



## Greetings from the Cerebral Palsy Research Registry!

Hello and Best Wishes for a safe and healthy 2013 to you and your family!

The second half of 2012 was a busy time for the CPRR team. Several professional conferences are held in the Fall. CPRR team members were represented at two of these meetings this past year: The American Academy of Cerebral Palsy and Developmental Medicine (AACPD) and the 4th International Cerebral Palsy Conference. Highlights from these meetings can be found inside this newsletter.

Researchers from five new studies have contacted the CPRR and requested assistance with study participant recruitment. These studies can be found on our website: <http://www.cpregistry.org> and include:

-  Recumbent cycling for adolescents with CP (ages 10-18)
-  Genetics and CP (ages 1-90)
-  Influence of vision on balance with persons with CP (ages 15-50)
-  Muscle and nerve properties of the arm and hand in adults with CP (ages 18-65)
-  Study drug effects on function in adults with CP (18-55)



### CPRR Research Symposium

The CPRR team is organizing our first CPRR Research Symposium to be held in 2013. The symposium will be targeted for parents of children with cerebral palsy and adults with a cerebral palsy diagnosis. We need your input to make this meeting a success!

A questionnaire has been included with this newsletter and it has been posted on the website under Participant Tab-Newsletters.

Send your questionnaires, thoughts and comments to Donna Hurley, PT, DPT, 645 N. Michigan Ave, Suite 1100, Chicago, IL 60611, [d-hurley@northwestern.edu](mailto:d-hurley@northwestern.edu) or call: (312) 503-3342

Remember that March 25th is Cerebral Palsy Awareness Day. Take this opportunity to increase public awareness and advocate in schools, communities and places of employment for persons with cerebral palsy.

Thank you for joining and participating in the CPRR. We appreciate your time and commitment to cerebral palsy research.

Donna S. Hurley, PT, DPT

visit us online at <https://www.cpregistry.org>

Cerebral Palsy Research Registry  
c/o Northwestern University  
Physical Therapy and Human Movement Sciences  
645 North Michigan Avenue Suite 1100  
Chicago, IL 60611



## National Cerebral Palsy Awareness Day is March 25



## Meet The Expert: Catherine Kushner, MS, PTA, ATP Assistive Technology Professional



### What is Assistive Technology (AT)?

AT as a device is any type of equipment or product system that is used to improve or maintain the functional capabilities of a person with a disability. AT as a service is related to using, choosing, or obtaining AT. AT is a process. It begins with the consideration of devices that are then selected, tested and supported and periodically reevaluated to determine its effectiveness for the particular person. AT services in the school system include provisions for an AT evaluation, purchasing or leasing of the device, coordinating the use of the device, as well as training or technical assistance for the child with a disability, his/her family, and those

who are involved with the child. In a nutshell, AT helps level the playing field so all students can participate with independence.

### What types of AT are available?

There is a continuum of AT from low tech to high tech. Low tech tools refer to items that are generally available at low cost, easy to use, and used by a wider variety of students. Low tech tools can include slant boards, specialized paper, pens, and weighted pencils. High tech tools are more specialized and costly. Typically they contain a higher level of complexity to operate, and are used to meet the specific needs of student. Samples of high tech tools include specific software programs, communication devices and some alternative keyboards, to name a few.

### Who can benefit from AT?

Any person with a disability, who can benefit from a tool, device, intervention or service to increase, maintain, or improve their functional capabilities, can benefit from AT. However, AT is only needed by some people to promote independence in all facets of life. In the schools, it is used by students who learn differently and/or by students who have physical challenges and require a different way of moving about the school environment. Having the right mix of appropriate AT tools or interventions is INVALUABLE to the person who uses them.

### What is covered by insurance and/or school districts?

There is no easy answer. However, one should know that if the AT device is considered to be needed by the student, to receive a Free Appropriate Public Education (FAPE), then the school provides it at no cost to the family. Students' wheelchairs are purchased either with Medicaid funds or private insurance. Some high tech communication systems are purchased in the same way as above; however in some cases the school purchases the device. It has been my experience that specific IEP team members and administrators work closely with the student's parents to obtain the appropriate equipment either paid for by Medicaid funds, purchased through the family's insurance, or by the school.

### What resources are readily available to families? ?

There are many resources available, but for those families interested in exploring AT, below are some websites dedicated to supporting students/parents through the AT process:

- <http://idea.ed.gov/explore/>
- <http://nichcy.org/schoolage/iep/meetings/special-factors/considering-at>  
- National Dissemination Center for Children with Disabilities
- [http://www.isbe.state.il.us/spec-ed/html/assist\\_tech.htm](http://www.isbe.state.il.us/spec-ed/html/assist_tech.htm)  
- IL State Board of Education
- <http://www.abledata.com/>  
- AbleData is an online resource for providing objective information related to AT products.



*Like many families and organizations, the CPRR has been affected by the economy. Our initial seed grant has expired and unfortunately this forced us to eliminate the CPRR recruiter position, affecting direct recruitment, correspondence and database/website management. Grants for funding are continuously submitted but resources are limited. This appears to be a similar trend for CP Registries around the world. The next step for the CPRR will be to go to industry for support. If you know of a corporation that would like to contribute to funding part or all of the CPRR please contact Donna Hurley at 312-503-3342 or [d-hurley@northwestern.edu](mailto:d-hurley@northwestern.edu)*



The CPRR would like to have photos of a variety of Registry participants with or without their families to be used to promote the CPRR. Types of advertisement would include the website header, brochures, scientific posters, etc. No names are included in these advertisements, a consent form needs to be signed prior to use and you will be notified if your photo is to be used.

E-mail photos to: [d-hurley@northwestern.edu](mailto:d-hurley@northwestern.edu) or mail photos to Donna Hurley, PT, DPT, 645 N. Michigan Ave., Suite 1100, Chicago, IL 60611

## Meet Daniel Oster

*Daniel is the 2012 Kane County Spelling Bee Champion and he also competed in the National Spelling Bee in Washington DC. Daniel is naturally talented at spelling because he has a good memory and can memorize the spelling of words, but his road to Nationals was harder than most people's. Like many students, he studied the spelling and origins of words from multiple lists and had his family quiz him numerous times. However, Daniel didn't have a lot of extra time to study for the contest because due to fine motor issues, it takes him a little longer than his peers to do homework and he also had to go to therapy sessions during this time. Daniel won the county Spelling Bee and was very excited because it was proof that his hard work had paid off.*

*Daniel's Words of Wisdom: "Don't give up because of a disability, because you may have talents that you hadn't discovered before; all of your hard work will eventually pay off. And, practice, practice, practice because that is the only way you'll be able to get better at something."*



## AACPDM Highlights



• **Go Baby Go!** Dr. Cole Calloway, PT, PhD from the University of Delaware has created a Facebook page (<https://www.facebook.com/UDGoBabyGo>) to teach parents how to modify child size cars, jeeps and moving toys for infants and toddlers who are unable to move/crawl/walk on their own. Babies as young as 6 months old have been successful in operating these wheeled devices. Research has shown that moving independently directly correlates with improved cognition, communication and socialization. Dr. Calloway's lab website is <http://www.udel.edu/gobabygo>.

• Dr. Edward Hurvitz, MD from the University of Michigan is studying "early aging" in adults with pediatric onset disability, such as cerebral palsy. Adults with cerebral palsy tend to lose function earlier and at a greater rate than the general population. Possible causes might be sarcopenia- a decrease in muscle quantity, dynapenia- a decrease in muscle quality, and poor levels of fitness. Ways to prevent premature aging include keeping physically active while protecting the joints, cardiac and resistive training and avoiding excessive weight gain.

• Apps have been increasingly used on iPads and iPhones for the general public. Persons with physical and cognitive challenges now have these interactive tools to assist with everything from learning how to write words to creating and teaching speech through graphics and everything in between. To find apps that would apply to you, go to the App Store on your iPhone or iPad and explore the options. There are several apps under Education – Disability. Also, you can search online for "apps for cerebral palsy" to get more specific ideas!



## 4th International Cerebral Palsy Conference Highlights

• **Droling and Dental Hygiene** was presented by a medical team from Australia. Management of drooling consists of 5 strategies: Conservation (oral-motor exercises, behavioral strategies), Appliances (ISMAR-Innsbruck Sensory Motor Activator and Regulator), Drug Therapy (oral medications- anticholinergics), Botulinum toxin (injected into the submandibular and parotid glands) and Surgery. Resource Book: Saliva Control in Children ([ww2.rch.org.au/emplibary/plastic/salivabook.pdf](http://ww2.rch.org.au/emplibary/plastic/salivabook.pdf)) has detailed information.

Dental Hygiene: brush twice a day using a fluoridated toothpaste, floss daily, visit the dentist every six months, placement of fissure sealants, application of topical fluoride and application of Tooth Mousse ([www.toothmousse.info](http://www.toothmousse.info)). Tooth Mousse provides calcium and phosphate, essential minerals to prevent tooth and gum decay- and it tastes good!

• **World CP Registers, Surveys and Networks Day** was attended by representatives around the world to discuss prevalence and trends in CP, neuroimaging information, quality of life issues, resources and the challenges CP registries face.

