



# United Cerebral Palsy Of Metropolitan Detroit

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Life without Limits for People with Disabilities™

Fall 2007

## A Message from the President

UCP of Metropolitan Detroit is an agency that is all about people—helping to create “Life without Limits.”

You will see evidence of that throughout this issue of our newsletter—from children who now have easier access to their community, to adults who are wage-earners, to seniors who are living in their own homes not nursing homes.

QuickRamps for Kids, Employment Support Programs and Adult Advocacy services are just a few of the things we do, every day, that make a real difference for real people. Check out the photographs sprinkled throughout the newsletter and you will see the positive impact of the programs and services of UCP/Detroit. The smiles on the faces of those we have served will, I hope, bring a smile to your face too.



*Leslynn R. Angel, President & CEO*

## Cerebral Palsy

*By Stephanie Herrle P.T., M.S.  
Providence Park Hospital  
Novi Rehabilitation Services  
With Carolyn Das, UCP/Detroit Staff*

*The following article is adapted from UCP/Detroit staff training by Ms. Herrle. In our agency's effort to focus on cerebral palsy as a human condition, it seemed important to begin by ensuring that all staff (from clerical support to the President) have a thorough understanding of cerebral palsy. We hope you find this information as helpful as we did!*

### Overview

Cerebral palsy (CP) is a medical label that means that the brain suffered an insult (a deprivation of oxygen) before, during or after the birth process. The characteristics of the resulting cerebral palsy are not the same for every person. Those characteristics will be different depending on when the insult occurred, the area of the brain affected, and the age of the person.

Because of this, CP is sometimes called an “umbrella term” in that it covers a wide variety of possible characteristics.

CP is distinguished from other brain insults and injuries in that it is an injury to the developing brain. Thus, by definition, CP results from injuries that only occur before, during or after the birth process. Depending on the resource, the upper age limit cited for the acquisition of cerebral palsy is 3 – 5 years. Because the injury is to the developing brain, and because ‘normal’ childhood development is affected, CP is called a developmental disability.

Cerebral palsy occurs with surprising frequency. It is the most common childhood disability and is seen in 2/2000 people.

### What does CP look like?

As mentioned above, the characteristics of CP are not the same for every person.

The primary, most basic physical expression of cerebral palsy is that muscle control is impaired. All muscle control originates from the brain's ability to interpret and direct neurological signals from the environment. The brain's ability to interpret and direct neurological signals enables muscles to work together to perform a specific task such as walking. All movement, resting postures and balance requires smooth coordination of muscles to ‘contract’ and/or ‘relax’. A person who has cerebral palsy has a brain that is not always able to interpret and direct these signals. Thus a person's movements may be jerky or uncoordinated; even his ability to maintain a quiet resting posture can be affected.

However, every single person with cerebral palsy has a unique brain and a unique insult/injury. So, one person's experience of living with CP may be that it affects him a little. For example, it may be difficult but not impossible to control the arm/leg on one side of

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## Cerebral Palsy (continued from page 1)

the body. Another person's experience might be that CP affects him a lot, perhaps their challenging the whole body. Even the ability to swallow or to breathe, are impacted. And, of course, there are infinite variations in between!

### Life Outcomes for People with CP

Today, people with cerebral palsy are living lives that are as rich and full of opportunity as any other person. For example, it is no longer true that a person with CP can expect a shortened life. Due to improvements in medical treatments and increased respect for the life and rights of all people with disabilities, people with CP are living longer than ever before. Adults with CP have access to advancements in medicine that control pain, muscle spasms and lessen the wear and tear on the body's joints and muscles.

This presents a new set of challenges to those agencies who strive to support people with disabilities. While 50 years ago (or even 20!) it may have been acceptable to simply ensure safety, relative comfort, and freedom from pain—today people with CP want real and active lives! Active and enriched lives stem from inclusive schooling, higher education, accessible recreational opportunities and the ability to work enabling people with CP to be a valuable and productive part of society. People with CP, more than ever before, are living their lives as part of the

community in the mainstream of life. United Cerebral Palsy of Metropolitan Detroit exists for the sole purpose of helping people with disabilities, particularly CP, to lead the full, community-based lives that they want. We are all about turning obstacles into opportunities. How can we help you?

*The next issue of Life without Limits will highlight medical research around Cerebral Palsy. A leading researcher, Dr. Edward Dabrowski, practices right here in Metropolitan Detroit. Our interview with him will highlight current research that may, someday soon, impact the life of you or someone you love!*

## UCP/Detroit Annual Meeting

The UCP/Detroit Annual Meeting took place on July 17 at Oakland Hills Country Club. Our guest speaker, First Gentleman Daniel G. Mulhern, spoke to a crowd of 75 people on the subject of everyday leadership. Afterward, he signed copies of his best-selling book *Everyday Leadership: Getting Results in Business, Politics and Life*.



*UCP President & CEO Leslynn Angel, UCP Board President Mark Lezotte, welcome Mr. Mulhern.*

*Life's most persistent and urgent question is: "What are you doing for others?"*

*~ Martin Luther King Jr.*

## UCP Day 2007

Thank you to the following organizations and their employees who participated in UCP Day 2007.

We expect the final tally to reflect donations of over \$24,000.

Bellaire Team Leader  
Collins, Einhorn, Farrell & Ulanoff  
Comerica Bank  
Hagopian World of Rugs  
Joyce Howe, GPA, P.C.  
Laurie Orlando P.C.  
Merrill Lynch  
Paychex Inc.  
Social Security Administration  
Vercruyssen, Murray & Calzone P.C.  
Wachovia Dealers  
Woods Construction Inc.

Special thanks to the employees of Comerica Bank for donations totaling approximately \$20,000.



# Meet Ethel Rabinowitz

By Sheryl Stumbaugh, Adult Advocate

Ethel Rabinowitz, a vibrant, 72-year-old woman with athetoid cerebral palsy, was placed in a nursing home for rehabilitation after falling in her apartment a couple years ago. After three months of rehabilitation and care, Ethel desperately wanted to return to her Southfield apartment. However, the nursing home staff was concerned that Ethel would not be able to live both independently and safely...and thus began Ethel's quest to return home.

Ethel first contacted her local **Area Agency on Aging 1B** (AAA-1B) and was deemed eligible for a **MI-Choice Waiver**. She was able to return to her apartment about eight months after her fall. The next step was to find personal assistance staff who understood her unique daily care needs – not to mention that she had a lot of living to do and wanted to be able to get back out into her community!



Ethel contacted UCP/Detroit and was connected with an Adult Advocate who introduced her to the **Person-Centered Planning** (PCP) process. This process allowed Ethel to develop a plan that expressed her needs, desires, and dreams as well as facilitated agency collaboration between AAA-1B, **Jewish Family Services**, **Macomb/Oakland Regional Center**, and UCP/Detroit. This collaboration was integral to the process of meeting Ethel's needs and desires.

For example, through the person-centered planning process it was revealed that although Ethel had a **Life Line**, she couldn't access it from bed at night, when her personal assistants were gone. This left her completely helpless in the event of emergency or if her aides didn't show up for their morning shifts. UCP/Detroit was able to help Ethel apply for a Bellows Fund grant that enabled her to obtain an adaptive 'pillow phone' that solved the problem.

The annual PCP process continues to assure that Ethel's needs are met. She has been able to return to her self-determined lifestyle, making personal choices that work for her life, allowing her to live in her apartment and access her community. With the PCP approach, agency collaboration, assistive technology, Ethel's self-advocacy skills and a little help from her UCP/Detroit Adult Advocate, she is truly living "Life without Limits".

## GLOSSARY

**Area Agency on Aging 1B:** A non-profit organization dedicated to preserving the independence, dignity, and quality of life of seniors, family caregivers and persons with disabilities residing in Livingston, Macomb, Monroe, Oakland, St. Clair and Washtenaw counties.

**MI-Choice Waiver:** A program through which eligible adults who meet income and asset criteria can receive Medicaid-covered services like those provided by nursing homes, but can stay in their own home or another residential setting. The waiver became available in all Michigan counties October 1, 1998. In addition to the basic services of Michigan Medicaid, participants may also receive services unique to the waiver including: medical supplies and equipment not covered under basic Medicaid, transportation, environmental modifications, and personal care supervision.

**Person-Centered Planning:** A process for planning that honors an individual's preferences, choices and abilities. The person-centered planning process involves families, friends, and professionals as the individual desires or requires.

**Jewish Family Services:** A non-profit organization that offers case management, individual and family counseling, adoption support, family violence counseling, educational consultation, volunteer services, outreach to schools, Homeshares, Meals on Wheels, respite, and homemaking.

**Macomb/Oakland Regional Center:** A non-profit agency that provides services to people with developmental disabilities. Examples include: case management, clinical services, respite services, vocational services, and family supports. In addition, they offer self-determination, which is a service model that allows clients to control their own annual budget and to hire their own staffing.

**Life Line:** A personal emergency system; this is not a telephone and can only be used to call for help in the event of a true emergency.

SERVICE IS THE RENT WE PAY TO BE LIVING. IT IS THE VERY PURPOSE OF LIFE  
AND NOT SOMETHING YOU DO IN YOUR SPARE TIME.

~ MARIAN WRIGHT EDELMAN

## SAVE the DATE & SPREAD the WORD!

November 5, 2007

### Symposium on Postsecondary Opportunities on College Campuses for Students with Intellectual/Cognitive Disabilities

The Developmental Disabilities Institute (DDI) at Wayne State University is pleased to announce an upcoming Symposium on Postsecondary Opportunities on College Campuses for Students with Cognitive/Intellectual Disabilities. The first ever Michigan event will take place November 5th, 2007 on the campus of The University of Michigan, Dearborn. The event will be held in the Fairlane Center.

This Symposium brings together leading experts, researchers, practitioners and consumers on postsecondary education (PSE) to provide an overview of PSE opportunities and discuss current trends, issues, and solutions for PSE initiatives. Two of the pioneers and researchers in the field, Dr. Meg Grigal, Director of the Postsecondary Research Center ([www.transitiontocollege.net](http://www.transitiontocollege.net)) and Dr. Debra Hart, Educational Coordinator at the Institute for Community Inclusion, University of Massachusetts will present at the Symposium. Exemplary models of learning on college campuses for students with cognitive/intellectual disabilities will be showcased. The goal of the symposium is to foster the growth of the knowledge and interest in providing opportunities for students with cognitive/intellectual disabilities to continue to learn in inclusive, post high school settings.

Reprinted from: [http://www.ddi.wayne.edu/postsecondary\\_symposium.php](http://www.ddi.wayne.edu/postsecondary_symposium.php)

United Cerebral Palsy of Metropolitan Detroit is a proud co-sponsor of this event.

For more information about PSE opportunities, please visit:

[www.thinkcollege.net](http://www.thinkcollege.net)  
[www.transitiontocollege.net](http://www.transitiontocollege.net)  
[www.education.umd.edu/oco](http://www.education.umd.edu/oco)  
[www.transitioncoalition.org](http://www.transitioncoalition.org)  
[www.STEPS-Forward.org](http://www.STEPS-Forward.org)

*“Through the Same Door: Inclusion Includes College,”*

a short documentary film that highlights the college experience of local student Micah Fialka-Feldman, is available at [www.danceofpartnership.com](http://www.danceofpartnership.com).

A copy of this film is also available for loan through the UGP/Detroit library.

## Family Life Advocacy: Community Focus Group Results

By Pat Dwelle, Advocate

In our efforts to establish a model for Person Centered Advocacy for families, UCP/Detroit conducted three Family Focus Group meetings in Wayne, Oakland and Macomb counties.

Our purpose was to gain a better understanding of the concerns parents have for their children with disabilities and identify needs that typically are not met using traditional models of advocacy. Parents used many words to describe the ‘best case’ adult life scenarios they hope for their children with disabilities. Their words can be grouped into four basic descriptors:

**Self-Determining:** their children will have options and choices

**Independent Living:** their children will have homes of their own

**Activities:** their children will work, travel and participate in recreation

**Community:** their children will be involved in their communities and will have access to friends and family

When asked to describe their ‘worst case’ scenarios for their children as adults, their responses fell into two categories:

**Isolated:** Being alone and lonely  
**Unsupported:** physically, financially, emotionally, and in decision-making

Parents reported a sense of being alone with no help, direction or guidance immediately following diagnosis and also a frustration that various systems are not connected. For example, your child might access Early On but you still might not be connected to Community Mental Health and other support systems. You may have an illusion of being ‘settled’ but the truth is that you don’t know what else is available to your child.

In order to do the planning that is neces-

sary for the “best case” scenario parents feel they need to have vision about possibilities and knowledge about how to turn their dreams for their children into realities. Key supports to this would be:

1. To have the opportunity to see, hear and engage in role models and examples of possibilities.
2. To have access to information when they need it.
3. To know how to navigate through barriers and problems.

As a result of our findings, UCP/Detroit is developing a specific Charter for Family Life Advocacy that focuses on creating Person Centered Plans for children and their families that promote personal choice, self-determination, and implement natural supports.

For more information about UCP/Detroit’s Family Life Advocacy, please contact Pat Dwelle at 248-557-5070.

# Making Life a Little Easier

By Pat Dwelle, Advocate

The QuickRamps for Kids project has made life a little easier for more than 20 families in metropolitan Detroit. Through a grant from the Community Foundation we were able to provide portable ramps to families whose children experience disability. These ramps have made it possible for families to have easier access in and out of their homes and vehicles. They also provide a means for families to visit friends and relatives, and participate in community activities.



Some of the comments made by parents who received ramps are:

- "we are able to get in and out of otherwise difficult areas when visiting others"
- "my child is using her wheelchair independently"
- "the ramp has relieved the stress of moving the wheelchair step by step"
- "my son gets out more to do more"
- "the ramp has relieved the painful burden of lifting"
- "my daughter feels much safer when she comes in and out of the house"



We are thankful to have had the opportunity to make a difference for so many families who otherwise have found it difficult, if not impossible at times, to engage in activities outside of their homes. Truly these ramps have made 'Life without Limits' a reality for many children.

## Keep QuickRamps (and other great projects) going!

As you plan your end-of-year giving, please consider a tax-deductible donation to UCP/Detroit. You don't have to wait to receive our annual appeal letter—just use the envelope enclosed in this newsletter or even call our office to make a credit card donation.

Would you like to directly sponsor a QuickRamp for a family? For only a few hundred dollars you make the world more accessible for a child and his/her family. Call us and we will make it happen! 248-557-5070

**Thank you, in advance, for supporting life without limits for people with disabilities!**

## UCP/Detroit Receives Grant

The QuickRamps for Kids program will continue through a \$13,361 Quality of Life grant from the Christopher and Dana Reeve Foundation.



Quality of Life grants, conceived by the late Dana Reeve, are given to programs or projects that improve the daily lives of people with paralysis-causing conditions.

"... there are millions of people with disabilities who deserve an improved quality of life. It is my passion to help disabled individuals, their families and caregivers in ways that will more immediately give them increased independence, day-to-day happiness and improved access. Our Quality of Life program is about freedom." --Dana Reeve

*Thank you to the Christopher and Dana Reeve Foundation!*

## Meet Bill Pattison

By Malena McGhee, Employment Specialist

Mr. William Pattison, who likes to be called Bill, contacted UCP of Metropolitan Detroit seeking assistance from our organization in an effort to maintain employment.

Bill enjoys working part-time. Until recently Bill worked three hours a day at a pharmacy in Oakland County. He is now employed with McDonald's and works as many as 24 hours per week. Bill enjoys staying fit by walking (sometimes biking) the 3 miles to and from work each day. When he is not working a favorite past-time is watching the Detroit Tigers.

I recently met with Bill at his favorite coney island restaurant. It was clear to me that Bill's social, outgoing nature makes an impression. Several workers approached Bill just to say hello and later spoke to me of their fondness for him. It occurred to me that, in addition

to providing Bill with financial stability, Bill's employment situation is the kind of natural outlet for sociability that all people, whether they have disabilities or not, desire and enjoy.

I am delighted to have met Bill and to be working with him to support his employment.

*Employment Supports Provided to Mr. Pattison by UCP/Detroit:*

*Maintenance of Social Security Benefits under the WIPA Program*

*Assisting Bill in balancing his work responsibilities and personal life*

*Helping Bill to work through issues with his employer*



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### Don't Forget to Register!

**What:** The Life without Limits through Assistive Technology Conference & Expo

**When:** Monday October 8, 2007 8:00 am - 4:00 p.m.

**Where:** Marriott Hotel at Centerpoint in Pontiac

**Cost:** FREE to people with disabilities, their personal attendants, family members; \$35 for non-profits; \$50 for all others

Go on-line to download the registration form:  
[www.ucpdetroit.org](http://www.ucpdetroit.org) OR

Call 248-557-5070 to request the registration form.

Co-Sponsored by:  
Michigan Developmental Disabilities Council -  
Oakland County RIGG  
Michigan Disability Rights Coalition



If you can't feed a hundred  
people, then feed just one.

~ Mother Teresa