



Registry Funding
We would like to acknowledge the generous support of the Staubitz Charitable Trust, Art & Linda Staubitz, and several donations made in memorial of Art Staubitz.
Our efforts are child and family driven and rely on support from the community. If you would like to make a donation to the Cerebral Palsy Research Registry, or if you have information on grants or other fundraising ideas, please contact Donna Hurley at d-hurley@northwestern.edu or 312.503.3342.

Greetings from the Cerebral Palsy Research Registry!

Fall is upon us, and with it brings a more hurried pace in our daily lives. Before the chaotic scheduling takes over your life, please find some time to not only read this issue of the Cerebral Palsy Research Registry newsletter, but also to visit our website at www.cpregistry.org. Our goal is to update the site quarterly, particularly the Research Studies and Community Links pages.

Below are some CPRR highlights from the past six months:

-  Enrollment has increased from 528 to 698.
-  The CPRR has participants from 33 different states. We're looking for participants from NV, ID, MT, WY, SD, NM, KS, AL, AK, WV, MD, DE, RI, NH, VT, ME, and MS to complete the Continental US.
-  Recruitment for five new research studies.
-  The CPRR team's manuscripte titled "The Cerebral Palsy Research Registry: Development and Progress Toward National Collaboration in the United States" was published in the *Journal of Child Neurology*, June 2011.
-  Presentations at three scientific conferences: American Physical Therapy Association (APTA) Combined Sections Meeting, APTA Section on Pediatrics Annual Conference, and the Cerebral Palsy Summit sponsored by the Cerebral Palsy Alliance Research Foundation



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CPRR DATABASE NEW LOOK-SAME MISSION

The CPRR has worked diligently with Northwestern University Biomedical Informatics Center (NUBIC) to create a new and improved database. This collaboration improves our current database in several ways:



- It will allow us to accept outside institutions to join the CPRR, therefore expanding the number of participants and research studies
 - It provides cutting edge data security
 - It contains age-specific questions and new questions for adults
 - It will automatically send out yearly email reminders to update your participant information
- This new program will be in effect December 1, 2011.
More detailed information will be sent to CPRR participants.

Meet The Expert: Denise Iwinski Southwest Special Recreation Association

Who is South West Special Recreation Association?

South West Special Recreation Association (SWSRA) is a 501(c) 3 non-profit organization that provides services for individuals ages 3 and up with special needs. Its mission is to serve individuals with disabilities in their need for recreation so that all persons in our member communities may experience and enjoy positive leisure opportunities.



Who are our participants?

SWSRA participants include individuals who have varying degrees of physical or mental disabilities, learning disabilities, behavioral disorders, and hearing or visual impairments.

What programs at SWSRA are geared towards individuals who have Cerebral Palsy?

SWSRA offers a variety of programs and special events that would be beneficial for individuals with Cerebral Palsy. Examples of these programs include: bowling, Challenger Little League, cooking clubs, day camp, everyone can dance, golf, movie nights, pet therapy, social clubs, swim lessons, and theater nights. Our more popular, annual special events include: a Spring Formal Dance, Feed the Hungry Dance, Walk, Run or Roll ½ Mile Race, and a Ladies Primping Night. SWSRA is also currently seeking

individuals who would like to participate in Paralympics. Within Paralympics, athletes must fulfill specific qualifying standards for each sport. Paralympics focus on elite performances where athletes must not only be qualified, but the best or highest qualified athlete based on performance in an activity.

What Paralympics sports are practiced by individuals who have Cerebral Palsy?

Archery, boccia, cycling, equestrian, 7-on-7 football, powerlifting, rowing, sailing, shooting, swimming, table tennis, alpine skiing, and ice sledge hockey are all sports that are offered by Paralympics as competition for athletes who have Cerebral Palsy.

What if I have Cerebral Palsy and want to participate in my Park District's programming?

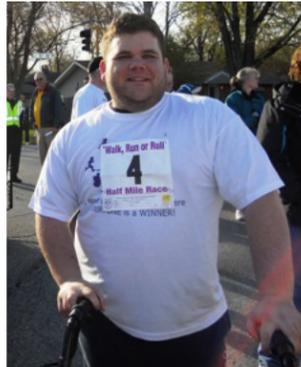
Inclusion would be your answer! Although many individuals perform at their highest level of ability through participation in a SWSRA program, others may have greater success by participating in a Park District program with assistance from a SWSRA staff member. Member agencies adhere to the following basic principles when providing accommodations to allow for successful inclusion of individuals with disabilities.

- The interests and needs of an individual participant will be addressed.
- The concerns of the family will be taken into account.
- The member agency staff will be given support by SWSRA.
- Options and choices will be made available to individuals with disabilities.

When signing up for a Park District program, just inform the staff of that Park District that you will be requesting additional services. It's as easy as that! The Park District will contact us and our Inclusion Staff will not only provide the appropriate assistance but will also continue to monitor progress throughout the program.

How do I get involved with a Special Recreation Association near me?

If you would like to find out which Special Recreation Association serves your community, please visit www.specialrecreation.org. If you would like more information regarding SWSRA, please contact our office at: 708-389-9423 or visit www.swra.com.



A special thank you to **Misty Campbell** and the **California Community Foundation** for their generous support to the CPRR.

Misty Campbell is the author of "Help is on the way-A real, true, and honest story of raising a child with disabilities."

The California Community Foundation is a nonprofit organization that helps strengthen communities through effective philanthropy and civic engagement.



NCPAD The National Center on Physical Activity and Disability

The National Center on Physical Activity and Disability (NCPAD) is an information center concerned with physical activity and disability. NCPAD offers information on many popular activities, games, recreational pursuits, and sports that have been adapted to allow people with disabilities to participate as fully as they wish, and to become as active as they wish. NCPAD's goal is to provide persons with a disability and their family members with options and information to help enable them in participating in the kind of physical activities they choose to enjoy. Indoor or outdoor, recreational or competitive, solo or team, easy or intensive, NCPAD has the resources, contacts, and assistance you need. Visit <http://www.ncpad.org> for more information.



Meet Freddy Gonzalez

Freddy is a Junior at Thomas Kelly High School in Chicago, IL. His favorite subject is History. After graduation Freddy would like to attend DePaul University in hopes of studying History.

During his free time Freddy enjoys listening to all types of music and playing wheelchair basketball at the Rehabilitation Institute of Chicago.

Freddy feels that wheelchair basketball has enabled him to become a better leader and has motivated him to achieve his goals. Freddy states that "wheelchair basketball has given me the opportunity to meet people that have changed the way I view my future and potential." Freddy's number one influence is his mother, who has always helped him maintain a positive attitude and makes sure that he makes all of his doctor appointments.



The purpose of the Cerebral Palsy Research Registry is to promote research in the field of cerebral palsy across the lifespan. One way we do this is to link researchers with CPRR participants and their families for possible enrollment into a research study.

After an Institutional Review Board (IRB) study is approved by the CPRR study committee, CPRR participants are notified via email, postal mail, or phone of the study. Unless permission has been given to the CPRR for the researcher to contact them directly, it is up to the participant or guardian to contact the researcher regarding enrollment.

New studies in the past six months include:

- Dance, virtual reality, and motor control
- Calf spasticity, medicine, and foot alignment with standing and walking
- Genetic links to cerebral palsy
- Hemiplegic cerebral palsy brain imaging and brain stimulation

All actively recruiting studies can be found on the CPRR website www.cprestry.org under the tab Research Studies. For more information on any study, contact the CPRR coordinator, Donna Hurley at 312-503-3342 or 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.

*Email photos to:
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