



PATHWAYS

Life without Limits for People with Disabilities

Stilt-Walking Across Michigan!

Standing about 8.5 feet tall on stilts, Neil Sauter, a young man with mild cerebral palsy, started a journey of a lifetime May 8, 2008 – he began an 830-mile journey across Michigan on stilts to raise money and awareness for UCP Michigan’s Assistive Technology Loan Fund. Neil started his journey in Lambertville and plans to cross the Michigan border into Wisconsin near Ironwood on June 28th.

Each dollar Neil raises will be matched with \$3.00 through a grant from the U.S. Department of Education’s Rehabilitation Services Administration.

When asked what he hopes to accomplish by trekking across the entire state on stilts, Neil says, “I hope to raise lots of money for UCP. I hope to establish relationships with people, schools, and communities all across the state. I hope to inspire many people to rise above their challenges and have an adventure of my own.”

Along his route, Neil hopes to visit schools, organizations, camps, churches, festivals, etc., and use interactive storytelling to advocate for people with disabilities, to encourage children to become active leaders in their communities, and to raise awareness and funds for UCP Michigan’s Assistive Technology Loan Fund.

You can read about Neil’s journey in his own words by going to www.stiltstory.org and viewing his daily journal. You can also send him words of encouragement by email at neil@stiltstory.org, and you can make donations in his honor through his website or by mailing a check to:

Michigan Assistive Technology
Loan Fund
c/o UCP Michigan
4970 Northwind Drive, Ste. 102
East Lansing MI 48823

United
Cerebral Palsy
of Michigan



Ben Franklin Memorial Poker Run

Saturday, July 26, 2008
11:00 Registration
11:30-4:30 Ride
4:30-9:30 Celebration



Sponsored by Plumbers and Pipefitters Local 333 Union. Ride starts and ends at the Union Hall, 5405 S. Martin Luther King, Lansing.

\$20 per bike/car, with proceeds benefiting UCP Michigan. Contact April Franklin at afranklin@local333.com or (517) 749-9583.

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From the Executive Director

If you live in Michigan, it's been hard to miss news reports about Neil Sauter, who is stilt-walking 830 miles through Michigan from Ohio to Wisconsin. We are grateful for his commitment to raise awareness about disability and about UCP Michigan.

By the time you read this, Neil will be in the second half of his walk, but I saw him on his stilts at the Lansing Lugnuts game as he finished his first week of walking. It was so much fun to watch people's faces when they noticed him, especially the littlest kids.

At first I followed Neil around the ballpark, thinking that a UCP staff member should be with him - not because I was worried - he was completely fine - but wouldn't he rather have company? It quickly hit me that this journey is **very personal** for Neil. While he surely welcomes an occasional companion on some of the lonely miles, Neil has chosen a very solitary adventure: he chose not to have an accompanying car; he knows he will walk alone for hours at a time. But precisely because he is alone, he will have countless serendipitous moments and meetings along his way: the family who bought him ice cream and drove his backpack 22 miles ahead; the firefighter who called for a police escort to cross a busy bridge; the child who skateboarded between his legs; the invitation for lunch as he passed a country club.

One of Neil's goals for his marvelous adventure is saying and showing that people should not assume what people with disabilities can or can't do, need or don't need. The impulse to help is strong, but sometimes we help most by standing back and honoring choice.



P.S. Neil: Back here at the office we read your blog 1st thing each day. We're so glad you walked our way!

Information presented in this newsletter is intended to provide people with current, accurate information about developments in treatment, education, technology and equipment, rehabilitation and therapy.

*Reference in this newsletter to any particular practice does **not** constitute endorsement or promotion of that practice by UCP Michigan. Decisions to select any course of treatment should always be made by an individual after consultation with his or her professional provider.*

Thank You Fourth Annual *Baby Boomer Bash* Supporters!



Kevin Conrad from WVIC Radio with
Jill Bailey from Michigan Association of Broadcasters
Photo: Terri Shaver, Lansing State Journal

Boarshead Theater
Woody's Oasis
PRP Wines
Creative Wellness
Panera Bread
Lansing State Journal
Curves
Olga's Kitchen
Buddies



Beth Shayne from Fox 47 TV with Barb Lezotte and
UCP Michigan Executive Director Linda Potter
Photo: Terri Shaver, Lansing State Journal

Comerica
Miller Canfield
The Grand Hotel
WVIC 94.1
Lansing Symphony
Golf Haus
The Cadillac Club
Royal Scot
WSYM Fox 47



UCP Michigan Treasurer Charlie Hawes with
President Josephine Jabara
Charlie was recognized for 14 years of
outstanding service to UCP.

Max & Erma's
Meijer's
Mitchell's
Dan Henry Distributing
Biggby's Coffee
Dean Trailways
PF Chang's
Target
Douglas J

Questions about Botox

In February, there was an announcement by the U.S. Food and Drug Administration (FDA) that it is investigating reported adverse reactions of people with cerebral palsy from botulism after injections of Botox, which is the brand name of "botulinum toxin A." Some people with cerebral palsy get Botox injections to reduce spasticity.

In 2005, the United Cerebral Palsy

Research and Education Foundation published a Fact Sheet on injections of Botox and children with cerebral palsy. The Fact Sheet was based on a review of research about use of Botox for children with cerebral palsy published in the Archives of Diseases of Childhood.

The Fact Sheet includes the following: "When Botox is offered, parents should be convinced that the physician administering the

agent is trained and experienced in its use in children and that it has been adequately studied for the specific indication for which it is being offered."

Remember that the FDA has not yet made any findings; it has only announced an investigation. We will report its findings when they are announced.

Disability and Health Office

For the first time, the Michigan Department of Community Health has an Office for Disability and Health, dedicated to improving the health of people with disabilities.

Although it is a myth that every person with a disability is by definition unhealthy, for a variety of reasons people with disabilities have, on average, poorer health than people without disabilities. One key health risk for people with disabilities is the risk of developing "secondary conditions," which have been defined as "Those physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible by virtue of an underlying condition, including adverse outcomes in health, wellness, participation, and quality of life."

Some examples are pressure sores (the term for wounds that develop when a person isn't moved often enough), pain, osteoporosis, renal insufficiency, chronic lower limb edema, obesity and depression. Two key elements of secondary conditions are that they may be preventable and may increase the severity of the primary disability.

Other reasons that people with disabilities have greater health problems are 1) inaccessible health care offices and screening devices such as exam tables and mammograms, 2) failure of some health care providers to distinguish between conditions that are and aren't related to the disability, 3) lack of health insurance or other access to health care, 4) health promotion activities (e.g., an anti-smoking campaign) may not be accessible to people with disabilities,

and 5) an unhealthy lifestyle, e.g., reduced physical activity and increased stress.

The new DCH Office on Disability Health will focus on health in 4 core areas: access of people with disabilities to healthcare services; management by people with disabilities of their own health, improving the effective response of health professionals to health needs of people with disabilities, and integrating the needs of persons with disabilities into existing health promotion activities.

The initiative will be guided by an Advisory Committee. At least half of the Committee will be people with disabilities. Candice Lee has been hired as coordinator of the Office.



Pathways is Going GREEN!!

We're hoping to save trees and money. If you'd like to receive our newsletter in electronic format, please send an email with your name and the postal address at which you currently receive *Pathways* to ucp@ucpmichigan.org and type "newsletter" in the subject line.

Michigan a Leader in Cerebral Palsy Research



*Michigan Cerebral Palsy
Research Consortium*

*Back Row from Left: Linda Potter, J.D., UCP Michigan; Nancy Dodge, M.D., DeVos Children's Hospital; Seth Warschawsky, Ph. D., U of M; Madeleine Lenski, M.S., MSU; Nigel Paneth, M.D., MSU.
Seated: John Eulenberg, Ph.D., MSU; Edward Hurvitz, M.D., U of M.*

United Cerebral Palsy of Michigan is proud to be involved with the University of Michigan, Michigan State University, Helen DeVos Children's Hospital, and the UCP Research and Education Foundation in Washington, D.C. on issues relevant to cere-

bral palsy research.

Recently, the partners orchestrated two conferences on cerebral palsy research. The first was an invitational symposium for researchers on March 13 at University of Michigan in Ann Arbor. The second, held at Michigan State University in East Lansing, focused on adults and aging with cerebral palsy for both researchers and the general public.

These conferences were very well attended and provided opportunities for researchers on cerebral palsy to compare notes on current research activities.

The group formed the Michigan Cerebral Palsy Research Consortium and will be meeting soon to plan future collaborative activities.

Project Success



UCP Michigan sponsored Project Success for the eighth year at Lansing's Everett High School. Project Success is an after school club for youth with and without disabilities to perform volunteer community service.

The youth held a drive to collect household items for refugees, sold candy to raise money to purchase toiletries for a domestic violence shelter, worked at a soup kitchen serving meals to homeless people, and held a drive to collect food for a food bank. To start a chapter in your community, contact Pam at schuster@ucpmichigan.org or (800) 828-2714.

*Leave a Lasting Legacy
and Fund the Future: Please
remember UCP Michigan in
your will or estate plan.*

Does Your Child Have Cerebral Palsy?

Are you interested in a free 4 week Conductive Education session at the Conductive Learning Center as part of a research study of children with Cerebral Palsy, ages 2 to 6?

Please call Su at (888) 817-1731 for more information at the Department of Epidemiology, Michigan State University.



Fraternity Raises Money for UCP Michigan



The Knickerbocker Fraternity of Hope College held a bottle/can drive on the campus of Hope College in Holland in April to raise money and awareness for UCP Michigan.

The staff and friends of UCP Michigan thank the members of the fraternity and everyone who donated.

Transportation Advocacy Training in Action

People with disabilities are becoming more skilled advocates through the UCP Michigan Transportation Advocacy Training project, which is training local groups on effective advocacy to improve public transportation.

Project Manager Glenn Ashley has led sessions in Shiawassee County with a group that wants public transportation available in all parts of the county. The training started with basic information about public transportation and how to be an advocate.

The first strategy is to make the public aware of its community's transportation and how to access it. The second strategy is to publicize stories of people who use or need public transportation in the community. Participants practiced telling personal stories and recording them. Ashley is

helping group members create video stories that can be put on YouTube or used for public presentations.

Group members practiced talking with public officials to secure their support for public transportation, then went to the state capitol and met with staff from their State Representative's office.

The group has evolved into a transportation coalition that will continue working on building community support for public transportation by demonstrating why it is beneficial to the community, including for those who do not personally need it.

Ashley is training groups in other counties about transit Local Advisory Councils (LAC). He is teaching "Rules for Running Meetings,"



Shiawassee Transportation Coalition Members
at Transit Advocacy Day

the basics of Parliamentary Procedure so people with disabilities can participate more effectively on coalitions and committees. Regional Transportation Advocacy Conferences are planned on these and other topics. They will be held in Baraga, Muskegon and Wayne County.

For more information contact ashley@ucpmichigan.org or visit www.transportationallies.net.

Medicaid Now Covers PAS in Workplace

Since passage of the Freedom to Work for Individuals with Disabilities Act of 2003 (FTW), eligible people with disabilities in Michigan have been able to work and increase their income beyond the usual cut-off amount, yet still keep Medicaid coverage. However, until recently Medicaid would not pay for personal care attendants (PAS) in the workplace; it would only pay for attendants in the home.

The MiJob Coalition, of which UCP Michigan is a member, and the Michigan State Office of Long-Term Care Supports and Services advocated that it is just as cost

effective to provide personal care in the workplace as in the home, and now the Medicaid Home Help Program will pay for personal care in the workplace.

The current Home Help assessment process that determines how many hours of care a recipient gets for personal care needs remains unchanged; a separate assessment for the workplace is not necessary. The hours approved may be used either in the home or in the workplace, but additional hours are not available as a result of employment. The consumer determines where services are to be provided.

Michigan has a grant from the federal government to address Medicaid infrastructure issues (MIG). MIG staff want to know how many people are using PAS in the workplace, especially if they are enrolled in FTW. If you use PAS/Home Help Services in the workplace, we need your input! Please contact Joe Longcor at longcorj@michigan.gov or (517) 241-1730.

If DHS workers have questions about PAS in the workplace, refer them to bulletin MSA 07-58 and Adult Service Manual 362, p. 2.

Yes, I want to support UCP Michigan's goal of *Life without Limits for All People with Disabilities!*

Enclosed is my tax-deductible gift of \$_____. Please make check payable to UCP Michigan.

Or charge my Visa/Master Card: Card number:

Signature: _____ Expiration Date: _____

Donor Information:

Name: _____

Address: _____

City: _____

State: _____ Zip: _____

Phone: _____

Email: _____

Please mail to:

UCP Michigan

3401 E. Saginaw, Suite 216

Lansing MI 48912

Thank you!

My gift is made:

In memory of In honor of Other occasion

Name: _____

Please send notification (your gift amount will not be disclosed) to:

Name: _____

Address: _____

City: _____

State: _____ Zip: _____

Please send me information about Planned Giving/Bequests to UCP Michigan.

Please send me information about volunteering for UCP Michigan.

Affordable, Accessible Housing

Advocacy Day on April 30, 2008, brought 1200 people with disabilities and affordable housing advocates to the Michigan Capitol to rally and meet with legislators about issues such as fully funding Michigan's Housing and Community Development Fund, created in 2004 to create additional affordable housing and stimulate economic growth.

The **Section 811 program** available through the U.S. Department of Housing and Urban Development (HUD) creates new supportive housing units. If passed, the Frank Melville Supportive Housing Investment Act of 2008 (HR 5772) will help address the housing crisis faced by millions of low-income people with disabilities and will spur the creation of thousands

more new 811 units every year.

Housing Locator Service

The Michigan State Housing Development Authority (MSHDA) offers a Housing Locator service online where one can search by location and get a list of available apartments and houses for rent. In addition to information such as number of bedrooms, parking, whether pets are allowed, laundry facilities, whether utilities are included, proximity to a bus line, etc., the service indicates whether units are accessible and whether they accept rental assistance such as Section 8 vouchers which limit rent to a percentage of the renter's income.

www.michiganhousinglocator.com

ZeroStep Across Michigan is an effort to promote universal design for homes, which creates a living environment that is easily usable by the entire family. Among other features, a universally designed home has zero-step entrances, making it easy to carry in the groceries, move furniture or appliances, and welcome friends and family who are elderly, injured or use wheelchairs or walkers. By 2025 the percentage of the population aged 80-85 will double. Mobility impairment often comes with age. ZeroStep Across Michigan has developed accreditation guidelines as a voluntary standard that builders may adopt in meeting the needs of the aging population.



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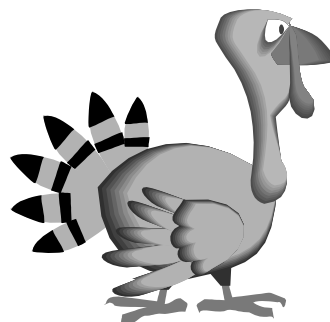


Our new address is:

United Cerebral Palsy
of Michigan
4970 Northwind Drive
Suite 102
East Lansing, MI 48823

We are located in the Executive
Office Park off Grand River, east of
Hagadorn.

Our phone and fax numbers, email
addresses and website remain the
same.



Scooter's
Wild Turkey Saloon
4th Annual
Poker Run and Auction
For UCP Michigan

July 12 and 13, 2008
2029 E. Miller Road
Fairview, Michigan

Contact Deb Abbe at
(989) 848-2711
www.scooterswildturkey.com