



United Cerebral Palsy Of Metropolitan Detroit

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Life without Limits for People with Disabilities™

Winter 2007

A Message from the President

As Fall turns to Winter, and the holidays and a new year rapidly approach, I have been reflecting on change and how ‘change’ has come to our agency over the last year.

UCP/Detroit looks much different than it did 12 months ago. We have developed a new set of action domains (Cerebral Palsy, Assistive Technology, Person Centered Advocacy and Employment) and have redirected staff and realigned resources appropriately. We are actively pursuing grant funding so much-needed programs like QuickRamps for Kids can continue. We hope that you have noticed, through our recent newsletter articles and photographs, our increased intensity in providing tangible supports to the very real people we serve.

As you plan your holiday giving, please consider UCP/Detroit. With your help we can assist more people throughout 2008 to live quality lives—lives without limits.



Leslynn R. Angel, President & CEO

Trends and Research An Interview with Dr. Edward Dabrowski

Our last newsletter featured an article about cerebral palsy—what it is and how it manifests itself. In this issue we address some common questions about, and the current research into, cerebral palsy. Dr. Edward Dabrowski, a local leader in medical practice for people with cerebral palsy, took the time to talk with us about current trends and research.

Q: *How is the new generation of people with cerebral palsy (CP) different from previous generations?*

A: The most common form of CP in the 1950s was choreoathetoid CP, predominantly secondary to hyperbilirubinaemia. With the advent of phototherapy, this has become a treatable condition,

and the incidence of choreoathetosis has dropped significantly.

Spastic quadriplegic CP is becoming more frequent as newborns that would not have survived in the past, are surviving due to advanced medical technologies.

Children with CP today have the good fortune of having a reasonable medical support structure with better access to health professionals. While this is by no means perfect, there are a larger number of physical, orthotic, pharmacologic (oral, injectable or implantable) and other surgical options that directly impact their quality of life.

Cognitive interventions (primarily pharmacologic) also are available now, that were not for previous generations.

Q: *Is it true that rates of cerebral palsy are increasing? Why or why not?*

A: This is controversial. It would however appear that the incidence of CP in the United States is 2.0 to 2.8 per 1000, with a prevalence of about 550,000 to

764,000 persons in the U.S. with CP at any given time. One of the problems with these numbers is the definition of CP itself. Over time, this definition has been in evolution, so people have been reporting incidence based on differing definitions.

The new definition developed by the UCP Research & Education Foundation in 2005 now reads: “Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.” (From: www.ucpresearch.org/cerebral-palsy-research/proposed-definition.php)

Q: *Anecdotal evidence suggests people with cerebral palsy are living longer. Do you see this happening? Why do you think that might be happening?*

A. Again, this is controversial. In my
Continued on page 2

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own practice this does not appear to be the case. In the literature there is some suggestion that this may be true, however at this point in time it's too early to say. One might be inclined to think that with improved medical care and technology, as well as adjunctive living arrangements (nursing homes, extended care facilities, etc.) life expectancy may become extended. Quality of life, including comfort, seems to be improving, however, this impression I think is at best anecdotal.

Q: *What challenges do people with cerebral palsy face as they age?*

A: There are many challenges including:

- Loss of mobility
- Access to health care with professionals familiar with CP and the effects of aging on an individual with CP
- Lack of facilities and/or support structures that are supportive of an environment which promotes as independent a lifestyle as possible.
- Job opportunities within the global economy
- Socialization opportunities

Q: *What are some promising new areas of research for the treatment of cerebral palsy?*

A: Research areas to watch include:

- Expanding pharmacologic research into motor development and remediation
- Research in understanding and promoting or facilitating brain plasticity
- Basic research into the mechanisms underlying CP
- New and upcoming techniques to promote ambulation (Lokomat, etc.)
- Stem cell research in the future

Q: *What does the data say about treatments like hyperbaric oxygen therapy, conductive education, and suit therapy?*

A: There is no body of objective evidence to suggest that HBOT, conductive education or suit therapy are effective. This doesn't mean however that, in the future, certain aspects of these interventions won't prove to be beneficial in certain sub-types of CP.

Q: *You have traveled to Poland and done work with the folks there regarding 'suit therapy.' What do your studies of this particular therapy reveal?*

A: Again, research so far does not support "Adeli" style suit /therapy for children with CP (DMCN 2006, 48: 324).

The study (manuscript in preparation) we conducted at Children's Hospital of Michigan/Wayne State University comparing intensive therapy with and without a suit found greater functional improvement with the suit (though minimal) in the highest functioning level of kids. The significant improvements found in all participants seemed to be related to intensity of therapy. There may be training applications in a therapy setting, as a set of "second hands" for the therapist, however, this therapy is not and should not be considered a universal remedy.

Q: *Treatment for spasticity is a major issue for people with cerebral palsy. Are there any particular resources you would recommend for investigation of treatments?*

A: Resources I recommend for investigation include: www.wemove.org and www.mdvu.org/library/pediatric/spasticity/spa_tre.html

Q: *What are some of the public misconceptions about cerebral palsy?*

A: There are many, including:

- That anyone with CP is "retarded." While cognitive impairments can be a co-morbidity in CP, there are numerous individuals with normal cognitive functioning and intelligence. Even individuals that are totally dependent upon a wheelchair and are unable to communicate without a communication device, can in fact be perfectly normal in their cognitive functioning.
- That people with CP are not educable or employable.
- That individuals with CP cannot enter professional careers.
- That all individuals with CP require group or nursing home placement in later life.
- That people with CP cannot drive independently.
- That people with CP cannot have kids, be effective parents and raise families.
- That people with CP with severe motor involvement and who cannot

speak, are assumed to be cognitively impaired and therefore are unable to learn to use a communication device.

- That people with CP cannot express their own wants and needs, or have feelings. (I see this expressed in that people tend to speak to their parents or caregivers, rather than to the individuals with CP.)
- That individuals with CP do not have a political voice.
- That CP is caused by birth trauma alone.

Q: *Is there anything else our readers should know?*

A: This is going to be the decade of expansive research into the causes, management and treatment of individuals with CP!

On a personal note, I would advise people with CP and their advocates to look critically at research, treatment interventions, and alternative therapies. Do not succumb to economic hardship in pursuit of false hope. Look at things critically so that you are not taken advantage of. Remember the old adage "If it looks too good to be true, it probably is."

Do you have a particular question about or topic idea related to cerebral palsy? If so, please contact Taryn Reid (248.557.5070 or treid@ucpdetroit.org) for its consideration as a topic in a future newsletter.

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Meet Dr. Dabrowski

Dr. Dabrowski is heavily involved with CP study, research and treatment.



He serves in two key positions locally. First, he is the Chief of Physical Medicine and Rehabilitation at Children's Hospital of Michigan, Wayne State University. Additionally he is the Medical Director of the Rehabilitation Research & Technology Program in the Motion Analysis Lab, Children's Hospital of Michigan, Wayne State University.

Dr. Dabrowski also has five current national appointments, including a seat on the Scientific Research Advisory Board of the United Cerebral Palsy Research & Education Foundation.

In addition, he has traveled to Poland numerous times to personally observe the "Adeli Suit Therapy" program there, has served on a variety of medical committees, and is an accomplished researcher and author of numerous peer-reviewed publications.

Ticket to Work makes Employment Possible

By Paul T. Landry
Director of Employment Programs

In the past, the Social Security Administration (SSA) has focused on providing Social Security (SS) benefits to people who are disabled and deemed unable to work. The enactment of the Ticket to Work legislation in 1999 has shifted the focus from simply providing benefits to providing opportunities and support so people with disabilities may enter (or re-enter) the workforce.

Since the Ticket to Work legislation was created, the SSA has been working with the State of Michigan's vocational rehabilitation agency and employment networks to give SS beneficiaries the opportunity to choose an employment network that will provide job development services to them. Employment networks are paid by the SSA when a

job is developed for the beneficiary. In addition, the SSA pays the employment network when a beneficiary is able to maintain employment over time. The concept being sustained employment will reduce dependency on SS benefits.

UCP/Detroit's Work Incentive Planning and Assistance (WIPA) project provides that mechanism. Under the project, which is funded by the SSA, Community Work Incentives Coordinators (CWICs) work with people who have an expressed interest in going to work. They provide a written benefits analysis plan, outlining the beneficiary's employment options. They help to develop long-term supports that may be needed to ensure a beneficiary's success in regards to employment. They also can make referrals to employment networks, vocational rehabilitation agencies, or One-Stop Career Centers.

The SSA is measuring outcomes and is targeting that .5% of social security beneficiaries nationwide will be able to work their way off benefits, through employment. It is hoped that the combination of benefit planning through WIPA, along with the employment supports provided through Ticket to Work, will together increase employment and decrease dependency on public benefits. SS beneficiaries have access to the resources they need to understand how their benefits are affected by employment and to seek future employment opportunities they desire.

UCP/Detroit encourages individuals who are receiving benefits from Social Security and want work to call UCP/Detroit and speak with a Community Work Incentive Coordinator.

The Basics of Transition Planning

By Pat Dwelle, Advocate
(This is the first in a series of articles about Transition Planning.)

The educational process takes on a new meaning when high school students with disabilities approach adulthood. Transition planning allows parents and students new support opportunities that are available through the 'adult' service system which becomes available at age 18. These opportunities may enable a student to do things they like to do, to live where they want to live, to work and to be involved in their communities.

The following describes the supports available for preparing for the future:

1. Employment - The high school career counselor, transition coordinator, other educational staff and a representative from Michigan Rehabilitation Services (MRS) can assist in identifying appropriate opportunities and classes; offer a vocational assessment to determine particular skills and interests.

2. Housing - Resources should be provided to the student regarding programs for home ownership, shared housing plus other opportunities along with funding options.

3. Independent Living Skills - Community Mental Health (CMH) provides Community Living Supports (CLS) to assist with personal care needs and meal preparation. For those daily living needs that require assistance such as laundry, shopping, cleaning, and meal preparation, the Department of Human Services (DHS) offers a Home Help (HH) program that will pay to have these services provided.

4. Community and Recreation - Everyone on the team can be helpful in identifying activities based on the student's likes and dislikes. Depending on the Individual Education Program (IEP), the school may provide support and in some cases, CLS hours may be an option.

5. Assistive Technology - All of the potential partners mentioned above can be instrumental in identifying assistive technology needs. The right assistive technology can make the difference in the student's ability to participate in activities, become employed and enjoy life.


6. Education - For the student who continues to receive public education services after high school, the local school

district will continue to play a major role in all areas mentioned. It is important to know that you do not have to be 'restricted' to the district's center-based program if the program is not focused around your child's area of interest.

Remember, Transition Planning is the key to a successful future for your child. More information on Transition Planning can be found at www.nichcy.org

Next issue: The IEP and the Transition Plan - Make It Count

SAVE THE DATE



Detroit
Red Wing Alumni
vs
United Cerebral Palsy
PUCKSTERS

March 15, 2008
8th Annual
UCP Hockey Fundraiser

Meet the Board

The Board of Directors for any non-profit agency plays a critical role in shaping and developing the mission and day-to-day work of the agency. Individually and as a group, the Board's credibility, competence, and commitment to the agency and its goals are crucial to protecting the public trust of the organization.

UCP/Detroit is fortunate to have a strong Board of Directors with a proven commitment to life without limits for people with disabilities. We would like you to meet them! The Directors are (names in bold indicate new and/or returning board members):

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Mary Ann Greenawalt – Secretary
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Mike Ward

Thank you to our Board of Directors for their commitment and support to the important work we strive to do at United Cerebral Palsy of Metropolitan Detroit.



Introducing...

Taryn M. Reid has joined United Cerebral Palsy of Metropolitan Detroit as the Director of Marketing and Development.

A 2002 graduate of Eastern Michigan University, Taryn launched her non-profit career while a student, working as an intern at the Detroit Institute of Arts (DIA). After college Taryn worked as Assistant Director at the Eastern Michigan University Alumni Office and, subsequently, returned to the DIA where she served as Events Manager. As a result of her formal education and work experience, Taryn comes to us with a wealth of knowledge in event planning and fundraising.

Are you a Dynamic Dad?

Would you like to be?

Oakland Family Services is excited to present its Dynamic Dads program! Dynamic Dads is a federally funded support and educational program for fathers of children who have delays or disabilities. Program services are absolutely FREE of charge! Services include confidential group support and education, individual support (for example, assistance in accessing community resources), and a Lekotek membership. Groups are scheduled at father-friendly times, with convenient locations throughout Oakland County. For more information or to register, call 248-858-7766, ext. 209.



Research Study:

Adults with Hemiplegic Cerebral Palsy

The University of Michigan Division of Kinesiology's Project ULTrA is currently seeking adults between the ages of 18 and 50 who are able to reach forward from a sitting position and who are willing to complete a 10 week, home-based upper limb training program. Participants are required to have enough strength to reach both arms forward to head height and partially open their hands.

Please contact Colleen Lewis, Ph.D. at (734) 763-5829 or via her email:caelewis@umich.edu

Research Opportunity:

Testing Your Child's Learning Skills

The University of Michigan Health System and Mary Free Bed Rehabilitation Hospital are conducting research on new ways of testing children's learning skills. Children who take part will be able to try computerized tests of learning. To take part in this study, children must:

- Be 6-12 years of age
- Have a previous documented medical diagnosis of Cerebral Palsy
- Have their parent (or legal guardian) provide written, informed approval to participate
- Not have a medical or psychiatric condition that affects the tests, including changing doses of medication or a history of brain injury.

Participants can expect to spend two to three hours in the study, and will be paid a \$50.00 honorarium for their time and effort.

For more information, please contact:

Donna Omichinski
325 E. Eisenhower, Suite 100
Ann Arbor, MI 48108
(734) 936-6023

UCP Hosts 2nd Annual AT Conference & Expo

On Oct. 8, United Cerebral Palsy of Metropolitan Detroit hosted the second annual Life without Limits through Assistive Technology Conference & Expo.

More than 100 people converged at the Marriott Hotel at Centerpoint in Pontiac for a day of information and education about assistive technology (AT). Speakers, product vendors and agencies who support access to AT provided a wealth of knowledge to all attendees.

After a welcome from our emcee, **Jerry Wolfe**, keynote speaker **Snoopi Botten** riveted the audience with his presentation of My Life without Limits. As a person whose life has been transformed by access to Augmentative and Alternative Communication (AAC), Snoopi had a great message for us about the absolute power of technology to change lives and make dreams come true.



Thank you to the following sponsors for their support to the 2nd Annual AT Conference and Expo:

BASF

Macomb Oakland Regional Center

Michigan Developmental Disabilities Council (Oakland County RICC)

Michigan Disability Rights Coalition

Michigan Protection and Advocacy Services

Oakland County Community Mental Health Authority

We Need YOU!

We are seeking organizations and agencies to partner with us on the planning, fund-raising and presentation of the third annual Life without Limits through Assistive Technology Conference and Expo in 2008. Please contact Leslynn Angel (248.557.5070 or langel@ucpdetroit.org) to get involved.

Your organization's involvement will make this event even more valuable and informative for people with disabilities, family members, and the professionals who serve them.

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Life without Limits for People with Disabilities™



UCP Chief Financial Officer LaToya Jones had as much fun as the kids at the UCP Craft Table at the NOMC/Europeds Family Fun Day.



UCP in the Community

UCP Holiday Canned Food Drive

Bring in canned goods or gift cards to the UCP office by Dec. 7 to help a needy family during the holiday season!

8th Annual Red Wings Alumni/UCP Charity Hockey Game

March 15, 2008

17th Annual UCP Casual Day

June 2008

QuickRamps for Kids

Apply now! If a child in your family needs assistance purchasing a wheelchair ramp, please call

(248) 557-5070 for more information.