



PATHWAYS

Life without Limits for People with Disabilities

Youth Essay Contest Winners

By Sarah A., Midland

I was adopted when my brother was four years old. In all the baby pictures, I see my brother caring for me and playing with me. If you were to look through our photo album, you would never be able to tell that my brother has Tourette's Syndrome. Despite the challenges he faces every day with his own problems, he has always had the attitude that he can do anything he wants to do. When I watch the struggles my brother goes through everyday, I have learned that we all have to deal with the cards we are dealt in life.

My older brother has what is called Tourette's Syndrome. Tourette's Syndrome causes my brother to have what are called tics. A tic is an involuntary, uncontrollable movement or action with a part of the body. A tic could be moving your hands a certain way or sometimes saying words over and over. My brother often snaps his fingers or rolls his shoulders. He does not let these tics stop him from moving on with life. Tics often cause my brother to lose focus when he is working on school work. This makes learning much harder for him than it is for most people. Since school is harder for him, my brother has a lower level of education than most students his age. Even though this is true, he is still very smart and is a great student in college. Through his disability, my brother has learned that perseverance and a good work ethic are as important as talent and natural ability.

When I was little, my brother helped me do many things I could not do alone. When I was in kindergarten and my brother was in fifth grade he made school less "scary" because he would walk to and from school with me. When I had to do reading homework we would snuggle up with the blankets and read together. He would help me to overcome challenging words I couldn't

read alone. One more way my brother has helped me is that when I was younger I had to learn how to write my name. He would help me to curl my "S" and finish with my "tall stick" on the "H." I still remember doing this every time I write my name.

Although my older brother is different from other brothers or sisters, he makes me think about the blessings of life, and to not take them for granted. Sometimes, when I'm doing homework and get distracted by the little things around me, I think about him and how much harder it is for him to concentrate. This always helps me to get busy. He has tics, but they don't stop him from anything. I don't have tics, but there are some things that get in my way. I am thankful that I can watch t.v. and listen to music without being distracted; my brother can't do that without finding himself unable to focus.

I love my brother and I am glad I have him, even though he can sometimes be annoying with his tics. I am his little sister, and I'm sure that I can be just as annoying to him. I think he has learned to tune me out when he needs to, and I know he loves me too.

The truth is, everyone has something to overcome. We can all learn about ourselves as we learn about others. I have learned patience, understanding, and especially not to judge people by the things they do or say because they might not be able to control themselves. I try not to judge others because I know my brother wouldn't want people judging him. We are people first, and we are all different. It is our differences that make the world such a fun and interesting place to live and learn in.

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**United
Cerebral Palsy
of Michigan**

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Youth Essays (continued)

By Justin L., Saginaw

People who have physical disabilities aren't as abnormal as the larger majority of people think, actually, we're quite similar. When people look at us, they will just assume that we must be some odd sub-species of human, but we aren't. People with disabilities are just like everyone else, they just have to live life through a different perspective, using different technology, learning in different ways. Through all of this, they still think the same though, they enjoy life, they like poetry, depending on the specific circumstances, they might even go mountain biking in their spare time.

People who are deaf still like music, people who are blind still enjoy going to the movie theatre. Life is just seen through different eyes when you're "disabled," you're not different, you still live life like a kid! Sometimes children with disabilities are actually more similar to other kids than what society thinks, usually actually. I know a girl in a wheel chair who still laughs and socializes, I know a blind man who goes to theme parks to enjoy life, I even know of a girl with cancer who never shows it! People with problems, physical, mental, or social, are still like other kids.

The reason that I am expressing a specific interest is because I am a child who lives with an interesting problem. I am thirteen years old, and have lived through many things, including blindness, but I don't let it hinder my enjoyment of life! I hang out with other children, I go to the movies, I even participate in martial arts! I attend middle school in Saginaw, Michigan, and I am in general education classes. I blend in with normal children though, there is no reason not to.

Children and adults alike find me to be fairly normal, people actually forget that I am blind because of my actions, being blind does not stop me from doing anything that I want to do! It doesn't stop other kids either, again, children with disabilities, or just problems in their life, can always overcome them to be as intelligent and free spirited as they want, life shouldn't be stopped because you can't see, hear, or anything else in the exact manner that other children do.

If you see a child with a disability, if you even know that they have one, don't think of it as a disability. When you see that a person is having a difficult time with something, don't look at them like they are weird or a freak, just acknowledge that some people live differently than other people, and try to help them out. They, no matter what, are still a human being and should be treated like the respectable individual that you should feel that they are. People are extremely normal no matter what ethnicity, nationality, gender or physical status. Human beings are all human beings, life is life, and nobody can be any stranger than another person because of this.

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.

Youth Essays (continued)

By Kaylah C., Holt

When my grandma was pregnant for the first time, she was having a rough experience. She went into labor and when she got to the hospital the doctor gave her some medicine to stop the labor. The doctor said, "It is too soon." She went home. Later that day she came back and the baby was born, 9 weeks premature. The doctor thought he wasn't going to make it but he did! He weighed just over one pound. Everyone always said he could fit inside a peanut butter jar. All that time my grandma was in labor the umbilical cord was wrapped around his neck cutting off oxygen supplies causing all brain cells to die. Forty-one years ago there was nothing anyone could do but wait and see what would happen to the baby. The doctor told my grandma that he wouldn't be able

to walk, talk, be potty trained, or do any normal activities. She proved the doctor wrong. At 15 months he could walk. At one and a half he could say "mom" and "dad." At two he was potty trained and at three he could say small sentences. He was a little slower than other people but that didn't stop him.

All through grade school he had to go with a special teacher. He did Special Olympics until he was twenty-four. Special Olympics are sports that include skiing, track, basketball, and many more, for people that are mentally and physically challenged. Now he is forty one and lives in an assisted living apartment. People will come in and help him cook, clean and make sure he takes his medication. My Uncle Tony now has a girlfriend. Her name is Rose and she has the same disability he does. Rose also lives in

the same apartment complex as Tony because she needs help too.

My uncle is nice and fun. We go get him as often as we can and visit him on the holidays. Even though he is different, I wish everyone could see past his differences and care about him as much as we do. Once you get to know him you can see what a great guy he really is.

"Don't dis my ability."

- Duncan Wyeth

THANK YOU TO ALL OUR DONORS!

YOU make it possible for United Cerebral Palsy of Michigan to:

- help people with disabilities lead meaningful and productive lives
- support groundbreaking research related to cerebral palsy and improvement in the quality of life for all people with all disabilities
- provide information and resources about housing, employment, public benefits and services
- advocate with state and federal lawmakers to promote important issues and policies related to disability rights

Learning Skills Research

The University of Michigan and Mary Free Bed Hospital are conducting research on new ways to test the learning skills of children with cerebral palsy. To participate, the children must:

- Be able to try computerized tests
- Be 6-12 years old
- Have cerebral palsy
- Be able to indicate a choice when presented with four options
- Not have a condition that affects the tests

Participation takes three hours, and families will be paid \$50 for their time. Contact Donna Omichinski at domichin@med.umich.edu or 734-936-6023.

In Memory of Kevin Granata

One of the people killed at Virginia Tech was a scientist who studied human movement, specifically how brain injury for children with cerebral palsy interfered with balance and movement.

Kevin Granata received undergraduate and doctoral degrees from Ohio State University in Engineering Physics and Biomedical Engineering. His research vision was to develop a center to study the essence of human movement and how machines, braces and walking devices could be developed to overcome human disability.

Priced Out: The Housing Crisis for People with Disabilities

Lack of affordable accessible housing for people with disabilities is a nationwide crisis.

Housing is considered affordable if one pays no more than 30% of income for housing. Today, 550,000 households in Michigan pay over 50% of their income for housing, placing them on the verge of homelessness with any financial setback.

Four million people in America ages 18-64 rely on Supplemental Security Income (SSI) to pay for their basic needs. In 2007, the monthly income of someone on SSI is \$623. The national average monthly rent in 2006 for a one-bedroom apartment was \$715!

Hundreds of thousands of people with disabilities live in care facilities unnecessarily because there is no affordable housing available. Efforts to develop

community-based programs so people with disabilities and seniors can get care in their homes rather than nursing homes are doomed to failure if there isn't housing available in the community.

The Section 8 program of the federal Department of Housing and Urban Development (HUD) pays part of the rent of low income people who qualify. But Section 8 has been cut in recent years, and HUD has repeatedly tried to end the program just as need for it continues to increase. In 2006, 150,000 of the most vulnerable Americans remained on Section 8 waiting lists without help due to insufficient funding.

Decent, accessible, affordable housing is cost effective. It is much cheaper to provide support services in a person's home than in a nursing home or homeless shelter. A \$5,000 annual rent subsidy plus the cost of in-home assistance

for a person with a disability saves \$10,000 - \$20,000 in Medicaid funding when compared with the cost of providing those same services and housing in a facility.

The barriers to affordable accessible housing are more than financial: one example is exclusionary zoning, where local governments use zoning restrictions to keep affordable housing out of their communities. Another barrier was constructed in 1992 when Congress allowed housing to be reserved for senior citizens only, excluding younger adults with disabilities from many affordable accessible apartments and condominiums.

UCP Michigan, along with our fellow advocates, is working to remove barriers to decent, affordable, accessible housing for Michigan's citizens with disabilities.



Book Corner:

A Special Education: One Family's Journey Through the Maze of Learning Disabilities By Dana Buchman & Charlotte Farber, DaCapo Press

Dana Buchman tells of her daughter Charlotte's struggle with learning disabilities and of her own steep learning curve to become the mother Charlotte needs her to be. Dana, a hard-driven perfectionist, knew nothing about "learning differences" when her daughter was diagnosed with neurological, spatial, and motor skill disabilities as a toddler. Dana's ability to "fix" things would not help her deal with Charlotte's disabilities; she would have to develop new skills to be able to see Charlotte as a person with unique abilities.

This is NOT a textbook on learning disabilities. It is a very personal account of one mother living with and learning about LD and the mistakes she made, with practical advice on "if I could do this again." The afterword is written by Charlotte, who now attends college in New England.

Ask UCP: Answers to Frequent Questions

I am unable to work and live on SSI. I need help to live independently. What services are available to help me?

Because you get SSI you are also automatically eligible for Medicaid. The Adult Home Help program and the MI-Choice Waiver program, through Medicaid, provide critical services to people with disabilities to enable them to live in their communities.

The Adult Home Help Program of the Department of Human Services (DHS) provides personal care and assistance with daily living activities such as feeding, bathing, transferring, housekeeping, laundry, meal preparation, and shopping. To apply for the Home Help Program, contact your county DHS office.

The MI-Choice Medicaid Waiver is available for seniors and persons with disabilities over age 18. It provides a range of similar services to people with disabilities and people who are elderly and need a nursing home level of care. Areas of assistance include homemaker

services, transportation, medical supplies, personal care, private duty nursing, home delivered meals, and more. The MI-Choice waiver is administered mostly through Area Agencies on Aging.

Community Mental Health (CMH) programs also offer Community Services. You can apply for eligibility at your local CMH. If you are Medicaid eligible and have a developmental disability or serious emotional illness, and if services are deemed medically necessary to enable you to live in the community, you may be eligible for community support services. You can ask for these services through the person-centered planning process. The services may include money management, snow removal, meal preparation, interpreting, nursing care, and more.

If you need assistance finding phone numbers for any of the above services, call UCP Michigan at 800-828-2714.

Life in Focus: *Where's the Ramp?*



MSU Library Entrance

Life in Focus is an exciting new UCP Michigan project that will help people with disabilities gain a more powerful voice. *Life in Focus* participants learn to use photos and stories to advocate for change in their own lives and in their communities.

Life in Focus is based on Photovoice methodology developed at the University of Michigan (see www.photovoice.org). Group members get cameras, learn how to use them, and then take pictures to represent issues and experiences in their daily lives. Next they come together as a group and discuss their photos and stories, learning to use the photos and

stories to communicate with policy makers and the community. The project emphasizes inclusion of people whose voices are often unheard, including people from diverse cultures. Communication and technology supports are provided.

The initial pilot group was the Capital Area People First groups and students from a Lansing school transition program. The members quickly learned to take pictures representing their lives and policy issues, and we can already see examples of their strengthened voices. For example, the group advocated about access problems at the Michigan State University library. The accessible entrance is at the back of the building, but there is no sign at the main entrance directing patrons to the accessible entrance, and all the handicap parking spaces require a key card for access. The group sent a letter to MSU President, Lou Anna Simon, with the photos they had taken describing the problem and pointing out that the MSU Historical Museum, across the street from the library, "is accessible, all through the museum. It has an elevator,

ramp, open spaces and handicap parking. The entrance is marked, and the doors open automatically."

The *Life in Focus* pilot group members also demonstrated their new skills during a recent advocacy meeting when they made phone calls to their Congressmen and Senators about crucial advocacy issues from a personal standpoint. Such messages help policy makers and communities see life through the eyes of people with disabilities.

UCP Michigan will train trainers for other *Life in Focus* groups throughout Michigan. Organizations are lining up to be trained to sponsor *Life in Focus* groups. An essential requirement for sponsors is that they support group members to use their new skills for ongoing advocacy after the *Life in Focus* training is completed.

This project is funded by the Michigan Developmental Disabilities Council. For more information, contact Glenn Ashley at ashley@ucpmichigan.org or 800-828-2714.

making stops at several Michigan events:

August 12, Lansing, 12 pm – 3 pm.
Family picnic at Durand Park. Contact Marsha Moers at the Capital Area for Independent Living (517) 241-0393.

August 13, Flint, 11 am – 12 pm.
The Disability Network will host a media and community leadership event. Contact Mike Zellely at (810) 742-1800

August 13, Mackinaw Bridge: 2 pm – 5 pm. A picnic near the bridge, with a group showing support by lining the "Big Mac" and waving as the bus crosses the bridge. Contact Amy Maes at the Superior Alliance for Independent Living (906) 228-5744.

August 14, Marquette, 12 pm – 3 pm. A picnic in downtown Marquette with food, music, information from local organizations. Contact Amy Maes at the Superior Alliance for Independent Living (906) 228-5744.

The Road to Freedom: ADA Restoration

In recent years, a number of Supreme Court and other court decisions have reduced the protections available under the ADA to people with disabilities within employment settings.

Courts have sided with employers against people with disabilities who challenge employment discrimination 97% of the time. Courts have created an absurd *Catch-22* by allowing employers to say that a person is too disabled to do the job but not disabled enough for ADA protection.

People with conditions like epilepsy, diabetes, HIV, cancer, hearing loss, and mental illness who can manage their disabilities with medication, prosthetics, or technology can be considered "too functional" to have a disability and denied the ADA's protection from employment discrimination. In fact, in a recent case in Illinois, judges declared that a

man with mental retardation failed to prove that he has a disability under the ADA.

Congressmen Sensenbrenner (R-Wis) and Hoyer (D-MD) will reintroduce the "Americans with Disabilities Act Restoration Act" this year. Representative Hoyer says: "The point of the law is not disability; the point is discrimination. Replacing 'against an individual with a disability' with 'on the basis of a disability' will enable individuals utilizing the ADA to focus on the discrimination that they have experienced rather than having to prove they fall within the intended scope of the ADA." You can sign an online petition in support of ADA restoration at <http://tinyurl.com/36p6ee>.

The Road to Freedom Bus Tour, sponsored by National Coalition for Disability Rights, is traveling the country to generate support for ADA restoration. It will be

Students May Work and Keep SSI/SSDI

Parents of students receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) should be aware of federal work incentives programs that allow their son or daughter to work and keep his or her benefits.

The Student Earned Income Exclusion (SEIE) is one example of a work incentive. It is available to students who are 1) under age 22, 2) on SSI (it is not available to students on SSDI), and 3) in grades 7-12, college or an employment training course. SEIE allows the student to earn up to \$1,510 per month without losing any of their SSI money, up to a cap of \$6,100 in earnings in a year. Once the cap is reached, SSI money is affected by the earnings.

This is just one of many work incentives available from Social Security. The Work Incentive Planning and Assistance Project (WIPA), which is funded by a grant from Social Security, provides free information on how wages affect SSI and SSDI benefits. This Project provides Work Incentive Planning to all people with disabilities who receive SSDI or SSI benefits.

The WIPA counselors are called Community Work Incentive Coordinators (CWICs). They have training and certification in counseling people on how income from work will affect their Social Security benefits and other benefits such as Medicaid, Medicare, food stamps, and housing vouchers or subsidies.

CWICs will meet with young people (14 years and older) and their parents to explain all work incentives available. It is very important for students to get accurate information so they can make good choices about work at this point in their lives. An analysis of benefits, work incentives and earnings should be part of every student's transition plan and process.

CWICs are also available to meet with SSI and/or SSDI recipients who aren't students about work incentives. Information can also be presented to groups. Call UCP Michigan at 800-828-2714 to locate a CWIC in your area.

UCP Michigan "A Godsend" to the Tolin Family's "Acres of Angels"



After raising five daughters of their own, Sue and Tim Tolin of Ruth, MI, are now the proud adoptive parents of 10 additional children, all with various disabilities. In May 2006, the Tolins received a loan from the UCP Michigan Assistive Technology Loan Fund to purchase a modified bus for the entire family and laptop computer for their daughter, Kim.

A Magic Bus

With the children, ranging in age from 1-18, needing frequent doctor visits in Detroit area, the new bus, with its four

sets of tie-downs for wheelchairs, and a ramp to enter and exit, lets the Tolins get where they need to go. Before the purchase of the bus, they were unable to go anywhere as a family. "Now," says, Sue, "we are so grateful to be able to ride together in one vehicle for all our outings, and the ramp has been so helpful in reducing the amount of lifting. The Huron County Fair is coming up and the kids are looking so forward to going on all of the rides again—the faster the better!"

Providing Assistive Technology for Kim

Kim was born in 1996 with congenital anomalies including missing her lower jaw and tongue, and she is a triple amputee. She has amazed many professionals by overcoming tremendous obstacles "with her determination and love of life." Now she has a new laptop computer at home, purchased with the AT Loan Fund, to help her communicate with her family and do her homework.

"UCP of Michigan and the Assistive Technology Loan Fund have been a godsend to our family. We have been so blessed to receive the AT Loan to buy the modified bus and Kim's laptop" says Sue.

Many people with disabilities in Michigan cannot afford to buy assistive technology devices and do not have other ways get them. UCP Michigan's AT Loan Fund gives them the chance to get the devices they need.

Your contributions have a direct impact on improving the lives of people with disabilities!

For every dollar you donate to the Michigan Assistive Technology Loan Fund, the federal government will match your donation with an additional *three dollars!*

Yes, I want to support UCP Michigan's goal of *Life without Limits for 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: _____

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

ACCESSIBLE VOTING

Michigan has made progress in making the voting process accessible. Yet problems remain, mostly due to uneducated poll workers, and people with disabilities are still underrepresented as voters. As 2007 is an "off" year for major elections, now is a great time to contact your local election officials and educate them about disability voting issues. Visit your local polling place and assess its accessibility. Don't wait until the last minute: register to vote TODAY.

Michigan Protection and Advocacy Services is collecting information about people's experiences with the Automark Voter Assist Terminal (the accessible ballot-marking device) in last fall's elections. Contact Kyle DeBuc at kdubuc@mpas.org or 800-288-5923.

Did You Know....

- The chances of having a disability increase with age.
- Currently in the U.S., 45% of people aged 65-74 have a disability, and 64% of people aged 75-84 have a disability.
- Over the next 40 years, the percentage of the U.S. population over age 65 will increase from 9% to 34%.
- One in three households in America currently has someone with a disability.
- People with disabilities face a crisis in the availability of decent, safe, accessible and affordable housing.



Orthodogs' Silver Lining Foundation

Silver's Cause is a fund administered by Orthodogs' Silver Lining Foundation that will help cover medical problems that threaten a service dog's quality of life or the dog's ability to perform its duties. Since many people with disabilities live on limited incomes, their service dogs' unexpected medical issues may impose insurmountable financial burdens. The fund seeks to preserve the special, and often essential relationship between a service dog and its owner. The fund does not cover routine preventive veterinary care. Contact Silver's Cause at www.oslf.org.



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Upcoming Events!

Scooter's Wild Turkey Saloon Poker Run

July 7, 2007, Third Annual Poker Run, and auction July 8 to benefit UCP Michigan, at Scooter's Wild Turkey Saloon in Fairview. Call Deb Abbe at 989-848-2711 to register.

Pro Wrestling!

Three days, three benefits for UCP Michigan! CIW wrestling and Nitro present Demolition Ax, The Honky Tonk Man, Lord Humongous, Doink the Clown, Nacho Libre, and Super Parka 2000!

July 13, 7 pm, The Garage, Jackson

July 14, 7 pm, Hillsdale Fairgrounds

July 15, 5 pm, Hope Center, Adrian

Tickets \$10 at the door, \$20 VIP ringside seats include refreshments! Contact UCP Michigan for advance ticket information.

Ben Franklin Memorial Poker Run

July 28, 2007, Second Annual Ben Franklin Memorial Poker Run to benefit UCP Michigan, starting at Plumbers & Pipefitters Local 333 Union Hall, Lansing. Call April Franklin at 517-749-9583 for more information.

Texas Hold 'Em Tournament

Friday September 7, 6 pm-2 am

Saturday September 8, 4 pm-2 am

Sunday September 9, noon-2 am

At Royal Scot, 4722 W. Grand River, Lansing.

Proceeds benefit UCP Michigan.

Cash Games Available, \$60 Tournament Fee, 50/50 Raffle.

License #M36918

Grand Rapids Marathon

October 28, Neil Sauter, a man with mild CP, is attempting to break the world record for walking a marathon on stilts! You can sponsor Neil and help raise money for UCP Michigan's Assistive Technology Loan Fund.



Volunteers are needed to staff an aid station for the runners and to walk the marathon with Neil. Relay teams are welcome! Visit www.ucpmichigan.org for sponsorship forms. Call 800-828-2714 to volunteer.