



United Cerebral Palsy of Southern Illinois



Summer 2009

United Cerebral Palsy of Southern Illinois

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UCP of Southern Illinois does not recommend or promote any therapy, treatment, views or opinions that are contained in the newsletter.

United Cerebral Palsy of Southern Illinois (UCPSI) covers a **27 county area** providing case management, information and referral services, equipment loan program, ability awareness programs in schools and a monthly orthopedic clinic.

ATTENTION: NEW CP CLINIC SITE

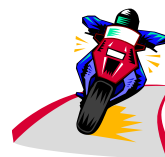
Our monthly CP clinic has moved to a new location beginning with our June 9, 2009 clinic. Our clinic is now located at **Dr. Froehling's** office at the **Neuromuscular Orthopaedic Institute (NOI)** at **302 Broadway in Mt. Vernon**. This is the same building as Hangar Prosthetics. The

appointment times will be **4:00, 4:15, 4:30, and 4:45**. The clinic will remain on the second Tuesday of the month. You will need to arrive 15 minutes prior to your appointment time and bring your medical card and/or insurance card. This clinic is still by appointment only. Appointments can be made by calling **UCPSI** at **(618) 244-2505** or on our **toll-free number** at **1 (800) 332-9745**.

In these tough economic times, UCPSI needed to look at ways to best utilize our funds. United Way of South Central Illinois funding has been used to fund the clinic at Good Samaritan Hospital.



Dr. Froehling has generously donated the use of his facilities and time. His staff will bill Medicaid, Medicare and/or insurance.



POKER RUN FOR UCPSI

UCPSI is having a poker run to raise much needed funds to help our consumers. These funds will be utilized for much needed equipment and expenses that can accrue with a serious medical diagnosis. UCPSI is more than our name (Cerebral

Palsy) as we work with both kids and adults with numerous other disabilities. **SO PLEASE HELP!**

This poker run is scheduled for August 15, 2009. For more information, visit our website at www.ucpsouthernillinois.org



20 FUN ACTIVITIES FOR KIDS TO DO WHILE STANDING

Bryanne Frietag has a son named Ryan who has a disability and uses an Easy Stand stander. She created this list that is posted on blog.easystand.com.

1. Place a variety of toys including sensory toys and toys with suction cups on the stander try and rotate toys.
2. Have them watch their favorite TV shows and movies, as well as action shows like "Price is Right" and "Sesame Street."
3. Make a video of your child doing their favorite things. If you don't have a video recorder, you can use an audio recorder. They will like to watch themselves.
4. You can adapt remote control for TV, computer, DVD to be able to turn these items on/off or change the channels by making a low tech remote control by use of a switch. You can also find adaptive and single switch computer games.
5. When you are in the kitchen, bring your child in to help. You can place the mixing bowl and other items on their tray. You can also use a device called Powerlink to connect items like a blender or mixer.
6. Let them color or draw. Items are available such as adaptive crayons a big paint brushes that are easy to hold. Let them use finger paint.
7. Read your child books or show family photo albums while they are standing. An angled tray may be more comfortable and allow them to hold their head up.
8. Use a bucket of water or sand and let them pretend they are at the beach. Add sand /water toys or bubble bath.
9. Get out the playdough. Let them use your large rolling pin which will be much easier to hold. Get out the cookie cutters.
10. Roll them down the hall in their schools and home hallways for short trips and a change of scenery.
11. The stander tray can be used to play board games and do flash cards.
12. Play music and use headphones or a boom box. There are switches that are available that can turn the music on or off.
13. Invite family or friends over to visit and hold conversations.
14. Give them hand puppets. Have a puppet show.
15. Play catch or shoot hoops at a gym, rehab or large room in their home.
16. Give them a camera to take pictures. You can take pictures.
17. Let them bake and decorate cookies. Add sprinkles. Have a tasting of cookies on their tray.
18. Sing together. Let them sing. Add a microphone. Standing and singing

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go together helping to get the lungs working.

- 19. Do a craft project using paper, yarn, macaroni and buttons. Make handprints with paint, cut and glue. Glue sticks are available in large easy-to-hold sizes.
- 20. Blow bubbles. You can purchase bubble wands that are easy to hold and can be waved. You can also blow bubbles.

UCPSI has numerous resource catalogs that have switches and all sorts of adaptive items. Just give us a call, and we can help you locate what you need to make standing and other activities fun.

SPEAKING OF FUN ACTIVITIES.....

FREEBIES!!!!!!!!!!!!!!

You can download a free computer painting program by visiting www.tuxpaint.com

Another website is www.theymaynotknow.com This site has the ten top picks for free online interactive programs to stimulate your brain.

You can practice your spelling this summer at www.spellingcity.com

Organize all your activities with calendar.google.com

We Magazine is a free magazine which is a life style magazine for all individuals with disabilities. For further information you may contact them at their toll-free number: (800)963-2426 email address is editors@wemagazine.com. Their website is www.abilitymagazine.com

www.theriotrocks.org. This site is for self advocates with disabilities to have their voices heard and share information with

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each other. They have a free e-newsletter that you can subscribe to.

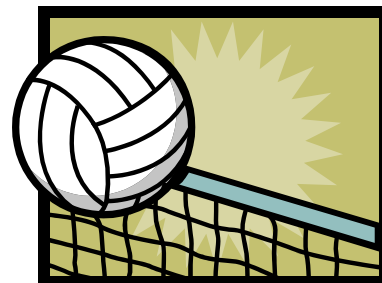
www.usa.gov This site is a comprehensive site that gives info on grants, loans, financial aid and other benefits from the government.

RAH RAH RAH!!!!!!! ADAPTIVE SPORTS

The **Vandalia YMCA** recently sponsored an adaptive sports activity called a “**Run, Walk, Jog and Roll**” at **Rogier Park in Vandalia**. It was a get acquainted activity and more activities are planned. YMCA is located in Fayette County and is starting an adaptive sports program beginning with an adaptive Frisbee golf activity scheduled for June 13 from 6-8 pm at Greer Park. (behind the Vandalia High School).

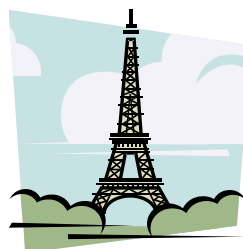
Adaptive sports activities are being planned for the second Saturday of every month

for children who have disabilities and are between the ages of 4-18. Please call the **YMCA** at (618) 825-4907 and speak to John Ashdown, Director. You may also contact Deanna Clark at (618) 283-1983 for more information. So **roll, run or walk** to your nearest phone and call them for a fun time.



ACCESSIBLE TRAVEL

Having a disability can make traveling extremely difficult. Traveling can take a lot of careful preparation. Here are some websites that have a wealth of Information:



www.globalaccessnews.com/

www.disabilitytravel.com/

www.disabletravelers.com/

(info taken from FCTD News and Notes June/July 2008 Issue 75)

NATIONAL SHAKEN BABY COALITION

NCSBS's mission statement is "to promote public awareness of **Shaken Baby Syndrome**, advocate justice for the victims of **Shaken Baby Syndrome**, and provide support, guidance, understanding and compassion for the families of **Shaken Baby Syndrome**." Their website has info about SBS, online support group, assistance programs, grief support and prevention just to name a few.

Debbie Dycus is cofounder. She can be reached at (618)792-5786 or through her email at SbcoalitionL@aol.com. Her website is www.shakenbabycoalition.org



WELCOME TO HOLLAND BY EMILY PERL KINGSLEY

It's like this...When you're going to have a baby; it's like planning a fabulous vacation trip-to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrase in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes and says, "Welcome to Holland." "Holland?" you say. "What do you mean Holland? I

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signed up for Italy!" I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

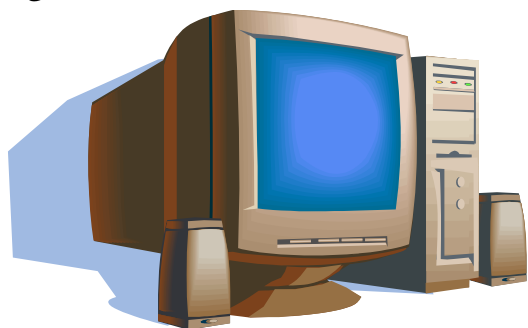
So you go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for awhile and you catch your breath, you look around, and you begin to notice that Holland has windmills. Holland has tulips, and Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they are all bragging about what a wonderful time they had there.

And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you will never be free to enjoy the very special, very lovely things about Holland."

(info from www.ableplay.org April 27, 2009)

Able play is a website "devoted to passing information on to families and professional who are focused on improving the lives of children with disabilities that often need different things."

Able play started a blog at [//ableplay.wordpress.com](http://ableplay.wordpress.com) (AblePlay is a toy rating system and reviewing resource and website at www.ableplay.org)



IEP WEBSITES to help untangled the many puzzling facts and information.

www.handsandvoices.org

contains the “Pop-up IEP” which has typical responses from educators to parents and information on how to respond such as “Sorry, we don’t have the money.” This sight has info on IDEA as law.

www.taalliance.org

This is a helpful information site on technology, resource data base, government and legislative links and Spanish resources to name a few.

www.wrightlaw.com

Pete and Pam Wright have are co-authors of numerous books on special education and the law. Their website is full of helpful information and links.

www.partnersix.org

This website has online courses available to assist parents and caregivers with knowledge necessary to be their child’s best advocate.

www.nclld.org

NCLD stands for the **National Center for Learning Disabilities**. This site is one of the sources for the IDEA Parent Guide along with other helpful information and links.

For much more information on special education, rights and the law go to

www.seriweb.com

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www.nectac.org/conatct/619coord.asp

www.nichcy.org

www.childfindidea.org

www.ada.gov

(website information taken from The HSC Foundation’s, “Partnering with Your Child’s School: A guide for Parents)



In this sometimes gloomy economy, ways to save money is essential. Every little bit helps. On www.freestyle.com people advertise free items. www.DifferentNeedZ.com you may buy and sell gently used medical equipment, therapy devices, adaptive toys and more. This website was “inspired by personal experience, thoughtfully designed for the special needs community.” Different needs also can be contacted by phone at 1(888) 343-3639.

AUTISM AWARENESS

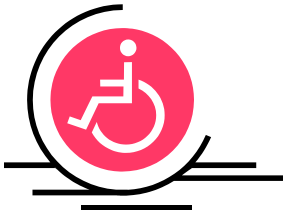
There is an **Autism Resource Room** located in **UMCH’s (United Methodist Children’s Home) Community Connections building in Mt. Vernon** made possible by the Southern Illinois Network of the Autism Society of Illinois, United Methodist Children’s Home, Mt. Vernon City Schools District 80, and SIU at Carbondale’s Center for Autism Spectrum Disorders. Books, learning aids, DVD’s, etc are available to families and those working with children and adults with autism. **UMCH** is located at **2023 Richview Rd in**

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Mt. Vernon. Their phone number is **(618) 242-1070.**

(Info from an article by Jason Silvey of the Morning Sentinel)

HEALTH BENEFITS FOR WORKERS WITH DISABILITIES



If you work and have a disability, you may be eligible for an **HFS** (Healthcare and Family Services) **medical card.**

This card has full benefits with \$2.00 co-pay for doctor visits, \$3.00 co-pay for brand drugs, \$2.00 co-pay per hospital day and free generic drugs.

Eligibility Criteria:

- **Resident of Illinois**
- **Citizen or eligible non-citizen**
- **Ages 16-64**
- **Employed** (defined as paying into FICA - minimum amount of work or hours required)
- **Disabled** (receiving SSDI, SSI, or current Medical card based on disability, or decision by DHS Client Assessment Unit that you have a disability)
- **Income Limit:** up to 350% of the Federal Poverty Level: 1 person \$3,159 per month, 2 people-\$4,250 per month, 3 people-\$5,341 per month, etc. All of these figures are after taxes and other deductions. Earned income deductions are allowed for transportation, childcare, child support, special tools, uniforms, etc.
- **Asset Limit:** \$25,000 in countable assets (HBWD) doesn't count your

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home, car, retirement accounts or Medical Savings Accounts)

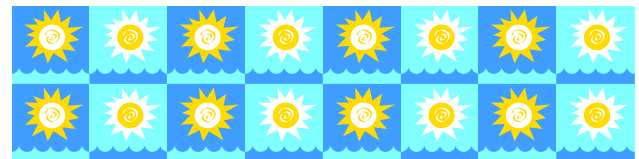
Your monthly premiums are based on your income. The average client pays about \$51.00 per month. If you have Medicare Part A or B, you will automatically be enrolled in Part D for Medicare with no deductible or premium. HBWD may also be able to pay the Medicare Part B premium, depending on income.

You may find out more information at www.hbwdisillinois.com or by calling (800) 226-0768

FEEDING THE HUNGRY

Tri State Food Bank, Inc. has been feeding the hungry since 1982. There are many food pantries benefiting from Tri State in UCPSI's twenty-seven counties. To find out where the food pantries are located in your county, visit www.tristatefoodbank.com.

Sun Fun Sun Fun



HAPPY SUMMER

From all of us at UCPSI

