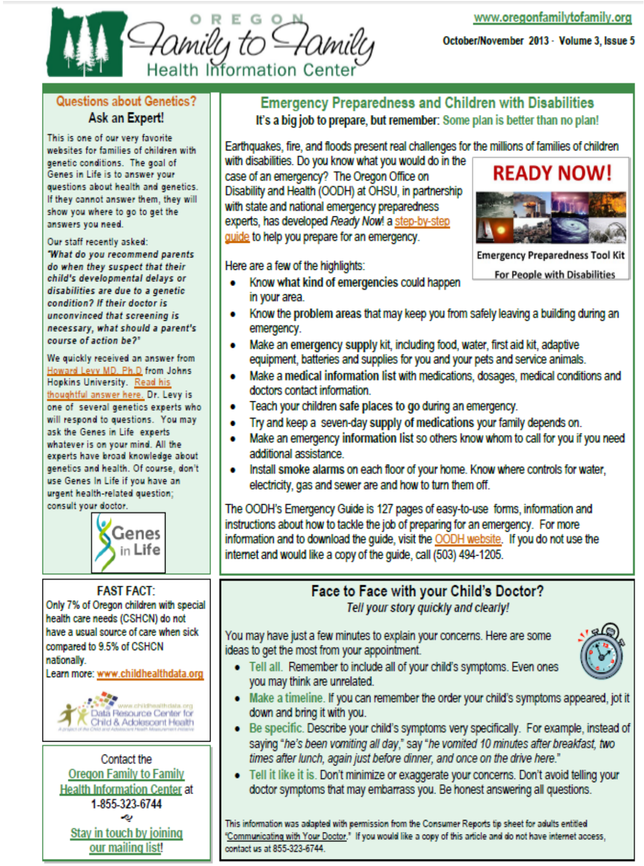
- Toll-free **phone** line (English and Spanish)
- Comprehensive **website** with information and links to key special-needs services
- **Newsletters and tip sheets** full of practical information written *by* families *for* families.
- **Regional Family Gatherings** and trainings in communities all around the state.

ere are 51 Family-to-Family Health Information Centers (F2F HICs) in the ited States and territories. Each is unique, reflecting the needs and

Family Liaisons in Your Community

Contact a Family Liaison in your area for support, information, and help t your particular situation.

- **North Coast**: Danielle Caplinger
- **Mid Coast**: Signe Miller
- **Southern Coast**: Tracie Skinner
- **Willamette Valley**: Tami Montemayor
- **Portland Metro**: Shauna Signorini
- **Hood River**: Marisa Marquez
- **The Dalles**: Aaron Bowman
- **Klamath Falls**: Valerie Smith
- **Umatilla/Morrow**: Sharyn Smith
- **Russian Speaking (all Oregon)**: Galina Burley
- **Spanish Speaking (all Oregon)**: Teresa Gomez, call 503-931- 89
- **For all other areas** call 1-855-323-6744



OREGON Family to Family Health Information Center

www.oregonfamilytofamily.org

October/November 2013 · Volume 3, Issue 5

Questions about Genetics?
Ask an Expert!

This is one of our very favorite websites for families of children with genetic conditions. The goal of Genes in Life is to answer your questions about health and genetics. If they cannot answer them, they will show you where to go to get the answers you need.

Our staff recently asked:
"What do you recommend parents do when they suspect that their child's developmental delays or disabilities are due to a genetic condition? If their doctor is unconvinced that screening is necessary, what should a parent's course of action be?"

We quickly received an answer from Howard Levy MD, Ph.D from Johns Hopkins University. Read his thoughtful answer here. Dr. Levy is one of several genetics experts who will respond to questions. You may ask the Genes in Life experts whatever is on your mind. All the experts have broad knowledge about genetics and health. Of course, don't use Genes In Life if you have an urgent health-related question; consult your doctor.

Genes in Life

Emergency Preparedness and Children with Disabilities
It's a big job to prepare, but remember: Some plan is better than no plan!

Earthquakes, fire, and floods present real challenges for the millions of families of children with disabilities. Do you know what you would do in the case of an emergency? The Oregon Office on Disability and Health (OODH) at OHSU, in partnership with state and national emergency preparedness experts, has developed *Ready Now!* a step-by-step guide to help you prepare for an emergency.

READY NOW!
Emergency Preparedness Tool Kit
For People with Disabilities

Here are a few of the highlights:

- Know **what kind of emergencies** could happen in your area.
- Know the **problem areas** that may keep you from safely leaving a building during an emergency.
- Make an **emergency supply** kit, including food, water, first aid kit, adaptive equipment, batteries and supplies for you and your pets and service animals.
- Make a **medical information list** with medications, dosages, medical conditions and doctors contact information.
- Teach your children **safe places** to go during an emergency.
- Try and keep a seven-day **supply of medications** your family depends on.
- Make an emergency **information list** so others know whom to call for you if you need additional assistance.
- Install **smoke alarms** on each floor of your home. Know where controls for water, electricity, gas and sewer are and how to turn them off.

The OODH's Emergency Guide is 127 pages of easy-to-use forms, information and instructions about how to tackle the job of preparing for an emergency. For more information and to download the guide, visit the OODH website. If you do not use the internet and would like a copy of the guide, call (503) 494-1205.

FAST FACT:
Only 7% of Oregon children with special health care needs (CSHCN) do not have a usual source of care when sick compared to 9.5% of CSHCN nationally.
Learn more: www.childhealthdata.org

www.childhealthdata.org
Data Resource Center for Child & Adolescent Health

Face to Face with your Child's Doctor?
Tell your story quickly and clearly!

You may have just a few minutes to explain your concerns. Here are some ideas to get the most from your appointment.

- Tell all. Remember to include all of your child's symptoms. Even ones you may think are unrelated.
- Make a timeline. If you can remember the order your child's symptoms appeared, jot it down and bring it with you.
- Be specific. Describe your child's symptoms very specifically. For example, instead of saying "*he's been vomiting all day,*" say "*he vomited 10 minutes after breakfast, two times after lunch, again just before dinner, and once on the drive here.*"
- Tell it like it is. Don't minimize or exaggerate your concerns. Don't avoid telling your doctor symptoms that may embarrass you. Be honest answering all questions.

This information was adapted with permission from the Consumer Reports tip sheet for adults entitled "Communicating with Your Doctor." If you would like a copy of this article and do not have internet access, contact us at 855-323-6744.

Contact the
Oregon Family to Family
Health Information Center at
1-855-323-6744
Stay in touch by joining
our mailing list!

OREGON Family to Family Health Information Center

2013 Septiembre

www.oregonfamilytofamily.org

Recursos e Información para Familias de
Niños y Jóvene

http://www.oregonfamilytofamily.org

¿Necesita aprender inglés y tiene un iPad o un iPhone?

Una colaboración entre la iniciativa del Impacto Académico de las Naciones Unidas del departamento de Información Pública y la Universidad de Rutgers y la Escuela Preparatoria Rutgers han desarrollado una aplicación para los dispositivos móviles para aprender inglés como segundo idioma (ESL, por sus siglas en inglés). Este "app" también ayudará a aprender sobre el trabajo y actividades de la ONU (UN, por sus siglas en inglés). Este "app" incluyen lecciones en inglés, vocabulario, audio, lecciones de lectura, juegos, y noticias e información virtual de la ONU-TV.

Lo puede descargar gratuitamente en: https://itunes.apple.com/us/app/unepdapp/id595093669?mt=8
Este "app" solo está disponible para los iPads y iPhones, ¡las versiones para los Android se esperan pronto!

Más sobre la Transición

Si tiene un hijo entre los 14 y 18 años de edad, tiene que comenzar a pensar sobre su transición a la vida de adulto. En el boletín pasado hablamos un poco sobre la transición en general, en este hablaremos sobre que es la transición en general. En los siguientes boletines tocaremos en preguntas más específicas sobre la transición y necesidades especiales

¿Qué es la "transición?"

Transición es cuando pasamos de una cosa a otra. La transición sobre la que hablaremos en este cuaderno de actividades tiene que ver con dejar de ser un niño para convertirse en un adulto. Si bien los 18 ó 21 años suelen ser las edades a las cuales las personas se convierten oficialmente en "adultas", el crecimiento no se produce en un solo cumpleaños. Es un proceso que se da con el tiempo. Desde que era un niño pequeño ha estado aprendiendo destrezas que le ayudarán a convertirse en un adulto exitoso. Pero continuará aprendiendo y creciendo, y cambiará de muchas maneras diferentes durante toda la vida.

La transición a la adultez implica muchas partes distintas de su vida, incluso: pasar de la escuela secundaria al trabajo, a la universidad o a otro tipo de escuela; decidir dónde vivirá; hacer nuevas amistades; y encontrar formas de mantenerse en contacto con sus viejos amigos. En este cuaderno de actividades, nos centraremos en su salud y en cómo pasar de la atención médica que recibía cuando era niño a la atención médica que necesitará como adulto.
(tomado del libro: Comportarse como un adulto saludable: Cómo defender su salud y atención médica, por Kathy Roberson, M.S.W.) Si quiere una copia de este libro, llámenos al 503-931-8930.

Formatos Alternativos Boletín Disponibles a Pedido
Las familias de niños con necesidades especiales que no tienen acceso a Internet puede recibir este boletín por correo llamando al 503-931-8930.

Servicios para Niños con Trastornos en el Espectro Del Autismo
Navegación de Su Ruta

Después de que es identificado un Trastorno en el Espectro del Autismo (TEA), a veces las familias no saben qué hacer a continuación. La cantidad de información sobre los TEA puede ser abrumadora. Esta guía ofrece información básica sobre los pasos a seguir, los recursos en su área y el apoyo en su comunidad. A continuación se presentan algunos de los temas clave relacionados con los Trastornos en el Espectro del Autismo que quizá usted desee explorar: Terapias del Comportamiento, Intervenciones Biomédicas, Herramientas de Comunicación, Modelos de Desarrollo, Intervención Temprana, Medicamentos, Nutrición, Terapia Ocupacional, Terapia Física, Recreación, Terapia de Integración Sensorial, Educación Especial, Terapia del Habla, Desarrollo de Habilidades Sociales, Grupo de Apoyo, Terapia Visual.

Servicios para Niños con Trastornos en el Espectro del Autismo
Navegación de Su Ruta
Oregon

Su jornada acaba de comenzar. Por favor sepa que no está solo en el trazado de su rumbo y en la navegación por los recursos disponibles. Para información en su área y para imprimir el mapa para su área visite www.oregonfamilytofamily.org/navigation.html.

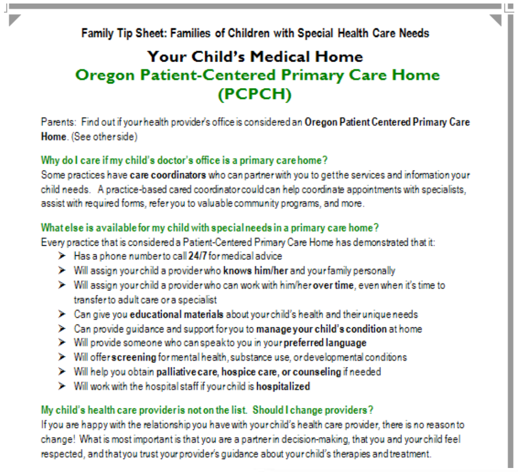
- Condados de Clackamas, Clatsop, Columbia, Hood River, Multnomah, Wasco y Washington (Metro)
- Condados de Benton, Lane, Lincoln, Linn, Marion, Polk, Tillamook y Yamhill (Mid-Valley)
- Condados de Coos, Curry, Douglas, Jackson, Josephine, Klamath, y Lake (Southern)
- Condados de Baker, Crook, Deschutes, Gilliam, Grant, Harney, Jefferson, Malheur, Morrow, Sherman, Umatilla, Union, Wallowa y Wheeler (Cascades)

Si quiere una copia de esta guía por correo llámenos al 503-931-8930.

Llame al
Oregon Family to Family
Health Information Center a
503-931-8930 (Español)
1-855-323-6744 (Inglés)
y
Manténgase en contacto al unirse a nuestra lista de correo!

Los recursos de esta página no son exhaustivos ni la inclusión implica aprobación por parte del Oregon F2F HIC de la Oregon Health & Science University (OHSU). Estos recursos están destinados a ser un punto de partida para la investigación adicional. El Oregon F2F HIC es un esfuerzo liderado por la familia, financiado por una subvención de los Recursos y Servicios de Salud de la Oficina de Administración de la Salud / Madre y el Niño. El F2F se encuentra estrechamente vinculado con el Centro de Oregón para Niños y Jóvenes con Necesidades Especiales de Salud (OCCYSHN), ubicado en el Desarrollo Infantil y Centro de Rehabilitación en OHSU.

Newsletters in English/Spanish
Mostly medical and community systems
Postal or Email



Family Tip Sheet: Families of Children with Special Health Care Needs

Your Child's Medical Home
Oregon Patient-Centered Primary Care Home
(PCPCH)

Parents: Find out if your health provider's office is considered an **Oregon Patient Centered Primary Care Home**. (See other side)

Why do I care if my child's doctor's office is a primary care home?
Some practices have **care coordinators** who can partner with you to get the services and information your child needs. A practice-based cared coordinator could can help coordinate appointments with specialists, assist with required forms, refer you to valuable community programs, and more.

What else is available for my child with special needs in a primary care home?
Every practice that is considered a Patient-Centered Primary Care Home has demonstrated that it:
- Has a phone number to call **24/7** for medical advice
- Will assign your child a provider who **knows him/her** and your family personally
- Will assign your child a provider who can work with him/her **over time**, even when it's time to transfer to adult care or a specialist
- Can give you **educational materials** about your child's health and their unique needs
- Can provide guidance and support for you to **manage your child's condition** at home
- Will provide someone who can speak to you in your **preferred language**
- Will offer **screening** for mental health, substance use, or developmental conditions
- Will help you obtain **palliative care, hospice care, or counseling** if needed
- Will work with the hospital staff if your child is **hospitalized**

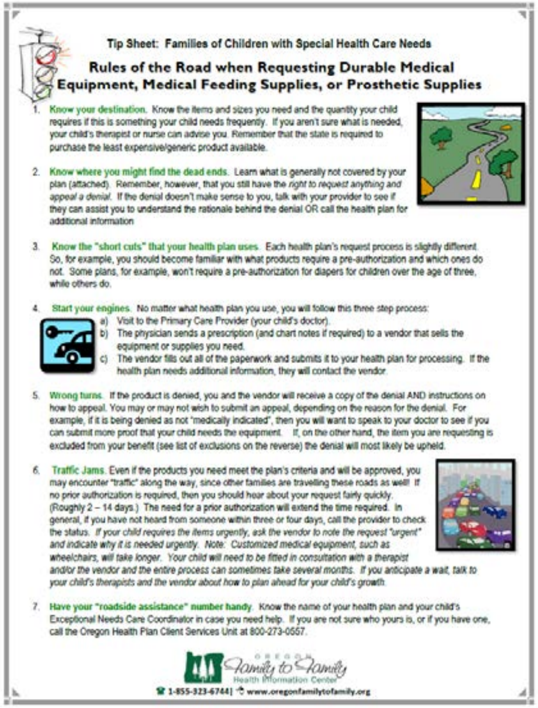
My child's health care provider is not on the list. Should I change providers?
If you are happy with the relationship you have with your child's health care provider, there is no reason to change! What is most important is that you are a partner in decision-making, that you and your child feel respected, and that you trust your provider's guidance about your child's therapies and treatment.

See other side for a list of Patient Centered Prin
your provider's office:

Read more about Oregon's PCPCH Program at: w

☎ 1-855-323-6744 | ww

The Oregon F2F HIC is a family-led effort, funded by a grant from the Heal



Tip Sheet: Families of Children with Special Health Care Needs

Rules of the Road when Requesting Durable Medical Equipment, Medical Feeding Supplies, or Prosthetic Supplies

1. **Know your destination.** Know the items and sizes you need and the quantity your child requires if this is something your child needs frequently. If you aren't sure what is needed, your child's therapist or nurse can advise you. Remember that the state is required to purchase the least expensive/generic product available.
2. **Know where you might find the dead ends.** Learn what is generally not covered by your plan (attached). Remember, however, that you still have the *right to request anything and appeal a denial*. If the denial doesn't make sense to you, talk with your provider to see if they can assist you to understand the rationale behind the denial OR call the health plan for additional information
3. **Know the "short cuts" that your health plan uses.** Each health plan's request process is slightly different. So, for example, you should become familiar with what products require a pre-authorization and which ones do not. Some plans, for example, won't require a pre-authorization for diapers for children over the age of three, while others do.
4. **Start your engines.** No matter what health plan you use, you will follow this three step process:
   a) Visit to the Primary Care Provider (your child's doctor).
   b) The physician sends a prescription (and chart notes if required) to a vendor that sells the equipment or supplies you need.
   c) The vendor fills out all of the paperwork and submits it to your health plan for processing. If the health plan needs additional information, they will contact the vendor.
5. **Wrong turns.** If the product is denied, you and the vendor will receive a copy of the denial AND instructions on how to appeal. You may or may not wish to submit an appeal, depending on the reason for the denial. For example, if it is being denied as not "medically indicated", then you will want to speak to your doctor to see if you can submit more proof that your child needs the equipment. If, on the other hand, the item you are requesting is excluded from your benefit (see list of exclusions on the reverse) the denial will most likely be upheld.
6. **Traffic Jams.** Even if the products you need meet the plan's criteria and will be approved, you may encounter "traffic" along the way, since other families are travelling these roads as well! If no prior authorization is required, then you should hear about your request fairly quickly. (Roughly 2 – 14 days.) The need for a prior authorization will extend the time required. In general, if you have not heard from someone within three or four days, call the provider to check the status. *If your child requires the items urgently, ask the vendor to note the request "urgent" and indicate why it is needed urgently. Note: Customized medical equipment, such as wheelchairs, will take longer. Your child will need to be fitted in consultation with a therapist and/or the vendor and the entire process can sometimes take several months. If you anticipate a wait, talk to your child's therapists and the vendor about how to plan ahead for your child's growth.*
7. **Have your "roadside assistance" number handy.** Know the name of your health plan and your child's Exceptional Needs Care Coordinator in case you need help. If you are not sure who yours is, or if you have one, call the Oregon Health Plan Client Services Unit at 800-273-0557.

Oregon Family to Family Health Information Center
☎ 1-855-323-6744| www.oregonfamilytofamily.org

Tip Sheets:
no jargon
written by family members
vetted for accuracy

- When Insurance Doesn't Pay
- DME
- Getting You to the Conference
- Partnering with your Provider
- Get to Know your ENCC
- What are DD services
- Intro to PCPCH
- Navigating your Health Plan
- Moving to Oregon?

Words of wisdom from families
Listening Sessions revealed what families appreciate:

- “(Our doctor) talks to my grandson first, and asks him how he is doing, but then turns to me and says “And how is Grandma doing?” *Not once, but every time we go in*.

  Metro

- “They have a care coordinator in the office that takes the time to go over everything with me.”

  Metro

- “ They respect us, even when we disagree.”

  South Beach

Questions? Comments?

Thank you!

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www.oregonfamilytofamily.org

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