



# United Cerebral Palsy of Southern Illinois



Summer 2007

## 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.

### UCPSI Equipment Loan Program

Our consumers need tumble form seats, strollers, feeder seats, an electric hospital bed, and any other equipment. So clean out your houses, garages and basements. Just give us a call at 1(800) 332-9745 and



we can pick up your donations.

### Country Idol 2

Joey Odum of Marion won 1<sup>st</sup> Place in the Solo Division.



Brooke Quinn, UCP of Southern Illinois Board President, congratulates Melanie Courter of Centralia who won 1<sup>st</sup> Place in the Karaoke Division.



Judges for Country Idol 2 were Ted Stice, CEO Outback Records; Gary MacPhee, of Troublebound; Brittany Clarke, Outback Records Recording Artist.



Country Idol 3 is planned for March 2008.

**Football Mini-Camp with players from the St. Louis Rams** was enjoyed by 40 area children. Starting linebackers Pisa Tinoisamoa and Brandon Chillar were on hand June 9, 2007 to provide tips from the pros.



Silent Auction items included an authentic autographed Isaac Bruce jersey, 2 team autographed footballs and a wooden autographed Brandon Chillar football. Watch our website [www.ucpsouthernillinois.org](http://www.ucpsouthernillinois.org) for information regarding the annual event in June 2008.



### **National Organization Caring for Kids (NOCK)**

**NOCK** has two **KIDS COUNT** programs that assist chronically ill children who need assistive technology devices.

#### **Wheelchairs for Kids**

**NOCK** provides custom-molded wheelchairs with seating systems to kids diagnosed with a degenerative chronic illness. Wheelchairs that have been customized can be critical in improving the quality of life for kids with cerebral palsy, down syndrome, spina bifida, muscular dystrophy and other degenerative disorders.

**NOCK** also considers requests for toddler seating, lifts, ramp, standers and other assistive and rehabilitative devices associated with seating and mobility requests.

#### **Expressions**

**NOCK** provides augmentative and alternate communication devices for kids with severe communication impairment caused by chronic illness such as cerebral palsy, autism, down syndrome and other neurological diseases that disable speech and communication.

**NOCK** considers requests for robotic and wheelchair mounting of augmentative and alternate communication device to also be able to communicate on the go.

You may contact **NOCK** at: P.O. Box 1822, Tacoma, WA 98401. **NOCK** phone number is (253) 851-6625 and their website is [www.nockonline.org](http://www.nockonline.org)

(info obtained from *Tech Talk*, Spring 2007)

### **Illinois Medicaid Covers Diapers**

Children over the age of two years with a qualifying diagnosis may have diapers or

pull-ups funded by Medicaid. You may call us here at UCPSI and we will be happy to give you the details and assist you with the process.

**Legal Advocacy Service**



The Legal Advocacy Service (**LAS**) “was created so that eligible children and adults, who have a disability, could obtain legal advice and representation to protect and enforce their rights guaranteed by Illinois’ mental health laws.

**LAS** attorneys “provide needed assistance to persons with disabilities in a variety of settings: mental health facilities, residential programs, community placements and nursing homes. Issues addressed include, but are not limited to: admission and discharge from hospitalization, adequate treatment, refusal of unwanted services and confidentiality of mental health records.”

In Illinois, you may call their toll-free number Central Intake at 1 (866) 274-8023. (info obtained from //gac.state.il.us/las/)

**Tech Talk**

**Tech Talk** has a new brochure. This brochure is very informative describing all of their programs and services. You may obtain this brochure in print, Braille, disk, audio tape and Spanish. To obtain this brochure you may call their toll-free number at (800) 852-5110V/TTY in Illinois only or by e-mail at [jap@iltech.org](mailto:jap@iltech.org) to let them know how many brochures you would like to have.

(info obtained from *Tech Talk*, Spring 2007)

**You Are Not Alone**

There are many services available for seniors. All older adults should have access to health care, prescription drugs and the services that they need. What can become extra difficult is if you are a senior or have a senior in your family that has a disability and may need additional services and resources. UCPSI can assist in services or finding appropriate resources for seniors with disabilities.

**The Senior Help Line** at 1 (800) 252-8966 is a toll-free number staffed by trained operators from Monday through Friday from 8:30 am to 5:30pm.

Examples of assistance this help line provides are: information on hot meal providers, transportation resources, job assistance, **Emergency Home Response Program**, the **Home Modification Program** and the **Community Care Program**. Also info on numerous other programs is available. (info obtained from Office of Governor August 2006)

**Helpful Website**

[www.caringtoday.com](http://www.caringtoday.com) is a useful website that caregivers can access on a variety of topics. Find new “talking points” every day including Healthy Monday Ideas, Tuesday Tips, Where to Look Wednesday, Time For You Thursday and Just Facts Friday. Many other topics are also available. (from *Caring Today Magazine*, May/June 2007)



**Grandparents Raising Grandchildren**

If you or someone you know has the responsibility of raising a

grandchild/grandchildren, **AARP** has website that you or they can contact for help. You may e-mail **AARP** at [GIC@AARP.ORG](mailto:GIC@AARP.ORG) (info obtained from *AARP Calendar* 2007)

### All Kids Health Insurance

**All Kids** is a new plan for all uninsured children under the age of 18 in the state of Illinois. This insurance has no income limit. Parents who enroll their kids in this program will pay monthly premiums and co-pays on a sliding scale fee that is based on the parent/parents income at rates they will be able to afford. This program uses a sliding scale fee which is based on income. Parents may apply by calling 1 (866)255-5437 or by e-mail at [www.allkidscovered.com](http://www.allkidscovered.com)

(obtained from the *Four Star Edition*, Winter/Spring 2007)

### ACCESS

Need resources? Contact **ACCESS**. **ACCESS** is a collaborative community information network sponsored by Man-Tra-Con Corporation Southern Illinois Healthcare, and The Verizon Foundation with the help from the AccessSI Steering Committee, including representatives of numerous agencies providing services in the thirty southern counties. You contact **ACCESS** by calling (618) 998-0970, ext.213 or visit their website at [www.accesssi.org](http://www.accesssi.org)

### Expand Your World!

The internet has a wealth of information on every imaginable topic. There are many, many websites on cerebral palsy.



[www.ucp.org](http://www.ucp.org) contains legislative updates, current info on cerebral palsy and resources just to name a few.

[www.ucpsouthernillinois.org](http://www.ucpsouthernillinois.org) can provide you with “tons” of information including upcoming events and fundraisers

[www.nichcy.org/pubs/factshe/fs2txt.htm](http://www.nichcy.org/pubs/factshe/fs2txt.htm) has an article entitled Jennifer’s Story. Jennifer’s Story has tips for teachers, parents and helpful resource base.

Additional websites

[www.disaboom.com/tmd](http://www.disaboom.com/tmd) is the” first interactive, online community dedicated to providing comprehensive resources to meet the needs of people with disabilities and functional limitations, their caregivers, families, rehabilitation providers and employers.”

[www.lburkhart.com](http://www.lburkhart.com)

ideas and instructions for adapting toys for use by children with CP

### Be Your Child’s Voice

It is so easy to get lost in all of the IEP’s, MRI’s, CT’s, evaluations, therapies, etc. Especially in the first few months after your child is diagnosed. I am honored to be able to write this and give my advice to you all.

I, too, was lost back in October of 2003 when Chance was diagnosed soon after being born. Overwhelmed might be a better word for it. I thought, I am just his “mom”, how can I know what he needs? But the answer lies within the question. I am his MOM, I know better than anyone what he needs. Now I need to learn how to get it. And after swimming and nearly drowning through articles, books, websites and list

serves I got a handle on it all and figured out what worked for us.

You have to find the inner part of you that is outgoing, assertive and ready to get things done at whatever cost. Before Chance, I was a quiet, shy and unassertive person. But I learned in order to be heard sometimes you just have to yell! Always go with your instincts, you know your child better than any one. Doctors and therapists don't always have the answers and the good ones aren't afraid to say "I don't know" when they truly don't and won't be offended when you request a second opinion. Keep searching until you find someone who will listen and help you find answers. And if a doctor or therapist ever tells you that your child will or will not do something, find a new doctor. No one knows what lies ahead for your child. Once you find this inner part of you to go forth into the world of special needs parenting.

First and foremost, call agencies, foundations, organizations locally that deal with special needs. **Early Intervention, Head Start, Cerebral Palsy, The ARC** just to name a few. Get involved with them and get your best ally when trying to find resources and information in your community. Apply for Supplemental Security Income or better known as SSI. If you are denied appeal the decision. Get together with the associations, organizations like the **Elks, VFW, Lion's Club, and the American Legion**. They usually will help you hold fundraisers for equipment, therapies, etc that insurance will not pay for.

In closing, the best way to be your child's voice is to never shut up! Even when

people beg you too! Keep asking, yelling and never give up! No one has your child's best interest at heart more than you do!

Much thanks to:  
Amy Henderson  
Mom to Chance  
Diagnosed with rare brain anomalies among other things!!-  
[www.Tknbychance.com](http://www.Tknbychance.com)

### Politically "In the Know"

The State of Illinois has a website [www.il.gov](http://www.il.gov) where you can gather updates on laws and new programs.

### Developmental Disability –The Importance of PUNS.

If you, a family member or someone that you know has a developmental disability, the **Department of Human Services (DHS)** is here to help.

**The Division of Developmental Disabilities (IDHS)** is a provider of person-first services and supports for individuals with developmental disabilities and their families. A wide array of possible services include in-home supports, respite care, training programs, job coaches, residential living arrangements, adaptive equipment and other supports.

When you set up an interview at your coordination agency, ( contact UCPSI for the appropriate agency) they will complete a "**Prioritization of Urgency of Need for Services (PUNS)**" form which will determine exactly what you need and place your needs in an emergency, critical or planning for need (a need for services in 1-5 years) category. PUNS is a requirement for people with disabilities and their families which helps the state know where the needs are.

This information is for **ALL** people with developmental disabilities from birth to adulthood. When the **PUNS** form is completed it does not guarantee that you are eligible for services nor that services will be provided, but it does guarantee that **IDHS** knows about your needs. Unless a **PUNS** is completed services cannot be obtained. **PUNS** is key to not only development of services, but deciding where funds are spent and need for additional funds to be requested.

To enroll or find out more about programs available, you may contact your local **DHS** office. If you are not aware of who to contact, you may call 1(888) 376-8446. For TTY users, you may call the Illinois Relay Center at 1 (800) 526-0844. You may also visit [www.dd.illinois.gov](http://www.dd.illinois.gov) or [www.dhs.state.il.us](http://www.dhs.state.il.us)

(info from *DD PUNS* brochure and *The Four Star Edition*, Winter/Spring 2007)

### Epilepsy Foundation of Southern Illinois

The **Epilepsy Foundation of Southern Illinois** is located at 1100D S 42<sup>nd</sup> St. in Mt. Vernon. Through prevention, education and advocacy, the Epilepsy Foundation of Southern Illinois will insure that people with seizures are able to participate in all life experiences." They offer epilepsy education to individuals and families, educational programs in schools and in the community, as well as current information on epilepsy. They provide or obtain transportation for consumers to be able to go to the neurologist.

The **Epilepsy Foundation** has a pediatric seizure clinic located in Mt. Vernon that provides free neurological evaluations by

appointment to consumers up to the age of 18 who have a "possible or diagnosed seizure disorder." You may call (618) 244-6680 for more information on their services or this clinic.

### Consumer Corner

Earl Marlette, a UCPSI, consumer is a talented poet and offered one of his many poems for our newsletter. So here's to Earl



#### Sir Robin

Sing Sir Robin your song so gay  
Sing Sir Robin it's a rainy day

Sing Sir Robin at the top of a tree  
Sing Sir Robin your song to me.

Sing Sir Robin your song so sweet  
Sing Sir Robin your song complete  
Sing Sir Robin then fly away  
Sing Sir Robin come back another day.

Sing Sir Robin get out of the rain  
Sing Sir Robin a sweet refrain  
Sing Sir Robin come back next year

Sing Sir Robin bring us some cheer.  
Sing Sir Robin your song inspired by all  
Sing Sir Robin before you leave this fall  
Sing Sir Robin your song once again  
Sing Sir Robin watch the strong winds.

Sing Sir Robin your song over and over  
Sing Sir Robin over fields of green clover  
Sing Sir Robin before away you fly  
Sing Sir Robin make someone happy I.