
United Children & Parents

UCP's Quarterly Family Support Newsletter

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

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Keeping Kids Busy in the Summer

As the long days of summer drag on, it's easy for kids (and parents) to get bored. When I first searched the internet (using GoodSearch of course) to find activities for the summer, I was led to sites that suggested academic activities to keep their minds ready for school. Yuck. Who wants more schooling in the summer? Not the kids I know.

Then I searched "keeping kids busy in the summer" and was led to this 17 page document, which is really four different documents with fun and easy activities, including activities relevant for our kids with disabilities:

<http://www.ebookpars.com/ebooks/KeepingKidsBusy.pdf>

Topics include fun activities, crafts, making treats, as well as 20 toys you don't have to buy, but can find or make around the house. There are even fun ideas for what to do with the art plastered all over the refrigerator. Here is one sample:

Make a story tape: Grab that tape recorder and a blank cassette, find a story you enjoy, and make your own story tape! Each child can read for a while, or for different characters. Be prepared for lots of giggles. Tip: a home-made story tape makes a great present for a child who has to go to the hospital or is bedridden.

Be sure everyone drinks plenty of water all summer long.

SAVE THE DATE: August 11, 2007
UCP FAMILY PICNIC AT CHAMPOEG STATE PARK

Fun in the Sun! 11am to 3pm

Clackamas High School Key Club will be there to help!

Call to register: 503-777-4166

Fathers Are Caregivers Too!

Steve Fischer

When the doctor walked in, his intense and focused eyes already communicated the message that his voice was about to deliver. The words he began so mechanically to speak did not come as a surprise. My daughter was extremely sick. Medical science had yet to determine the cause of the illness that resulted in her being born profoundly retarded, with cerebral palsy, and a myriad of other problems. I do not remember much of that day. I believe the mind may have a method of protecting us by somehow clouding the details of extremely traumatic events. I do however remember a peculiar occurrence of that day that has since repeated itself time and time again.

When the physician walked in to deliver the message he looked squarely into my wife's eyes. Even though we were sitting side by side on a chair turned hospital bed, his eyes never made contact with mine. I can surely empathize with the physician, who no doubt recognized the pain in my beautiful wife's eyes. The fact remained however that I, the father, was also in a state of complete emotional collapse. The failure of this particular physician to even make eye contact with me seemed to send the message that either I was not hurting, or I was to simply "take it like a man." I have to believe that this extremely capable physician did not do this with any degree of premeditation. Rather, he avoided eye contact with me, much less a dialogue, out of conditioning. While the mother-child bond is undeniably powerful, recognition within our health care providers to the equally powerful father-child bond must occur. Countless nights spent with grieving fathers over late night coffee has made me realize that many of my brothers are hurting and have minimal outlets for emotional expression.

I readily admit that my wife assumes the greater percentage of the day-to-day care of our child. However, I am also a caregiver in my little angel's life, and therefore deserve the respect and consideration shared by my wife.

I have come to realize that we have a long way to go in educating our health care providers to the emotional needs that fathers have with special needs children. I have also realized that fathers must take it upon themselves to be an advocate for this learning. We must support each other, encourage each other, and when comfortable, share with each other. We must remind our health care providers that fathers are caregivers too.

Published in "Fathers Voices," Exceptional Parent magazine, August, 1994

Found on the Father's Network: <http://www.fathersnetwork.org/572.html>.

Geri Jewell to be Keynote Speaker at UCP Family Conference!!!



Geri Jewell is best known as Cousin Geri on the NBC sitcom, "The Facts of Life." She was the first person with a disability to have a regular role on a primetime series. She began her career doing stand up comedy at the Comedy Store in 1978. In 1980 she performed at the 2nd Annual Media Access Awards, when she was introduced to Norman Lear by producer Fern Field.

After her ground breaking role on "Facts," she has appeared on such shows as "The Great Space Coaster," the Emmy award winning movie "Two of a Kind," "Sesame Street," "21 Jump Street," "The Young and the Restless," "Strong Medicine" and the HBO hit series, "Deadwood."

When Geri is not working in television, she is a highly sought after motivational speaker and trainer in the areas of disability and diversity. She has consulted for such companies as Hewlett Packard, Master Foods, Johnson Wax, AT&T, and Amgen. She has also trained such government agencies as the C.I.A., the U.S. Treasury Department, Defense Intelligence Agency, and the U.S. Army.

She is famous for her uncanny ability to captivate the hearts of her audiences by using humor to facilitate attitudinal change. Geri brings to her presentations her personal experiences in life, which in turn allow people to gain insight into the prospect of seeing disability in a totally different light, creating hope where there is none, and joy where there is pain.

In addition to her ongoing speaking circuits, she has never forgotten her roots in comedy. She has appeared on many of the cable comedy shows, including Evening at the Improv on A&E, and Stand Up Spotlight on VHI. She has opened for Paul Anka, Robert Goulet, and Judy Collins. She has been featured on Entertainment Tonight, E Hollywood True Story, and ABC's 20/20.

She is co-starring in a new independent film, "Night of the White Pants" which will be released in 2007.

All in all, Geri has enjoyed a thriving career expanding now over two decades. She has been the recipient of many awards, including the 1992 Founders Award, the 2005 Independent Living Legacy Award, and the 2006 Victory award.



SAVE THE DATE: UCP 12th Annual Family Conference: November 2-3, 2007

After Graduation I Will...

Graduating from high school is an exciting time in life. It often represents a transition to adulthood. Graduation takes young adults into the world of college or a new job, or for some into the unknown. For students with disabilities, this is an especially significant time.

A typical school day occupies 6-8 hours of a person's life, five days per week. Without the proper preparation, graduation can leave students with disabilities (and the parents who care for them) with too much unscheduled time on their hands. Instead of dreading that the doldrums of summer will become the monotony of fall, plan ahead!

Students planning to graduate at age twenty-one should begin thinking about what they want to do after graduation three to five years prior. Parents can expect a support system around this transition called an Individualized Education Planning (IEP) team. This team is usually comprised of the student, their school guidance counselor, parents, a vocationally-related person they've been working with, a county case manager and other person/organization that will make the transition smoother.

The first step in writing the transition IEP is to assist the student in identifying their skills, interests, dreams and talents. In order to accomplish this, some teams may elect to conduct a Person Centered Plan (PCP). In preparation for a PCP (or in lieu of one) the following interest survey may help the student and their team identify their desires:

I want to...

- Find a job
- Go to college
- Attend a trade school
- Take some time off

Answer these questions:

- What are some of my hobbies?
- What do I like to do in my spare time?
- What do I like to collect?
- What am I an expert at?
- If you could do anything after graduation, what would it be? Why?

Circle the following things you like:

- People
- Animals
- Outdoors
- Indoors
- Plants
- Helping people
- Helping animals
- Factories
- Food service
- Office work
- Calling people on the phone
- Construction sites
- Grocery stores
- Hospitals
- Computers
- Restaurants

This article is simply an overview of the transition process. For more information, please check with your student's guidance counselor or call Melissa Miller (Job Developer) at United Cerebral Palsy, via phone at 503-777-4166 or email at mmiller@ucpaorwa.org.

Advocating for Your Child by Susan Blanchard

You're the One. You understand your child like no one else. You are the permanent member of the IEP team – you have more to offer and more to lose or gain. Being told that I'm the expert on my child used to be overwhelming. Here I was bringing my 5 year old daughter to school and being told I'm the expert. I was hoping THEY were the experts and were going to teach me how to help my child live a life full of opportunity and choices.

The truth is that I AM the expert when it comes to my daughter. Now that she's 15, I have more confidence and knowledge than I did when she was 5. Be gentle with yourself as you learn how to navigate the school system. Below are some strategies to be a better advocate.

1. Communication skills go hand in hand with advocacy.
 - a. Be aware of your tone of voice, your judgments, and your expectations.
 - b. Recognize your communication style: Friendly? Assertive? Negative?
 - c. Listen more than you speak. Communication is a two-way process.
 - d. Ask questions – we often don't know how much we don't know.
 - e. Request an assistive technology assessment and services if you think your child might benefit. There are many excellent resources in this area.
 - f. Be clear and honest – don't blame.
 - g. If your child is unable to communicate with you about their day, send a journal back and forth with your child every day to communicate with the teacher.

 2. You shape the future.
 - a. When you advocate for your child, you act in the present to make a difference in the future. Every time you stand up for your child, you are modeling an essential skill: self advocacy.
 - b. It is always appropriate to advocate for your child, even if you make mistakes. Learn from them and do better the next time.

 3. You know more about your child than anyone.
 - a. Educate staff about your child's unique needs. People have a tendency to lump children into categories and lose sight of the individual. Their past experience may not apply to your child at all.
 - b. Consider creating a person centered plan or one-page family vision statement to help the team get to know your family and to see your child as an individual.
 - c. Plan with teacher and staff to integrate as much of your child's services and support into their daily routines to minimize pull-outs.
 - d. Remember, you have the right to call an IEP meeting at any time during the year to revise goals, discuss placement, etc. You are an equal with the rest of the IEP team.
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Resources

Announcing the First Ever Challenge Air “Fly Day” in Oregon!

Challenge Air for Kids & Friends, a national children’s nonprofit organization, is recruiting children with disabilities and volunteers for its first ever “Fly Day” event to be held Saturday, August 18th at Aurora County Airport, hosted by Aurora Aviation. Highlights of the day include: an educational ground school, a 30-minute flight over Portland, face painting, clowns, cool static aircraft, lunch, service animals and much more! To register as a participant (*first-come, first-serve and free for all children with disabilities ages 7-17*) or a volunteer log on to: www.challengeair.org.

For more information contact Lonna Gibson at (818) 741-6906 or email lonna@challengeair.org.

Challenge Air for Kids & Friends offers motivational, inspirational, and life-changing experiences to physically challenged children and youth through aviation.

WHO TO TURN TO WHEN MEDICAL INSURANCE CLAIMS ARE DENIED:

SNAP – Special Needs Advocate for Parents. They teach you how to get the most of your medical insurance coverage to benefit your child. Toll-free phone: 888-310-9889 or email at info@snapinfo.org. Their website is: www.snapinfo.org. NOTE: SNAP will lead a workshop at this year’s UCP Family Conference about medical insurance empowerment.

National Disability Rights Network. Their website is: www.ndrn.org. They’re a membership organization of the federally mandated “protection and advocacy” systems and client assistance programs for people with disabilities.

Council of Parent Attorneys and Advocates (www.copaa.org). They maintain a database of attorneys on their website, many experienced in dealing with legal issues involving children with disabilities.

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

July

- 21 12 noon **Third Annual Walk 'n' Roll for UCP!** fundraiser at the Eastbank Esplanade – to benefit Family Support. Call UCP 503-777-4166 for more information and to register, or visit us online at www.walknrollforucp.kintera.org.
- 24 [3 days] Oregon Conference on Direct Supports, July 24-26 in Corvallis. Visit the website for more info: www.directsupports.com, or email info@directsupports.com.

August

- 4 11am-1pm Sibshop for siblings ages 7-13. In SE Portland. Call 503-636-1676 to register.
- 9 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
- 11 11am-3pm **Family Support Picnic** at Champoeg State Park. Call UCP 503-777-4166 to register. Clackamas High School Key Club members will be there to play games with the kids.

September

- 1 11am-1pm Sibshop for siblings ages 7-13. In SE Portland. Call 503-636-1676 to register.
- 13 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
- 19 6:30pm Switch Workshop – learn how to adapt toys and build switches. Workshop will be held at the UCP office. Call to register: 503-777-4166.
- 29 all day **Ride Without Limits** – a fundraiser benefiting UCP. It's a scenic 50 or 100 mile bike ride through the Willamette Valley. Call to join a team as a rider or to volunteer as a crew member: 503-777-4166.

SAVE THE DATE: UCP Family Picnic on August 11, 2007

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.

UCP believes in advancing the independence, productivity and full citizenship of people with cerebral palsy and related disabilities.