



# United Cerebral Palsy of Southern Illinois



Summer 2006

## 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 and provides case management, information and referral services, equipment loan program, ability awareness programs in schools and a monthly no-cost orthopedic clinic.



United Cerebral Palsy of Southern Illinois (UCPSI) held a football mini camp at Mt.

Vernon High School with players from The **St. Louis Rams** on Saturday June 17, 2006.

Autographs were signed and expert tips on how to toss a ball and get in shape were given by **Victor Adevanju No 94** and by **Claude Wroten No 99**. **Natalie** and **Emily** of the **St. Louis Rams Cheerleaders** were also on hand to greet and sign autographs. **Thanks** to the **St. Louis Rams players**, the **St. Louis Rams Cheerleaders** and **Jim Lake** for making this event possible. **GO RAMS!**



A **VERY SPECIAL THANKS** also goes out to **Mt. Vernon High School** and **Coach Mings** and his **coaching staff**.

**UCPSI** is planning to have this mini camp as an annual fundraising event.

This past March, **UCPSI** had a successful **Country Idol Amateur Talent Contest/Silent Auction** in Mt. Vernon on March 17, 2006.

Autographed items donated from country music stars were auctioned off. A wealth of talented performers performed for prizes

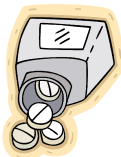


singers  
and

trophies. **UCPSI** plans on having another **Country Idol in March of 2007** so get practicing your favorite country tunes.

### HELP HELP HELP HELP HELP PRESCRIPTION ASSISTANCE

The high cost of medication can “**break the bank**” for most of us even if we have some type of medication assistance coverage, but it may not always cover the necessary medication.



Seniors and some persons with disabilities are eligible for Medicare Part D. Some persons have Medicaid coverage. Some people have **ABSOLUTELY NO MEDICATION COVERAGE! .... As sad as that sounds.**

What to do? Here are some options:

#### **Partnership for Prescription Assistance**

**(PPA)** This plan is for people who work, people without jobs, seniors and retired people, students, families and single people which means just about everybody. Here’s what you do.....

Call **toll-free 1(888) 477-2669** with the medicines that you take and a trained specialist will answer your questions and help you apply. You may also visit their web site at [www.pparx.org](http://www.pparx.org). You may be able to receive your medications free or nearly-free.

#### **I—SAVE RX**

Governor Blagojevich created **I—SAVE RX** to give all Illinois residents regardless of age or income the opportunity to purchase 120 of the most common brand name prescription drugs from licensed and inspected pharmacies in Canada and the United Kingdom at an average savings of 25-50%. This is a mail order program for refills only. You can access this program by calling **1 (866) I-SAVE33 (voice**

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and TTY) or by visiting their web site at [www.I-SAVERX.net](http://www.I-SAVERX.net)

**Rx for ILLINOIS** is a clearinghouse for eligible patients to access approximately 1,800 frequently prescribed drugs for free or at a discounted cost.

Visit [www.RxforIllinois.org](http://www.RxforIllinois.org) or call **877-793-6745** to see if you qualify.

#### **Together Rx Access**

This is a prescription savings card that provides instant savings right at your pharmacy counter. Most cardholders save 25-40% on brand name medicines. You must not be eligible for Medicare, have no prescription drug coverage and be in the income guidelines. You can call for more information or to apply at 1 (800) 444-4106 or online at [TogetherRxAccess.com](http://TogetherRxAccess.com)

#### **Rx Free Medicine Foundation**

This is a free organization staffed by volunteers that put you in touch with sponsors willing to provide free medication. The fee is \$5.00 for each medication request. Some of the primary requirements are that you not have medical insurance coverage that pays for prescriptions drugs, you have exhausted all insurance and or aid from Medicaid and social agencies, you have financial hardship due to high medication costs and/or you are taking care and paying for loved ones medication they cannot afford. You may apply to find out more information by calling 1 (573) 996-3333 or online at [www.FreeMedicineFoundation.com](http://www.FreeMedicineFoundation.com)

### MORE HELPFUL MEDICATION ASSISTANCE WEBSITES

**RxAssist.org**

**HelpingPatients.org**



These are web sites can help you access to apply for free or low cost medication.

**Needy meds.com**

This web site will assist you and your doctor in obtaining the necessary application to apply for meds that are little or no cost to you.

**RxOutreach.com**

This web site dispenses more than 50 generic medications for asthma, depression and more. You pay only \$18.00 for a three-month supply.

You may also contact your local hospital Social Service Department for additional resources.



**FREE RESPITE CARE**

The **Delta Center Inc.** is proudly providing free respite care services to residents of the following counties: **Massac, Alexander, Pope, Williamson, Franklin, Union, Johnson, Jackson, Hardin and Pulaski.**

**The Delta Center Inc.** offers respite care workers for any person of any age that was diagnosed before the age of eighteen with any disability such as the following: mental retardation, cerebral palsy, epilepsy and autism at **NO COST TO THE FAMILY.** You may set up services or find out more information by calling the **Delta Center Inc.** at (618) 734-2665 ext. 257 (TTY: 734-1350 to speak to Becky Fisher. Pager # 1 (888) 960-1589.



**PROJECT NEXT GENERATION**

**Jessie White,  
Secretary of State and**

**State librarian** developed **Project Next Generation** “to encourage greater success in all aspects of young people’s lives by enhancing their skills to effectively deal with the future. By empowering students with technological and interpersonal skills, Illinois libraries are

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bridging the traditional with the innovative to influence the next generation.”

**Project Next Generation** is the first-ever statewide mentoring program administered through Illinois public libraries. It’s about “today’s heroes shaping tomorrow’s leaders.” Their mentors work with junior high students to expand their technological skills and help guide them in life skills to help them be effective and be successful in this world. These students will learn how to use computers, Internet, digital cameras and other technologies while practicing problem-solving and communication skills.

To find out more about this program, contact your local library. For administrative information (curriculum, funding, contracts) you may contact Karen Muskopf at (217) 782-7749 or on her web site at [kmuskopf@ilsos.net](mailto:kmuskopf@ilsos.net). For technical support (equipment, software, Web pages), contact Bob Long at (217) 558-4031 of on his web site at [rlong@ilsos.net](mailto:rlong@ilsos.net). For additional information, you may visit **Project Generation** web site at [www.cyberdriveillinois.com](http://www.cyberdriveillinois.com)

**SPEAKING OF TECHNICAL SUPPORT**

Here are some helpful resources for computers which are low cost.

**Computer Banc**



**Computer Banc** is a not-for-profit volunteer organization that recycles and refurbishes computer systems to help area youth and the environment. Their mission “is to provide technology through refurbishing computers for children and not-for-profit agencies.”

Does your child receive services from special education? **OR** Has tested 2 years behind in reading or math? **AND** Does your household have limited income and no computer at home? If you have answered **yes** to the above questions, your child may be eligible to receive

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a low cost (\$10-\$70) computer for their home. These Pentium 3 computers are loaded with: Licensed Windows, a word processing program, a text reader program with an 80 volume library (Kk-12) and educational software games. Two trips to Springfield may be required. Let them know if you have to drive more than 40 miles.

**Computer Banc** is open from 1-4 p m on M/W/F and you may find out more information on eligibility and income guidelines by visiting their web site at [www.computerbanc.org](http://www.computerbanc.org) or by calling (217) 528-9506. Families must call to register for the required 1½ hour orientation. At this time you will be asked questions such as total household income to determine your child's eligibility. Each eligible family is required to help cover part of the \$70.00 expense of refurbishing your computer and you will be given the approximate amount of your share of the cost for your system. This cost will range from \$10.00 to \$70.00. At the end of your orientation training, an appointment to pick up your computer will be scheduled. Your share of the cost will be required at the time of pick up.



### DME (Durable Medical Equipment)

Durable medical equipment is available through [www.INFINTECDME.ORG](http://www.INFINTECDME.ORG) You may search for equipment most at no charge except for shipping. Equipment includes such items as bath seats, wheelchairs, scooters, commodes walkers, canes, car seats and positioning devices, etc. Also **Infinitec** takes donated equipment and makes it available by posting it on their web site. You may find out more about equipment available by visiting their web site or by calling (708) 444-8460.

### Disabled Children's Relief Fund (DCRF).

**DRCF** is a not-for-profit organization that provides children with disabilities with assistance to obtain needed equipment including

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eyeglasses, hearing aids, physical therapy and surgery especially those children that do not have adequate health insurance. Applications are available between March and September by writing to: **The Children's Relief Fund, P.O. Box 7420, Freeport, New York 11520**

### ATEN (Assistive Technology Exchange Network)



**ATEN** refurbishes and recycles donated computers for children with disabilities and distributes them free of charge to your child's school. The computers will be donated to the child's school to benefit his/her special education.

For more information or to apply for a computer or to donate computer equipment, please call their toll-free number 1 (800) 476-**ATEN** or visit their web site at [www.ucpnet.org](http://www.ucpnet.org)

### BUY IT! SELL IT! DONATE IT!

Use the **IATP'S (Illinois Assistive Technology Project)** online Classified Ads. Visit [www.iltech.org](http://www.iltech.org) or call Jane at 1(800) 852-5110 v/tty, (Illinois only)



### INTRODUCING JOEY



Joey Odum is a 17 year old high school student from Marion, IL who has cerebral palsy and uses a wheelchair for mobility. Joey has had dreams of being a musician since early childhood, and has worked very hard to

accomplish his dreams. In his early years, Joey was disappointed that his hands wouldn't cooperate to form chords on his guitar, but with hard work and dedication has succeeded in playing & singing entire songs, as well as written some of his own music. Joey has performed for many events, competitions and fundraisers and has his own recorded CD (and another coming soon!). He has performed with 50's rock personality Edgar Winter, & B.B. King's daughter Shirley. Joey favors soft rock sounds of 50's 60's and 70's and is a member of the band "Loose Wheels". Joey personally plays & sings rock, country, gospel, and jazz. Anyone listening to Joey can recognize his talent and definite gift for music.

Joey also has a strong interest in cooking, and got to meet famous chef Emeril Lagasse, courtesy of the Dream Factory, Inc.

Joey's parents attribute his success to his grateful attitude and generous caring heart, despite his challenges. Joey is kind and friendly to everyone and meets no strangers.

**GO JOEY!!!!!!!!!!!!!!**



### **BECOME A KEY COMMUNICATOR**

The **Family Support Network (FSN)** is seeking "eager and energetic" persons to be an advocate and get involved. The **Family Support Network** has a mission "to unify individuals with disabilities and their families to advocate for legislation, funding, services and community resources that strengthen and support the individual and the family directly by responding to their individual needs and empowering them to live in their homes. **The Family Support Network** further seeks to ensure the continuation of all individual supports throughout the life span of the individual.

### **A Key Communicator**

- is given a group of 12 **FSN** members in your area, you may even select people that you know
- as needed, you will be asked to make phone call and/or e-mails to your group on key issues that can be done from your home and at your convenience
- all necessary information that you need to inform your group will be provided to you
- keep updated information on your group such as any change of addresses
- when you hear of any needs in your group, contact **FSN** so those needs can be met through future advocacy efforts
- when you hear any new people that are wanting to support the **FSN**, you will sign them up to be added to the database

**To become a Key Communicator**, e-mail [Teresa@familysupportnetwork.org](mailto:Teresa@familysupportnetwork.org)

### **DON'T BE INTIMIDATED!!!!!!**

You are your own or your loved one's best advocate. Whether you have a concern, gripe or want to voice your support, you need to have to right legislator to contact. By contacting your legislator and letting him or her know how you feel, you are expressing your right to be heard. To be able to advocate for yourself or your loved one, it is very important to know who to contact. To find the legislators in your district, you may look up their names and addresses at <http://www.elections.state.il.us/DistrictLocator?SelectSearchType.aspx>.

Your Governor's address is **The Honorable Rod Blagojevich, 207 State House, Springfield, IL 62706.**

If you do not have a computer to access the addresses, you may call us at UCPSI and we

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will give you your appropriate legislator covering your district.



### LEGISLATIVE NEWS

The **ARC of Illinois Star News** publishes **Issues of the Day** and can be accessed by sending them your e-mail address by contacting them at [www.thearcofil.org](http://www.thearcofil.org)

[www.ucp.org](http://www.ucp.org) has legislative updates that can be accessed.

**The Family Support Network (FSN)** publishes a newsletter. You may e-mail them at [Teresa@familysupportnetwork.org](mailto:Teresa@familysupportnetwork.org)

### ILLINOIS LIFE SPAN PROJECT

**Illinois Life Span Project** is a free service for people with developmental disabilities that has an information and advocacy coordination system that is statewide. This project is funded by the Illinois Council on Developmental Disabilities. Need help advocating services for yourself, a family member or friend? **Illinois Life Span Project** can connect you to an advocate and/or a program to help you. They have a 24- hr hot line and can be reached by calling 1 (800)588-7002. TDD: (708) 206-0450.

**Vicki Wilson**, recently hired as an **Advocacy Resource Specialist**, has an extensive background in advocacy and can be reached by calling (217 )527-1755 or E-mail: [mike@illinoislifespan.org](mailto:mike@illinoislifespan.org) Web site: [www.Illinoislifespan.org](http://www.Illinoislifespan.org)

### HELP IS ONLY A YARDSTICK AWAY

**Judy Hoit** relates that she is a woman who has been a wheelchair user since 1949 when she contracted polio. She recommends that “you measure life by yards, not feet and be creative.” Judy states that in her own household the

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yardstick has been an invaluable tool to get what she wants. Some of her ingenious ideas are:

- ❖ slide the shower curtain open and shut
- ❖ reach or move things stuck behind something
- ❖ straighten pictures on the wall
- ❖ turn a light switch on
- ❖ drop a moistened cloth on floor and use yard stick to mop up spills
- ❖ move your blanket or sheet on the bed or rearrange your pillows
- ❖ push stove buttons or other buttons
- ❖ retrieve hangers of clothes
- ❖ place scotch tape on end to pick up tiny items
- ❖ shoo bugs away

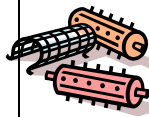
She is a very imaginative lady. There are many, many more ideas you can come up with.

(From EP Magazine, July 2006)

### OTHER GREAT ADAPTIVE IDEAS

#### ADAPT MY WORLD: Homemade Adaptations for People with disabilities By J. Rose Plaxen

How many times have we all said, “I could make that or I need something for...” Well, **J. Rose Plaxen** has come up with a lot of innovative and practical equipment made from common things around the house. If you have ever researched adaptive play things, kitchenware, and games, etc., the prices are just **CRAZY**. **Ms. Plaxen** uses Velcro, hair rollers and other easily accessed items to assist children and adults with disabilities be more independent by helping them do more for themselves. You may purchase her book, **ADAPT MY WORLD:**



**Homemade Adaptations for People with Disabilities** by contacting the EP Library at (800) 372-7368x110.

### GOODSEARCH



Raise Money for United Cerebral Palsy by Searching the Web!

By using **GoodSearch.com** to search for information from cerebral palsy to a new cheesecake recipe, monies could be donated to **UCP (United Cerebral Palsy)**. The earning potential is without limits. To use the service, open **GoodSearch.com**, type in "United Cerebral Palsy" or "UCP in the "I'm Supporting" textbox, and click "Verify". Choose **UCPSI (United Cerebral Palsy of Southern Illinois)**. Then simply search as you would with any other popular search engine. The next time you go to **GoodSearch.com**, the last charity you picked (hopefully **UCPSI**) will already be selected.

### ENERGY ASSISTANCE GRANTS

If summer temperatures stay at dangerous levels, the Illinois Dept. of Healthcare and Family Services (HFS) will open its Summer Cooling program. The program has the ability to distribute up to \$8 million in Low Income Home Energy Assistance (LIHEAP) funds to low-income families to assist them with their utility bills, so they can keep their air conditioners and fans running. Through LIHEAP, a state and federally funded energy assistance program, utility bill payments are made on behalf of households with incomes of up to 150 percent of the federal poverty level.



For more information, or to locate a LIHEAP office near you, call 1-800-252-8643.



The Keep Cool Illinois Campaign includes the [www.keepcool.illinois.gov](http://www.keepcool.illinois.gov) website, a statewide network of cooling centers targeted outreach to vulnerable senior citizens, energy assistance programs, public service announcements, fire safety, water safety and other tips to help families across Illinois prepare for the summer.

### CAMP

It's never too early to plan for camp. This summer camp resource site lists 72 special needs camps nationwide.

[www.campresource.com/camps/spec\\_needs\\_camps.cfm](http://www.campresource.com/camps/spec_needs_camps.cfm)

### THOUGHT FOR THE DAY

From what we get, we can make a living, what we give, however, makes a life.

**Arthur Ashe**