
United Children & Parents

UCP's Quarterly Family Support Newsletter

United Cerebral Palsy Association of Oregon and SW Washington, Inc.

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www.ucpaorwa.org

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Organizations Every Family of a Child with a Disability Should Know About

You can access services through the following organizations – Oregon resources are listed on pages 1 and 2, and Washington resources on page 3.

OREGON

County Development Disability Services (*lifespan*)

County DD Services provide service coordination and Family Support for families of children birth-18, as well as being the access point for in-home services and supports, Medicaid programs, and crisis services. www.oregon.gov/DHS/dd/county/services.shtml

Disability Compass (*lifespan*)

Disability Compass is an easy-to-use resource website, created to improve access to services, products, and programs for Oregonians with disabilities and their families.
www.disabilitycompass.org

Early Intervention/Early Childhood Special Education Services (*birth – five*)

Special education and therapeutic services provided under federal law (Individuals with Disabilities Education Act: IDEA) – entitlement to services for all eligible children and families.
www.ode.state.or.us/groups/supportstaff/specializedservices/oregonmap/eiecse/

Head Start / Early Head Start (*prenatal/pregnancy – five*)

Comprehensive educational and support services to children and families. *Families of children with disabilities; you do NOT have to meet income criteria to be eligible.* Programs are required to include minimum of 10% children with disabilities. www.ode.state.or.us/gradelevel/pre_k/ohspoverview.aspx

(continued on page 2)

SAVE THE DATE: January 19, 2008 UCP FAMILY OUTING ON MT. HOOD

Fun in the Snow! 10am to 3pm

Clackamas High School Key Club will be there to help!

Call to register: 503-777-4166

OREGON RESOURCES (continued)

Family Action Coalition Team (*lifespan*)

FACT is a statewide non-profit coalition of family-driven organizations and individuals. FACT supports family leadership development and involvement, empowerment of families in systems change and policy decisions, advocacy for stable funding and resources to meet families' needs and individual support for families and small family-led volunteer groups. www.factoregon.org

Inclusive Childcare Program (*birth – 18*)

The Inclusive Child Care Program offers assistance, training and information about supporting children with disabilities in traditional childcare settings, as well as a subsidy program that helps pay for extra supports in child care that are related to a child's special needs.

www.ocdd.org/inclusive_child_eng.htm

Lifespan Respite (*lifespan*)

The Oregon Lifespan Respite Care Program helps counties develop and implement community-based lifespan respite care networks. The Lifespan networks help families and caregivers locate respite care services in their communities. www.oregon.gov/DHS/spd/caregiving/ls_respitem.html

Municipal Parks & Recreation Programs (*lifespan*)

Many cities offer inclusive and specialized recreation programs for people with disabilities, sometimes with additional staff supports and other accommodations. (For example, Portland Parks & Rec offers 1:1 swim lessons, and inclusive aides for participation in standard recreation programs. Portland Park & Rec also has a teen outing program for ages 12 through high school.)

<http://www.pnwatra.org/internship/portlandparksandrec.htm>

Oregon Council on Developmental Disabilities (*lifespan*)

OCDD supports empowerment, advocacy, training, education and information efforts across the state through programs like Partners in Policymaking, collaborative efforts such as the Oregon DD Coalition and the Oregon Cross-Disability Coalition, and publications such as the Oregon Perspectives and People First Connection. www.ocdd.org.

Oregon Parent Training and Information Center (*birth – 26*)

OrPTI works to educate and support parents, families and professionals in building partnerships that meet the needs of children and youth with the full range of disabilities, focused primarily on Special Education resources. www.orpti.org.

WASHINGTON RESOURCES

Washington DD services provided through a caseworker include: respite care, therapies, architectural and vehicular modifications, equipment and supplies, specialized nutrition and clothing, excess medical costs not covered by another source, co-pays for medical and therapeutic services, transportation, training, counseling, behavior management, parent/sibling education, and recreational opportunities. <http://www1.dshs.wa.gov/ddd/>

Washington Children's Administration, Department of Social and Health Services. Respite care available on a case-by-case basis through caseworker. <http://www.dshs.wa.gov/ca/general/index.asp>

Every state is federally mandated to have a parent training and information center with information on children's rights to an education. Washington's is called PAVE: <http://www.washingtonpave.org/>

Family caregiver support program by county: <http://www.adsa.dshs.wa.gov/Resources/clickmap.htm>

Washington State Accessible Outdoor Recreation Guide:
<http://www.parks.wa.gov/ada-rec/>

Vancouver-Clark County Disabled Recreation:
<http://www.cityofvancouver.us/parks-recreation/recreation/disabled/>

Washington State Developmental Disabilities Council: <http://www.ddc.wa.gov/>

Washington Children with Special Health Care Needs Program 3-18:
http://www.doh.wa.gov/cfh/mch/cshcn_referrals.htm

Infant Toddler Early Intervention Program (ITEIP) Birth to 3:
<http://www1.dshs.wa.gov/iteip/CountyOrgLinks.html>

School Districts for Special Ed 3-18: <http://www.k12.wa.us/maps/SDmainmap.aspx>

ARC of Washington: <http://www.arcwa.org/>

Disability Rights Washington: <http://www.disabilityrightswa.org/>

Washington State Childcare Resource and Referral: <http://www.childcarenet.org/>

Cerebral palsy children 'happy'

Children with cerebral palsy are just as happy as children without the condition are, a study has shown.

Their physical impairment does not have a negative effect on their relationships, moods or welfare, researchers report in *The Lancet*. Experts said the study of 500 children aged 8-12 years with cerebral palsy underlined the importance of supporting children with disabilities to lead full lives. Cerebral palsy affects around one in 400 children in the UK. It results from the failure of a part of the brain to develop before birth or in early childhood, or brain damage which permanently affects body movement and muscle coordination.

Parents can be upset when their child is diagnosed with cerebral palsy, but they can now be reassured that most children with cerebral palsy experience a similar quality of life to that of other children their age. Professor Allan Colver, study leader

Previous studies have attempted to look at the quality of life of children with cerebral palsy but they focused on physical effects of the condition or relied on the views of parents. A team of European researchers, led by the University of Newcastle, asked the children themselves about several aspects of their lives and compared their responses with those from children of the same age in the general population. The questionnaire covered areas such as physical and psychological well-being, moods and emotions, self-perception and relationships with parents, friends and school.

No difference - - On most of the areas, children with cerebral palsy had similar scores to the general population. The only exceptions were schooling for which the results were not clear and physical well-being which could not be compared. The study leader said that doctors needed to learn to talk more directly to the child.

"For example, for a lot of children, there's a lot of effort in helping them to walk. But usually if a child goes into a wheelchair they suddenly become much more mobile and from the child's point of view it can transform their lives even if from an adult's point of view it seems like a step backwards." Policies and resources must be in place to make sure children with cerebral palsy are allowed to participate fully in society, he added.

Andy Rickell, an executive director at the cerebral palsy charity Scope, welcomed the study. But he cautioned: "The action it recommends on social and educational policy must include tackling the specific barriers faced by disabled children, such as not being able to attend a local school near their family or to access vital equipment in order to communicate. These findings based on children's perceptions of their quality of life, whilst instructive, should not detract from the stark reality for hundreds of thousands of disabled children across the UK."

Story from BBC NEWS:

<http://news.bbc.co.uk/go/pr/fr/-/2/hi/health/6248332.stm>

Resources



Zetosch Fund – UCP is one of four organizations in Oregon that administer funds from the Zetosch Family Fund for the educational needs of children with disabilities. To access funds from UCP's Zetosch fund, the requirements are that the child be school-age, have cerebral palsy, and be low income. Most Zetosch grants in the recent past have been for laptop computers. The grants can be used for a wide variety of equipment that will assist the student in their education (including wheelchair repairs). It is easy to apply, and there is up to \$1,500 available per child per year. Please contact Susan at UCP at 503-777-4166 x232 or sblanchard@ucpaorwa.org.

Lifetime National Park Pass

This is a great benefit from the National Forestry & Wildlife Division. It is a free lifetime access pass for any person with a disability or for the caregivers of a person with a disability. It allows access to ALL national parks for free.

All that is required is a letter from the physician stating the disability which is taken to your local National Forestry & Wildlife Division to get the pass. Each pass will admit up to 4 adults, and children under 16 are always free. This link provides lots of helpful information about the program: <http://store.usgs.gov/pass/access.html>

Equipment Exchange – if you have any walkers or wheelchairs (or other equipment) that your child has outgrown, let us know and we'll see if we can find a child who could use it. While we don't have room in our office to store equipment, we can facilitate equipment exchanges between families. Contact Cari at UCP Family Support: 503-777-4166.

CALENDAR OF EVENTS....CALENDAR OF EVENTS....CALENDAR OF EVENTS

January

- 10 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
- 19 10am-3pm **Day at the Mountain** – our annual family winter outing at Mt. Hood Kiwanis Camp. There will be sledding in the snow, hot chocolate and a warm fireplace. Clackamas High School Key Club students will be there to help with the kids. Come join in the fun. Call to register: 503-777-4166.

February

- 8 Twice this day: "IEP Process and Advocacy Through Effective Letter Writing" from 9am to 12noon at the Linus Pauling Middle School, 111 NW Cleveland in **Corvallis** AND at the Grace Lutheran Church in **Corvallis** from 6:30 to 8:30 PM . For information, or to register call Leah Skipworth at 541-791-4415 or email lskipworth@orpti.org
- 14 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.

March

- 8 6-11pm **UCP Spring Fundraiser: Casino Royale, a night of Monte Carlo style gaming with a Texas Hold 'em Tournament and a silent auction. Prizes include a trip to Puerto Vallarta, stays at resorts, wine tasting tours, and more.**
- 13 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
- 20 6:15-8pm "Planning, Organizing and Preparing for your Child's IEP" at the Guy Lee Elementary School, 755 Harlow, **Springfield** OR 97477. For information, or to register contact Leah Skipworth at lskipworth@orpti.org

April

- 10 6:30 pm Gimme A Break **Call UCP 503-777-4166**
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SAVE THE DATE: Mt. Hood Sledding Outing: January 19, 2008

The persons, products and services listed in this newsletter are for informational purposes only and as a service for our readers. No endorsement by UCP should be inferred.

The 12th Annual UCP Family Conference was a Huge Success

We had almost double the number of attendees from the previous year's conference. The Red Lion was a spectacular venue, with views of the Columbia River from most of the rooms. The food was great, and service by hotel personnel was excellent.

We found out that Geri Jewell is more than a celebrity. She shared her humanity and real life experiences during her keynote in a manner that was both inspiring and educational at the same time. During her afternoon workshop, a mom asked whether Geri was ever afraid of how people treated her because of her disability. Geri walked over to the mom's daughter and kneeled in front of her, and said "Don't ever give up. Don't ever let people's attitudes keep you from being who you are, and if you can, don't be afraid."

All of the 16 workshops received rave reviews. If you weren't there, we wish you could've joined us. It was a fantastic two days of networking, meeting new friends, greeting old friends, gaining new information, and becoming inspired. Being at the conference reiterates our need to reach out to other parents who are raising a child with CP – to know we're not alone, that there are others who know exactly how we're feeling.

Please plan on joining us for the 2008 conference. It will be held at the same location, at the Red Lion in Jantzen Beach, on October 3 and 4, 2008. Share this information, and the benefits you received from this year's conference, with your circle, including other families and professionals.