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# United Children & Parents

## UCP's Quarterly Family Support Newsletter

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

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## BOTOX WARNINGS URGED

On January 23, 2008 the consumer advocacy group Public Citizen petitioned the FDA to require the manufacturers of Botox and Myobloc to issue warning letters to physicians about the serious problems, including hospitalizations and deaths, resulting from the spread of the toxin from the site of the injection to other parts of the body. They also requested that patients be warned in the form of a black box in the product label.

Public Citizen's analysis of the FDA adverse event database revealed that from 11/1/97 through 12/31/06, there were 16 deaths (4 in children under age 18) in the total of 180 cases. The main problems included aspiration, dysphagia or pneumonia.

It is recommended that if your child is receiving botox treatments, that you consult with your physician about these warnings and the risks associated with injections. Below is a statement from UCP National.

### Greetings from UCP National,

Recently, the press has reported about the possible connection between use of Botox and deaths in several children with Cerebral Palsy. UCP National has received calls from the media and families wanting to know our "opinion" on the matter. It is important that we communicate with a common voice to all audiences.

UCP is very concerned to hear that deaths of children with cerebral palsy have been linked to Botox.

The National Office does not provide any direct services related to Botox injections nor do we promote its use. Rather, we provide information on the range of treatments available to people with cerebral palsy. Every medical treatment carries some degree of risk and we urge parents to discuss the benefits and risks of any treatment or medication with their healthcare providers.

The FDA is investigating the matter and will continue to update the public when additional information or analyses become available. For more information please review the FDA's statement on Botox and Botox Cosmetic (Botulinum toxin Type A) and Myobloc (Botulinum toxin Type B) and continue to check their website for updated information:

5H[http://www.fda.gov/cder/drug/early\\_comm/botulinium\\_toxins.htm](http://www.fda.gov/cder/drug/early_comm/botulinium_toxins.htm)

Please feel free to contact me with any questions.

Lara Terrell, MSW, Information and Referral Specialist

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# Supreme Court says parents don't need lawyer to sue over children's special education needs

In 2007 the Supreme Court ruled that parents do not need to hire a lawyer to sue public school districts over their children's special education needs.

The decision came in the case of an autistic boy from Ohio, whose parents argued they were effectively denied access to the courts because they could not afford a lawyer.

Federal law gives every child the right to a free appropriate public education, which in the case of special needs children, sometimes means enrollment in a private facility.

But most federal courts had concluded that parents who are not lawyers and who want to challenge decisions have to hire an attorney to represent them. The court sided with the Winkelman family in their fight against their school district. The Winkelmans cannot afford a lawyer or the cost of private schooling for their son, Jacob.

The parents objected to the schools' plan to educate Jacob at a public school. They wanted the district to pay for his \$56,000 yearly enrollment in a private school that specializes in educating autistic children. The Winkelmans have spent about \$30,000 in legal fees since first contesting Jacob's treatment in 2003. Jeff Winkelman has taken a second job while his wife has researched previous court rulings and written her own filings.

It is unclear how many parents forgo lawsuits because they can't afford them, although advocates for disabled children said in court papers that most parents of disabled children lack the means to hire a lawyer.

Parents unhappy with a district's plan can appeal the decision through an administrative process. If they remain dissatisfied, they can file a civil lawsuit on their child's behalf, federal courts have said. At that point, however, most courts have said the parents must hire a lawyer.

Whether Jacob should have private schooling at public expense was not before the Supreme Court, only his parents' right to go into federal court without a lawyer.

(Article from BostonHerald.com, May 21, 2007)

## “Darius Goes West,” A Movie Review by Kris Haines

I would bet that nearly everyone in a wheelchair has heard the suggestion at least once: You should take your chair on “Pimp my Ride!” *Darius Goes West* is a superb film that aims to do just that. Fifteen year-old Darius Weems sets-out on a cross-country trip from his home in Athens, GA to Los Angeles in the hopes of convincing MTV to revamp his rapidly deteriorating chair. But his goals are loftier than merely getting a stylish new ride; he wants to use the trip to test the nation’s accessibility, and raise awareness of his disability (Duchene Muscular Dystrophy) among his peers, who happen to make up MTV’s audience and belong to the age-group affected by DMD.

The film is truly unique, not only because it showcases the one-of-a-kind bond that exists between the twelve members of the fiercely determined crew, but also because it uses unconventional techniques to tell its extraordinary story. I’m thinking particularly of the use of raps performed by Darius to replace traditional narration. At times these songs do much more than help advance the story, sometimes the lyrics are startlingly poetic and provide deep insight into the philosophy of this effortlessly inspiring person.

The trip itself was not all smooth-sailing, Darius encounters commonplace inaccessibility and we are quickly shown how unnecessary and avoidable it all is when we see that Carlsbad Caverns has been made fully wheelchair-friendly. Carlsbad Caverns! Not to mention the trip almost didn’t happen at all. UCP rescued the film from a budget shortfall in exchange for handing out wristbands for the “Who will Care?” campaign. The trip’s largest mechanical snag comes when the RV breaks down in Las Vegas, and the day is quite possibly saved through the spiritual intervention of a praying Chihuahua (yes, you read that right.) When the intrepid travelers finally arrive at their destination, UCP once again steps in and provides some very classy accommodations at the Beverly Hills Hilton, and arranges for a VIP tour of Universal Studios with UCP Ambassador William H. Macy as a guide. The tour ends with the crew becoming delightfully ugly Desperate Housewives.

Everyone who sees this film will gain some knowledge that they need. For those of us with any type of disability; our lesson is not to surrender to apathy and become as Darius puts it, “bumps on the wall.” For able-bodied people, the lesson is to treat us normally. This message is conveyed hilariously when Darius has his first experience with wasabi sauce....

See “Darius Goes West.” It documents a journey so amazing and special that you will be thankful just to be invited to watch the exhilarating ride....

*“Darius Goes West”*

*Directed by Logan Smalley*

*\$19.99 + s & h*

*All proceeds benefit Charley’s Fund, an organization dedicated to finding a cure for DMD*

*Buy at: [dariusgoesweststore.com](http://dariusgoesweststore.com)*

# Follow Your Dreams

My name is Melissa Draper and I'm 31 years old. I have cerebral palsy. I moved to Oregon in June, 2006 to do an internship with Ron Heagy, Jr. He is a motivational speaker. Ron is a quad and in a wheelchair himself.

I came here from Monticello, Indiana. I've always wanted to be a motivational speaker, so I could help people understand persons with disabilities better and also help kids not to give up and to follow their dreams. Ron has given me the chance to do this. I've spoken to over 4,000 people in the last two years.

I have written a book called "Follow Your Dreams." My book was published in 2006. My book is about my life dealing with my disability and never giving up so I could follow my dreams. My number one reason why I wrote my book is so I could get my story out to the public to open their minds up that disabled people are no different than anyone else. We just may have to do things differently, but we can get it done. Please give us a chance! You can get my book at [www.barnesandnoble.com](http://www.barnesandnoble.com).

God Bless you, Melissa Draper

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## Take a break

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<http://www.nlconcepts.com/>

In order to recharge your batteries, you need to take a break. Many people say "How could I possibly take a break? Nobody else can take care of my child!" My answer to this is "Treat it like an emergency". You would have to take care of the emergency and leave somebody else to take care of your child. This could be your family, your friend or a babysitter and while they might not do as good a job, I'm sure your child will get through it. Let's take a minute to define a break. A BREAK does NOT mean doing all your regular chores, doing homework with your child, making dinner, cleaning up, bathing your child and putting your child to bed. By this time, you're totally exhausted but you take a "BREAK" by meeting a friend for coffee. NO, a BREAK means ABSTAINING from your regular chores! It means going out of your house and letting somebody else take care of the rest. Think about it for a second. What is really going to happen if your child doesn't eat a balanced meal one night? Or watches too many videos? Or doesn't do homework? It's not going to affect your child's final outcome but it's going to do wonders for your spirit. By taking care of yourself you teach your children to do the same. So pick up the phone and call your family, friends or a babysitter!

# *Words to Live By*

A lecturer, when explaining stress management to an audience, raised a glass of water and asked, "How heavy is this glass of water?"

Answers called out ranged from 20g to 500g. The lecturer replied,

The absolute weight doesn't matter. It depends on how long you try to hold it.

If I hold it for a minute, that's not a problem.

If I hold it for an hour, I'll have an ache in my right arm.

If I hold it for a day, you'll have to call an ambulance.

In each case, it's the same weight, but the longer I hold it, the heavier it becomes.

And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on. As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden.

**Whatever burdens you're carrying now, let them down for a moment if you can. Relax; pick them up later after you've rested. Life is short. Enjoy it!**

Here are some thoughts to deal with the burdens of life:

- \* Accept that some days you're the pigeon, and some days you're the statue.
- \* Always keep your words soft and sweet, just in case you have to eat them.
- \* If you can't be kind, at least have the decency to be vague.
- \* If you lend someone \$20 and never see that person again, it was probably worth it.
- \* It may be that your sole purpose in life is simply to serve as a warning to others.
- \* Nobody cares if you can't dance well. Just get up and dance.
- \* Since it's the early worm that gets eaten by the bird, sleep late.
- \* When everything's coming your way, you're in the wrong lane.
- \* You may be only one person in the world, but you may also be the world to one person.
- \* Some mistakes are too much fun to only make once.
- \* We could learn a lot from crayons. Some are sharp, some are pretty and some are dull, some have weird names, and all are different colors, but they all have to live in the same box.
- \* A truly happy person is one who can enjoy the scenery on a detour.

*-Anonymous*

# Resources

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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](mailto:sblanchard@ucpaorwa.org).

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## 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>

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**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.

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**April**

10 6:30 pm Gimme A Break **Call UCP 503-777-4166**  
Monthly Resource & Support for anyone parenting a child with a disability.

23 9am-3pm OrPTI workshop  
"Electronic Books: Tools for Struggling Readers" in Hood River. Registration is required. Call OrPTI: 1-888-505-2673. **(Also May 14<sup>th</sup> in Tillamook.)**

26 8:30-5:30pm All Born "In" Cross Disability Inclusion Conference  
See the website for more info: [www.nwdsa.org](http://www.nwdsa.org).

**May**

8 6:30 pm Gimme A Break **Call UCP 503-777-4166**  
Monthly Resource & Support for anyone parenting a child with a disability.

30-31 Both days 2008 Oregon MegaConference at the Riverhouse Conference Center in Bend.  
See the website for more info: [www.oregonmegaconference.org](http://www.oregonmegaconference.org).

**June**

12 6:30 pm Gimme A Break **Call UCP 503-777-4166**  
Monthly Resource & Support for anyone parenting a child with a disability.

**July**

10 6:30 pm Gimme A Break **Call UCP 503-777-4166**  
Monthly Resource & Support for anyone parenting a child with a disability.

20 11am-2pm Children's Course Golf & Picnic Outing in Gladstone  
Play 9 holes of golf, or just take some easy lessons. We'll picnic in the park.  
Call UCP 503-777-4166.

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**SAVE THE DATES:**

UCP Annual Family Picnic: August 16, 2008

Walk 'n' Roll for UCP!: September 13, 2008

13<sup>th</sup> Annual Family Conference: October 3-4, 2008

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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.

## Would you like a night at a hotel for free?

Respitality is one of the most popular services we offer to families at UCP. We never have enough rooms to cover the requests. One reason is that two of the hotels who regularly donated rooms stopped being part of our program in 2007. Also in 2007, we had 75 new families join UCP.

We need new hotels to join our program! That's where YOU come in. If you have ANY hotel contacts in Oregon or SW Washington, we would love to hear from you.

The best requests to prospective hotels would come from you: **Visit a hotel in your area and tell them about the benefits of the Respitality Program to you and your family.** You could encourage them to donate rooms to our program when they have the availability. We can provide you with a script to help you make your presentation, as well as some Family Support brochures to hand out. Let us know if you'd like these materials.

The following hotels ARE a part of our program and donate rooms to UCP Respitality. Please use them when traveling and thank them for their support: Holiday Inn-Portland Airport; Marriott City Center-Portland; Marriott-Downtown Portland; Rogue Regency Inn-Medford; Doubletree-Lloyd Center; Shilo Inns.