
United Children & Parents

UCP's Quarterly Family Support Newsletter

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

11731 NE Glenn Widing Drive, Portland OR 97220

503-777-4166

www.aCommunityforeveryone.org

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Airplane Accessibility Petition

My name is Sally O'Neill. I am 17 years old. Like most girls my age, I love animals, going to the theatre with my friends on the weekend, and skiing in the winter. I dream of traveling after high school. I want to see places like Ireland, Italy, and India. Unfortunately, an accessible airplane ride is not an option for me.

I am writing this because I believe the airline industry should have to comply with the mandates of the Americans with Disabilities Act of 1990. I have cerebral palsy. That means although I have a normal mind, I still have uncontrollable spastic limb movement. I cannot talk or hold my own body upright. I need my wheelchair to keep me in the right posture, and to restrain my arms and legs. The problem is the airline companies make all disabled people check their wheelchair with other baggage. I have visited my grandparents in Ohio and Florida many times. My parents have spent up to 7 hours trying to keep me seated between them. I don't have the motor function to sit upright on my own. The airplane chairs are not big enough for a seat insert and do not support my upper body. When my shoulders are not in front of my hips, I go into an extension pattern. Due to my spastic limb movement, my parents have to physically restrain my arms and legs. I have strong tone, so this is not easy. None of us can eat, drink, read, or make ourselves comfortable in any other way. As I get older and bigger, each flight gets more difficult.

There are many other disabilities that have this same need for different reasons. I don't think it makes sense that all other places open to the public are made accessible to every type of disabled person, especially transportation companies, but the airline industry is allowed to force the disabled into able-bodied standards or medical transport. I've heard of an airline removing a whole row of seats to accommodate a Sumo wrestler. If they can do that for a special athlete, why can't they do it for a person with special needs? Have you ever wondered why you see so few people with

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cerebral palsy on airplanes? I think it's because the airlines do so little to accommodate their needs to ensure their comfort. It's discrimination. I looked up online how easy it is to remove any seat on the plane. I'm not asking for the bathrooms to be made accessible.

I am proposing that the first seat in the first row of the airplane be removable and tie downs be inserted. These tie downs are used in automobiles to keep the chair in place during crashes. They are as strong as anything on a plane.

I really believe with some small modifications airplane transportation can be made accessible to everyone. I hope you see the need and join me in this change.

Here is a proposed petition (when it's formalized, we'll send it everywhere):

We, the undersigned, petition the airline industry to make airplanes accessible to passengers who need their own wheelchairs for support. We ask that at least one aisle seat of every airplane be available for wheelchairs to roll in and be tied down.

* * * * *

Since Sally wrote her essay, UCP Family Support and/or Sally's family has contacted the Oregonian, **the Willamette Week (they ran a news story in the August 20th issue!)**, Senator Smith's staff, CDRC's ADA proponent, and a school for children with CP in Philadelphia. Do we petition Congress to change a law? Do we petition the airlines directly? Are wheelchairs structurally sound enough to withstand take-off and landing? Would each wheelchair have to be tested before being allowed on an airplane? There are a lot of questions to consider.

However, the important issue here is accessibility. There are a lot of people who cannot comfortably ride in an airplane, or who simply cannot ride at all. **We want to collect stories of your experiences riding in an airplane. Please call or write or send an email. The more stories, the better.**

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Movie Review: “The Music Within” by Kris Haines

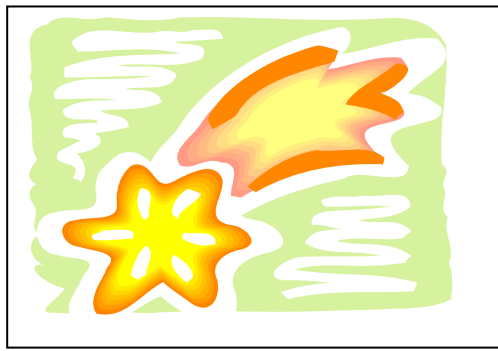
“The Music Within” is a masterful film, and a film that gives Portlanders reason to swell with pride. It tells the story of Richard Pementel and Art Honeyman, two friends who would craft the prototype for the ADA. Honeyman has CP and Pementel was nearly-deafened by an explosion in Vietnam. Their relationship is mutually beneficial because Honeyman’s speech is slurred and Pementel cannot yet read lips, so they must act as each other’s translators. In lesser hands this situation would be made intolerably “cute.” Not so here. One reason is because the translation is a two-way street, rather than one “speaking” for the other. Most importantly, each of them has occasion to “edit” the other, as only a friend can. This provides for some raunchy exchanges, which I believe are meant to demonstrate just how far from “cute” they’re striving to be. There is also a fair amount of what I like to call “handi-humor” that had me laughing pretty hard. (Watch out for the scene where Pementel works the phones trying to convince reluctant employers to hire people with disabilities.)

However, not everything is funny. Honeyman and Pementel encounter a truly bizarre form of discrimination, known as an “ugly” law. That is, Honeyman’s appearance is considered by the public to be so disturbing and “ugly” that the police are called in to arrest him and Pementel for creating a nuisance. That was an eye-opener....

I was so impressed with “The Music Within” that I started to wonder how I had not heard of it earlier. So I looked up Roger Ebert’s review. In it, Ebert complains that no one else is mentioned by name as the ADA is being drafted, and that this implies that Honeyman and Pementel did it alone. I would answer Ebert’s criticism by arguing that Honeyman and Pementel stand as representatives for all the rest. This is a wonderful, revolutionary thing. Finally, a character with a disability gets to represent others like himself, rather than some other larger “concept” which is so often the case. For instance, in a different film Pementel could be treated as nothing more than a symbol of the horrors of war.

“The Music Within” is a great film because it illustrates the power of self-activism and shows just how much can be accomplished when someone fights for their own rights. I for one needed the reminder.

Here’s the official movie website: <http://www.musicwithinmovie.com/>



13th Annual UCP Family Conference is Coming Up!

The 13th Annual UCP Family Conference for Cerebral Palsy and Related Disabilities is approaching quickly. It's a month earlier than usual this year: October 3rd and 4th at the same location as last year, the Red Lion in Jantzen Beach.

Tom Ritter, John's brother and Tex's son, will be our keynote speaker. Tom has cerebral palsy and will share his life experiences with us, as well as his work helping the media change their depictions of people with disabilities. As Tom says: "Disability has become more visible, and with visibility comes greater acceptance. Still, we are not there yet. There is more to be done to continue to change attitudes toward disability, and to provide more opportunities."

There are great workshop sessions planned. Here are a few of the topics: Risks and Benefits of Botox & Intrathecal Baclofen; CP & the GI Tract; Finding Friends; Growing Up with Cerebral Palsy; Special Needs Planning; Accessing Resources; What to Expect When Your Child Becomes an Adult; and more.

If you've never attended a UCP Conference before, you have yet to experience all the wonderful connections that are made each and every year. If you've attended, you know what I mean. New information is imparted, and hope and inspiration are commonplace. Come take part in this wonderful forum that happens only once a year. Call Susan or Cari for info: 503-777-4166, or visit the website for registration forms: www.acommunityforeveryone.org.

Medical Expense Deduction for Medical Conferences and Seminars

The IRS allows parents of children with special needs to deduct amounts paid for conference registration and travel expenses as a medical expense on their taxes per Revenue Ruling 2000-24 (2000-19I.R.b. 963). This means that all of the conference registration fees and travel expenses incurred attending the conference can be added to the rest of your medical expenses for the year!



On My Way to College, by Cory Brianna Andreatta

How does one describe in a page one's life? How do I start? Perhaps I shall start the same way David Copperfield did - from the beginning.

I was born a statistic, one of the lucky few who survive a three-month premature birth, one of the continually lucky who survived, as they say, "virtually unscathed," having only a mild case of Cerebral Palsy.

However, while I am grateful to be alive, having a life-long disability, even a small one, has been a challenge. I have, for the majority of my life, often been mistakenly attributed with mental retardation. I cannot in words describe to you the pain one experiences when one walks into a store to purchase something and the sales person begins speaking as though one were incapable of understanding speech. This has happened more the once.

I think it was these sorts of instances, which led to my infatuation with learning and knowledge. It was relatively unavoidable, even in attending school with the same peers for years, not to find someone who was willing to make me a joke, and there was, and is, no greater way of dealing with such things than by calmly explaining to the particular individual, in what most would consider very large words, that you are by no means retarded. I think it was when I realized this that I really saw the power of knowledge for what it was: an equalizer. I would never quite be able to do what others could physically, but I could make up for it in what I could do mentally.

This is why I'm strongly considering becoming a teacher - to show others the power of knowledge, the healing benefits of education - to spread what has become my passion to others. No matter how horrible life becomes, no matter what else is happening in one's life, there is always a way to improve it, a means of escape, through learning, through education. Education now is what I require to make my dream a reality, to begin the conquest of my passion, as it were.

[Above is an essay Cory wrote to apply for a college scholarship, which she later received.]

Resources

CAR SEATS AVAILABLE

The Kyle David Miller Foundation provides 5-point harness car seats for children over 40 pounds, and up to 105 pounds. (There are two car seats that go up to 105 lbs. and also have a 5-point harness: Traveller Plus by Britax, and Columbia Medical Orthopedic Positioning Seat.)

The application is available on their website:

http://www.kyledavidmiller.org/pages/3007/Apply_for_Help.htm

You must be receiving some kind of financial assistance, and you must provide a letter written on official letterhead from the agency you're receiving assistance from, showing your current status of receiving financial aid - WIC, Medicaid, Unemployment, etc.



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.

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

September

- 11 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
Topic: Opening up the world for our children
- 13 12-3 **Walk 'n' Roll for UCP!** The Family Support fundraiser at the Portland Eastbank Esplanade. Sign up a team, register as an individual, sponsor another. Visit www.walknroll2008.kintera.org.

October

- 3-4 9am-3:30pm **13th Annual UCP Family Conference on Cerebral Palsy and Related Disabilities.** Held at the Red Lion-Jantzen Beach, in Portland. The keynote speaker is Tom Ritter. Visit our website: www.communityforeveryone.org or call UCP for more details: 503-777-4166.
- 9 6:30 pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
Topic: Relaxation: How to care for the caregiver

November

- 13 6:30pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
Topic: De-stressing the holidays

December

- 11 6:30pm Gimme A Break **Call UCP 503-777-4166**
Monthly Resource & Support for anyone parenting a child with a disability.
Topic: Holiday Potluck

SAVE THE DATES:

Walk 'n' Roll for UCP!: September 13, 2008: www.walknroll2008.kintera.org

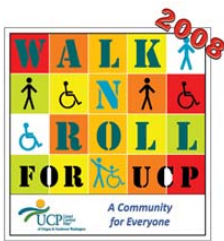
13th Annual Family Conference: October 3-4, 2008

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No endorsement by UCP should be inferred.



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4th Annual Walk 'n' Roll

If you haven't registered already, please visit the website for the 4th Annual Walk 'n' Roll: www.walknroll2008.kintera.org. The event is scheduled for September 13, 2008 in Portland. We hope you can join us! If you can't join us, you could sponsor another walker/roller.

WALK 'n' ROLL BUDDY PROGRAM: Members of the UCP Family Support Program who have NEVER participated in a Walk 'n' Roll event could be eligible for FREE registration. Call 503-777-4166 x227 to find out how to qualify.

Family Conference on Cerebral Palsy and Related Disabilities

The 13th Annual Family Conference is a wee bit earlier this year: October 3rd and 4th at the Red Lion by the River in Jantzen Beach. Tom Ritter will be our keynote speaker. Visit the UCP website for more information: www.ucpaorwa.org.