



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.

Cerebral Palsy Research Registry Newsletter

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Greetings from the Cerebral Palsy Research Registry!

The fall season is upon us and life seems to be moving from the slow, lazy days of summer to the fast paced, activity packed days of school, work, sports and anticipation of upcoming holidays.

The CPRR team has been busy, attending scientific conferences and collaborating with local and international colleagues. Cerebral palsy is a condition that affects children and adults worldwide, and with modern technology, we are able to learn how other countries are conducting research studies regarding the prevention of cerebral palsy as well as intervention techniques.



Over the past six months,

- 🍁 The CPRR has been represented at the following scientific conferences:
 - American Academy of Cerebral Palsy and Developmental Medicine
 - Child Neurology Society
 - Michigan Cerebral Palsy Research Consortium
 - PT OT Coordinator's Conference
 - United Cerebral Palsy Annual Meeting
 - Illinois American Academy of Pediatrics
 - LaRabida Hospital CP Symposium



- 🍁 The CPRR has grown from 315 participants to 360 participants.
- 🍁 The CPRR has teamed up with the Northwestern University Clinical and Translational Sciences Institute to upgrade the CPRR's database structure, security and ability to collaborate with outside institutions.
- 🍁 The CPRR has been in communication with three medical and research institutions that want to join the CPRR as a participating institution.
- 🍁 The CPRR has hired an additional staff member, Maria Isabel Aguilar, to assist with recruitment and database updates. Isabel will be contacting participants and/or families yearly for updates on participant contact, medical and developmental information.



Isabel Aguilar

The CPRR team is excited with the progress we have made and are making strategic plans to build on this success. We are grateful to all the participants and families that have joined the CPRR and those who have shared their stories, hopes and dreams. Please continue to call or email with your ideas, thoughts and concerns.

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



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Ask the Expert... Car Seat Safety

Car crashes are the leading cause of death for kids. In Illinois, over 80% of child car seats are not installed correctly. Certified Child Passenger Safety Technicians can check your child's car seat and help you with proper installation and use. **Lynn Purdy, RN** is the Coordinator of the Child Passenger Safety Program at La Rabida Hospital located in Chicago, IL, and funded by a grant from the Illinois Dept. of Transportation. Lynn answers some frequently asked questions about car seat safety.



1. My sister has given me her child's old car seat. Is it ok for my baby to use?

If you don't know the history of a car seat, do not use it. A parent should be especially cautious of car seats sold in resale shops. Car seats that have been in an automobile accident are to be discarded. Also, car seats expire after six years because the plastic deteriorates.

2. My child has poor control of his head and trunk. How can I get him to sit properly in the car seat?

It's best to purchase a car seat that has an internal harness, often called a 5-point harness. This strapping device supports the hips, shoulders and a strap across the chest. It is important to read the weight limits on the seat before purchasing. Most forward facing seats with internal harnesses have a weight limit of 40 lbs., but there are an increasing number that go up to 65 or even 80 lbs. Medical car seats with internal harnesses have a 100 lb. weight limit. These seats are very large and bulky. A parent needs to consider the size of the child, the car seat and the car prior to purchasing this item. An alternative is using a van equipped with a wheelchair lift for transportation.

3. My child has cerebral palsy. Does she need a special car seat?

Not necessarily. If your child fits properly in a commercial car seat, that is fine. One exception would be if, after surgery, your child has casts on both legs, a special car seat called a Hippo Seat, or a vest restraint that would allow the child to lie down on the seat of the car would be beneficial. La Rabida Hospital is a satellite center for the Special Needs Child Passenger Safety Resource Center of Children's Hospital of Peoria and can loan families these car seats after surgery.

4. Does my child need to be in a rear facing car seat?

When a child is in a rear facing car seat, the head and neck are maximally protected in case of an accident. It is a state law that children under one-year-old and 20 lbs. is required to use a rear facing car seat. The American Academy of Pediatrics recommends using rear facing car seats for as long as possible. There are rear facing seats available for children up to 40 lbs. Rear facing car seats should be placed in the middle (van) or back seat (car). If it is necessary to place a car seat in the front seat, DE-ACTIVATE THE AIR BAG on that side.

5. How long does my child need to use a car seat? It can be inconvenient at times.

All children should be in a car seat or booster chair until they are 4'9" tall. Booster seats raise the child, so that the seat belt is positioned correctly. The straps over the shoulder and hips need to be positioned properly, not across the neck or under the armpits.



6. Where can I go to have my car seat checked?

- www.buckleupillinois.org
- www.nhtsa.gov go to "Child Passenger Safety" then "Seat Inspection Stations"
- Chicago Police Department, dial 311 for car seat check sites

For more information regarding car passenger safety seats, contact Lynn Purdy, RN at 773-256-5714 or lpurdy@larabida.org.

Good Shepherd Center

Good Shepherd Center has been assisting and advocating for children and adults with and without disabilities living in the South Suburbs of Chicago, IL since 1963. They provide a variety of services (from therapies to counseling to respite care) that can be viewed on their website: www.gscenter.org.

Good Shepherd Center's In-Home Respite Care Program provides short-term, intermittent care for persons with developmental disabilities in their natural, guardian or foster family home. Professional respite staff offers care for individuals of any age with special needs. Siblings under the age of 18 are included. The majority of this program is funded from the Department of Human Services, so there is no charge to qualified individuals and their families.

For more information on this program, please call Dawn Dixon at 708-335-0020 (ext 22).

If you know of anyone interested in becoming a Respite Care Worker who has experience working with children with developmental disabilities, please contact Vernola Thomas at 708-335-0020 ext 23.

WANTED

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.

REWARD

Email photos to d-hurley@northwestern.edu or mail photos to Donna Hurley, PT, DPT, 645 N. Michigan Ave, Suite 1100, Chicago, IL 60611



Jennifer Dixon

Research Corner

Various CPRR participants have expressed the following concern: "I enrolled in the Cerebral Palsy Research Registry but I haven't been contacted for any studies."

The main reason why you have not been contacted for a research study is that there currently isn't an open study you are eligible to participate in.

What determines eligibility? Researchers have to state inclusion and exclusion criteria for their studies. Both criteria need to be met in order to participate in the study. Examples of inclusion criteria are developmental status (persons who walk independently 500 feet or persons using power wheelchairs), age (children aged three to six or adults over age 20) or medical status (drooling or no seizures). Few studies only have the inclusion criteria of having cerebral palsy or being a caretaker of a person with cerebral palsy.

Exclusion criteria are the developmental or medical conditions a person cannot possess if they join the study. For example, an exclusion criteria for a study investigating walking might be no Botox injections in the leg(s) within six-months and inability to walk.

What is an open study? An open study is currently seeking participants. Once the study has recruited their maximum number of participants, or if it runs out of time or funding, the study is considered closed.

The CPRR is continually recruiting both participants and researchers so that more cerebral palsy research studies can be

Family Focus Meet Jennifer Dixon

When you think of an "extraordinary 16-year-old" girl, Jennifer Dixon should come to mind. Jennifer is a National Honors Student at Thornwood High School in South Holland, IL. She loves participating in NHS and Poetry Slam at school, singing with her Church choir, playing computer games, talking and taking photos on her cell phone, recording a number of TV shows she just can't miss and shopping at the mall with her friends. Favorite foods? Skittles, Lemonheads and Buffalo Wild Wings of course!

Jennifer plans on attending college to study music and computers. She and her family are exploring options for the best college that will be able to accommodate her physical limitations. Jennifer, of course, wants to fly off to New York City, the Big Apple, but mom might not be able to let her go that far away.

Jennifer has been writing poems "forever" and is kind enough to share one with us.

Feedback

Written By: Jennifer Dixon

Sometimes people don't like being told what to do,
And it makes them want to say I hate you, but
All they're doing is giving you feedback, so
You can stay on track, don't fall off and
Follow into the wrong footsteps,
Feedback can be harsh but once you
Deal with it and take it all in,
There's no turning back again,
So when someone tells you
Something you don't wanna
Hear, don't tune them out,
Just try to think clearly,
Remember feedback
Will never leave, it
Will always be
There when you
Need it

Teaching Opportunities



The Department of Physical Therapy and Human Movement Sciences, located in downtown Chicago, IL is looking for children and adults with cerebral palsy, as well as their families, to assist teaching physical therapy students about this condition. Lab sessions are generally two hours with compensation of free valet parking and a small stipend. If you are interested, please contact Kristin Krossschell, PT, MS, PCS at 312-908-6790 or k-krossschell@northwestern.edu.