



Keep dough in a ziplock baggie in refrigerator to maintain freshness.

Mix the dry ingredients. Add salad oil and boiling water. Stir with spoon then knead with hands.

3 cups flour  
 1/2 cup salt  
 1 tablespoon talcum powder  
 2 three-oz packages unsweetened Kool-aid  
 3 Tablespoons salad oil  
 2 cups boiling water.

**Homemade play dough recipe**



Not only is play dough fun to play with, it's also fun to make.

**Family Fun**



Our efforts are community based and rely on support from the community. If you would like to make a donation to the Cerebral Palsy 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.

We would like to acknowledge the Staubitz Charitable Trust and Art & Linda Staubitz for their generous support of our CP Registry efforts. Their financial donation has allowed us to actively recruit, produce publications, and develop the online database and website for the registry.

**Registry Funding**

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



# Cerebral Palsy Registry<sup>©</sup> Newsletter

2009 Volume 1, Issue 1

**WELCOME**

Hello and welcome to the first Cerebral Palsy Registry<sup>©</sup> newsletter! The Registry has been growing and evolving this past year with increased public awareness and an increased enrollment of 125 families.

To make enrollment easier, we have begun the credentialing process for having online consent and intake questionnaires. We anticipate this option will be on our website, [www.cpregistry.org](http://www.cpregistry.org), by June 2009.

If you know individuals or families that might be interested in joining the Cerebral Palsy Registry<sup>©</sup>, they can contact Donna Hurley at d-hurley@northwestern.edu or 312-503-3342.

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# Have you seen our website?



## Cerebral Palsy Registry



**The Cerebral Palsy Registry**® is a multi-institutional collaborative effort whose primary mission is to improve the scientific knowledge base in the area of cerebral palsy. We believe that by working together, families and researchers can make a difference in the lives of people affected by cerebral palsy.

Northwestern University Department of Physical Therapy and Human Movement Sciences, the Rehabilitation Institute of Chicago, the University of Chicago and their affiliates have developed and expanded this Registry with two goals in mind:

- The Cerebral Palsy Registry® is a database that can connect interested families with researchers studying cerebral palsy. Researchers are often required to dedicate a large portion of time and budget to recruit participants for their studies. The Registry can assist with this situation.
- The Cerebral Palsy Registry® is a tool to investigate surveillance data such as the natural aging process of persons with cerebral palsy, current interventions, environmental modifications and services utilized by children and their families.

[More Information...](#)

Did you know that The Cerebral Palsy Registry® has a website? Check it out at <https://www.cpregistry.org>. If you have ideas or suggestions for the site, feel free to send an email to [t-sukal@northwestern.edu](mailto:t-sukal@northwestern.edu).



### Family Focus Meet Patrick Mullins

Patrick is a fun-loving five-year-old boy who lives with his parents, Mary and PJ and his new baby brother, Matthew. The Mullins' are fortunate to have a large extended family living near them to not only assist with life's unexpected trials, but also to share happy times together.

Patrick loves to play with his cousins. Because he is unable to walk, Patrick and his cousins play on the floor; rolling, chasing, laughing and of course, hitting, crawling on each other and rough housing. The rougher the better, as far as Patrick is concerned and he expresses his pleasure with loud belly laughs.

Patrick's day begins early. Up at 6:00 am, he gets ready for school; dressing, eating and brushing his teeth (he hates that!). But it is all worth it when he sees the school bus. Patrick loves riding on the bus as much as he loves school. His favorite classes are art, circle and music time.

After school, Patrick attends private physical and occupational therapy or he might have a play date with his cousins. In the summer, he loves to be in the family swimming pool or take walks around the neighborhood. Patrick loves to be around people.

Because of Patrick's aversion to food, he gets his nutrition via a g-tube. By 7:00 pm it's bath, book and bedtime. And well deserved, too, for such a busy, active boy.

Patrick, you have infused laughter into our lives. Thanks for being you.

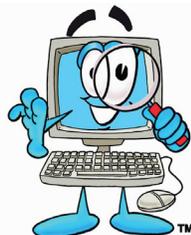
If you would like to share your story for a future issue, please contact Donna by emailing [d-hurley@northwestern.edu](mailto:d-hurley@northwestern.edu). We'd love to hear from you!

## Volunteer Opportunities



Northwestern University School of Physical Therapy and Human Movement Sciences is looking for children ages 5-18 with neurological disorders to participate in student learning experiences supervised by an instructor. The school is located at 645 N. Michigan Avenue (Michigan and Erie) in Chicago, Illinois. Volunteers will receive valet parking and \$25 for participation.

Contact Kristin Krosschell, Assistant Professor NU-PTHMS at [k-krosschell@northwestern.edu](mailto:k-krosschell@northwestern.edu) for more details.



The Cerebral Palsy Registry® is looking for 10 parents willing to test our online enrollment process. This would involve accessing our website, reading and filling out the consent form, then entering information on the questionnaire. We are trying to work out all of the "bugs" before launching it to the public.

Contact Donna Hurley, CP Registry Coordinator, at [d-hurley@northwestern.edu](mailto:d-hurley@northwestern.edu) for more details.

## International News

Our Registry had the honor of being asked to participate in the World Cerebral Palsy Registrar Congress, which met at the 3rd Annual International Cerebral Palsy Conference, held in Sydney, Australia.



There are 39 Cerebral Palsy Registries in the world and three in the United States - ours and two sponsored by the Center for Disease Control (CDC). Dr. Michael Msall (University of Chicago) and Dr. Donna Hurley (NU-PTHMS) attended the meeting to share information about our Registry and to work in small group sessions to discuss issues concerning Cerebral Palsy Registries from around the world.



**Mary and Patrick Mullins**