



United Cerebral Palsy of Southern Illinois



HAPPY HOLIDAYS FROM UCPSI! Winter 2008

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 no-cost orthopedic clinic.

Just a reminder: Do not call Dr. Froehling's office regarding questions or concerns about clinic such as: prescriptions, equipment needs, hygiene supplies, to cancel or reschedule appointments or to ask questions. Dr. Froehling **does not** have a copy of clinic files in his office. All calls must go through UCPSI. Thank you.

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10 Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. **Reward yourself** with respite breaks often.
2. **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
3. When people offer to help, **accept the offer** and suggest specific things that they can do.
4. **Educate yourself** about your loved one's condition and how to communicate effectively with doctors.
5. There's a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence.

6. **Trust your instincts.** Most of the time they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing, and pulling. **Be good to your back.**
8. Grieve for your losses, and then allow yourself to **dream new dreams.**
9. **Seek support** from other caregivers. There is great strength in knowing you are not alone.
10. **Stand up for your rights** as a caregiver and a citizen.

Info obtained from National Family Caregivers Association Nov 2008.

Keeping Kids Insured

In Illinois more than 300,000 people between 19 and 25 are uninsured, making up the fastest-growing group of the population without health insurance. Insurance companies set the age limit on a policy-by-policy basis. However, beginning next year, families will have the opportunity to add dependents up to age 26 to their health insurance policies or to age 30 for veterans. Info obtained from AARP Nov 2008.



UCPA (United Cerebral Palsy Associations), of which UCPSI is an affiliate, was rated #32 in the 2008 Non Profit Times Top 100. The annual NPT 100 examines the financial data from the fiscal year ending 2007 and ranks the largest non profits by total revenue. A key qualification of the NPT100 is that the nonprofit must receive at least 10% of total revenue from public support. For national organizations, such as UCPA, data from affiliates are requested and not just information from the national office headquarters.

HandiExchange.com

A new website is being developed where individuals can buy, exchange, and sell pre-owned equipment as well as find local service and equipment providers needed to make their lives a little easier. With the economy getting tighter this is a place you can save by purchasing pre-owned equipment rather than buying new. If you have equipment that you are not using but believe someone may need, list it in a for sale classified on the website. The classified listing is FREE! If you know someone that has a piece of excess equipment please let them know they can make a classified ad on-line, if they wish to give it away set the asking price at \$00.00.



Info obtained from www.handiexchange.com 12/3/08.

Ten Dollar Tech

"Ten Dollar Tech is a regular column featuring low cost technology and adaptations. The idea is a Seat Belt Handle. It snaps onto the seat belt and gives the user a six inch handle to grab making it easier to pull the belt across your chest and into the buckle. It has an added feature in that it glows in the dark making it easier to find your seat belt at night." Cost: \$10.00 Ten Dollar Tech Column Fall 2007.



United Cerebral Palsy of Southern Illinois receives Ameren grant

United Cerebral Palsy of Southern Illinois received a grant from Ameren to purchase handicapped accessible playground equipment for the Primary Center in Mt. Vernon. UCPSI is grateful to Ameren for the opportunity to provide children with disabilities the same recreation experiences as their peers. Thank you Ameren!



Iris Rudd (center) Ameren representative presents a check to Kevin Settle (left) District 80 Superintendent and Sharon Hale (right) Executive Director UCPSI.

Travel Tips

Attempting to travel with a child who has a disability can be difficult and exhausting. Here are some tips that may ease frustration.

- If traveling by airplane read all rules and regulation. Some airlines do not automatically seat families together; you do not want to be moving around the whole trip to accommodate your child. Ensure wheelchairs are easily available if you cannot bring your own. If you do travel with your wheelchair check to see where it will be stored; airlines may require the battery be removed before boarding. Removal of the battery before reaching the airport can save time. Notify the check-in agent you will be requiring assistance. Airports and airlines have special assistance coordinators that can assist you before, while, and after flying.

- Planning ahead can be essential when traveling by car. Make sure to pack all medications in an easy to reach place in the



car. Stop at wheelchair friendly road stops, gas stations, and restaurants if your child uses a wheelchair. Most rest stops on interstates are handicap accessible however, rest stops on county roads or other back roads may not be. When planning a trip use websites such as www.mapquest.com or www.AAA.com to find out the distance between exits to ensure you will have a place to stop when needed.

- In order to ensure your hotel will be able to accommodate you, contact the hotel directly. Unless you contact the hotel you cannot be sure what floor your room is going to be on, whether the hotel is handicap accessible or if special accommodation will be provided if needed.



Planning ahead for a child with special needs is vital for a smooth trip. Directly contacting airlines, hotels, and other businesses will be your best bet. Info obtained from www.nineblue.com 11/12/08.

Assistive Technology in the Workplace

There are 33,153,211 individuals aged 16-64 with disabilities in the U.S. Of these individuals, 55.8% are employed. The following list has examples of assistive devices that can level the playing field for people with learning disabilities.

- Portable spell checkers read text has a dictionary and thesaurus.
- Reading Pens scan and read aloud single words or lines.
- Portable word processors can draft documents or take notes.
- Digital recorders can document spoken instructions and be downloaded to a computer
- Color coded jump drives to transport data to and from computers.



- Personal digital assistants (PDA's) have alarms, calendars, calculators and global positioning systems (GPS).

At the workstation there is software available to read, type, and provide spell check to documents along with organizing messages, schedules, notes, and contact information.

Computers can be customized to fit someone's specific needs. Accessibility features include adjusting contrast, enlarging print, adjustable keystroke and mouse controls.

Info obtained from LD: Online,
<http://www.ldonline.org/article/11908>

New Case Manager

We would like to introduce and welcome Lindsay Fowler as the new Case Manager for the southern counties. Lindsay is a 2008 graduate of Southern Illinois University. If you have any questions or need assistance please don't hesitate to call her!

Federal Government Grants

Grants.gov is a source to find federal government grants. Grants.gov does not provide financial assistance but sources where you may be able to find help. Check Government Benefits, Student Loans and Small Business Start-up Loans. For more information visit <http://www.grants.gov/>
Info obtained from grants.gov Dec 2008



Adaptive and Inclusive Recreation

SIUC has an adaptive and inclusive recreation program (AIR) offered through recreational sports and services. They sponsor recreational activities with modifications to meet the needs of



individuals with disabilities. The Student recreation center is fully-equipped and accessible for people with disabilities. Some of the programs include fitness, swimming, horseback riding, and sports such as wheelchair basketball and seated volleyball. To find out more information or find out registration instructions and deadlines, you can contact Kathy Hollister at (618) 453-1267 or visit www.siu.edu/rss.

Talking Books

The Southern Illinois Talking Book Center is a free library, providing books and magazines on cassette and Braille free to individuals who have vision impairment or physical limitation making it difficult to hold a book, or have a reading disability. For more information visit www.shawls.lib.il.us/ or call 1-800-455-2665.



New Approach to Photograph

Lankford Photography has introduced an innovative approach to photography. Lankford provides in-home photography to individuals with special needs in Pennsylvania. John Lankford, owner, brings the portrait studio to the client. He says when working with special needs, "the challenge becomes: How do I capture the individual, not the disability?" His daughter has cerebral palsy making it difficult for her to sit up; you would never know that by looking at the portrait. Although Lankford is not in our area his photography technique may be useful in pictures taken at home.



John says, “Rachel is 3 ½, but she can’t sit up by herself. So what we like to do is: mom wraps her hand around the back of Rachel’s neck to support her head (see black and white picture). Mom’s arm supports her back. Rachel’s long hair helps to hide her fingers, but on a short haired child we’ve hid mom’s arm behind a blanket or towel (preferable one that matches the



background). Then mom leans back, out of the shot; it’s uncomfortable, but it works. The picture is cropped tightly around Rachel so you don’t see mom’s arm. Here I’m using one of my professional backdrops, but a blanket or a bedsheet would work equally well.”

For more information on Lankford visit their website at www.lankfordphoto.net. UCPSI would like to thank John and Rebecca for sharing this wonderful technique. John was born and raised in Evansville so he is a local.

Info obtained from *The Insider-UCP* of Southern Alleghenies Newsletter winter 07-08 and John Lankford 1/11/09

Claim Earned Income

A Claim your earned income tax credit (EITC) is a tax break for hard-working people. You can reduce your federal taxes or get a bigger refund if you meet the following criteria:

- Your family earnings were less than \$38,646 (single-head of household) or \$41,646 (married filing jointly) and you were

raising two or more children in your home. You could get up to \$4,824.

- Your family earnings were less than \$33,995 (single-head of household) or \$36,995 (married filing jointly) and you were raising one child in your home, you could get up to \$2,917.
- Your family earnings were less than \$12,880 (single) or \$15,880 (married filing jointly) you had no children and you are between ages 25 and 64 you could get up to \$438.

If you were raising children in 2008 file federal form 1040 or 1040A to apply and attach schedule EIC. If you were not raising children file any federal income tax return.

Illinois residents who claim the federal EITC may also get a State EITC which save you up to \$241. For more information you can call (888) 827-8511 or the IRS at (800) 829-1040 or (800) 8294059 (TTY).

Info obtained from DHS 4406 (R-10-08) EITC flyer.



Bright Idea

Brooke is a beautiful, determined little girl. As she draws near her 11th birthday, she has overcome many obstacles in her life.

Brooke has Autism and Cerebral Palsy. After her diagnosis, her mother, Terra, heard about UCP. “UCP has always been there for us. I can count on them for information, help getting a doctors script, equipment, and support,” says Terra.

In 2008, Brooke’s parents saw a program about Autism, and how some children with Autism can learn to communicate with a communication device. “I wanted a communication board for Brooke, but I didn’t know how to go about getting one,” says Terra. The next day, Terra called Mary Jones of UCP. Mary set up an appointment for Brooke at the CP clinic. There she received a script for an Augmentative Communication Evaluation.

After everything was done, Brooke finally received her Dynavox communication board, but there was a problem. The device was too heavy for Brooke to carry. She could only use her device at her desk. My husband and I wanted it to be mobile so Brooke could communicate where ever she goes. They were shocked to find out that there was nothing to assist a child with mobility.

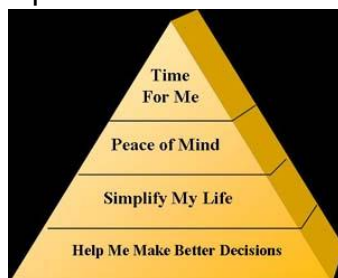
Thanks to UCP, who found and purchased a utility cart, Brooke is now able to push her communication device down the hall and everywhere else she goes at school. Her PaPaw painted the cart a



beautiful purple and her little sister decorated it with butterfly stickers. "It is our hope that one day Brooke will be able to talk; until then we are very thankful for technology that allows Autistic children and adults to have a voice. We will forever be grateful to UCP, all teachers, therapists, doctors, family, and friends," says mom. Info obtained from Brooke's mom, Terra.

Care for the Caregiver

Did you know that more than 75% of people who care for their older parents or relative also have children under 18 living at home? More than 50% of caregivers are employed full time. Research has helped to identify how



caregivers can prepare for and perform all their care giving duties. Solutions that can help are identified in the caregiver needs pyramid.

The caregiver needs pyramid contains four parts. The bottom part of the pyramid is the foundation while the top represents the ultimate goal. The foundation refers to things that help caregivers make better, faster, and appropriate decisions. Without this foundation a caregiver may find they do not have the time to do everything that needs to be done.

The next need is simplification. As a caregiver you must figure out things that absolutely must be done and do those first; don't try to do everything at once. The less complicated each task that a caregiver performs is, the easier it is for the caregiver to move up to the next step: Peace of mind.

When a caregiver feels the needs of their recipient are being met, the caregiver's needs tend to shift from the needs of their loved one to their own needs. It is vital for a caregiver to take care of themselves in order to provide the best care to a loved one. At this point, peace of mind can occur.

The greatest unmet need among caregivers is finding personal time for themselves. This is the ultimate goal within the pyramid and reflects the importance of maintaining one's own health. The pyramid offers framework to help caregivers identify needs.

Info obtained from www.strengthforcaring.com.

Buying Toys for Children with Disabilities

Choosing toys for children with disabilities can be difficult. The National Lekotek Center developed the AblePlay toy rating system and website to provide comprehensive information on toys for children with special needs so parents, special educators, therapists, and others can make the best choices for children with

disabilities. The National Lekotek Center recommends the following top ten things to consider with buying toys for children with disabilities:

1. Multisensory appeal: Does the toy respond with lights, sounds, or movement? Are there contrasting colors? Is there texture?
2. Method of activation: Will the toy provide a challenge without frustration? What is the force required to activate?
3. Where will the toy be used? Can the toy be used in a variety of positions such as side-lying or on a wheelchair tray? Will the toy be easy to store?
4. Opportunities for success: Can play be open-ended with no right or wrong way? Is it adaptable to the child's individual style, ability, and pace?
5. Current popularity: Is it a toy almost any child would like? Does it tie-in with other activities like T.V. or movies?
6. Self-expression: Does the toy allow for creativity and choice-making?
7. Adjustability: Does it have adjustable height, sound volume, speed, level of difficulty?
8. Child's Individual Characteristics: Does the toy provide activities that reflect developmental and chronological ages? Does it reflect the child's interest?
9. Safety and durability: Consider the child's size and strength in relation to the toy's durability. Are the toy parts sized appropriately? Can it be washed and cleaned?

10. Potential for interaction: Will the child be an active participant during use? Will the toy encourage social engagement with others?

For additional information on toys, visit the Lekotek web site. Additional resources for finding adaptive toys:

Toys "R" US Guide for differently-abled kids www.toysrus.com

Infinitec Toy Guide www.infinitec.org

Toy Directory.com

www.toydirectory.com/specialneeds.htm

Touch Heal Feel

www.specialneedstoys.com

Info obtained from www.ucp.org Parenting & Families

UCP's national website has a wealth of information. Go to www.ucp.org for information on education, employment, health and wellness, housing, parenting and families, products and services, sports and leisure, transportation, and travel.

A Few Resources

- Flaghouse www.flaghouse.com
- Exceptional Parent www.exceptionalparent.com
- Abilitations www.abilitations.com
- UCP www.ucp.org
- Family Matters www.fmptic.org

Need Fundraiser Ideas

We are starting to think about a spring fundraiser. If you have any ideas, please email us at UCPSI@onemain.com

Mark your Calendars for

football mini camp with players from the St. Louis Rams. Watch our website www.ucpsouthernillinois.org for the June date.



Happy Holidays!