



Department of Physical Medicine and Rehabilitation
 Volume 1, Issue 2: Winter 2014

THE CP RESEARCH REGISTRY OF MICHIGAN NEWSLETTER

**Welcome to the second issue of
The CP Research Registry of Michigan
 Newsletter!**

The continued purpose of this newsletter is to provide you with a resource that will update you on the current research projects and events occurring in the CP community of Michigan. Additionally, our office will include facts about CP and available resources in the hope that this newsletter will become another source of information on CP for you and your family. As Winter is fast approaching, this issue is dedicated to health and wellness. Our experts will provide you with helpful fitness and nutrition information that will help you to beat the cold this Winter!

Thank you for your continued support.

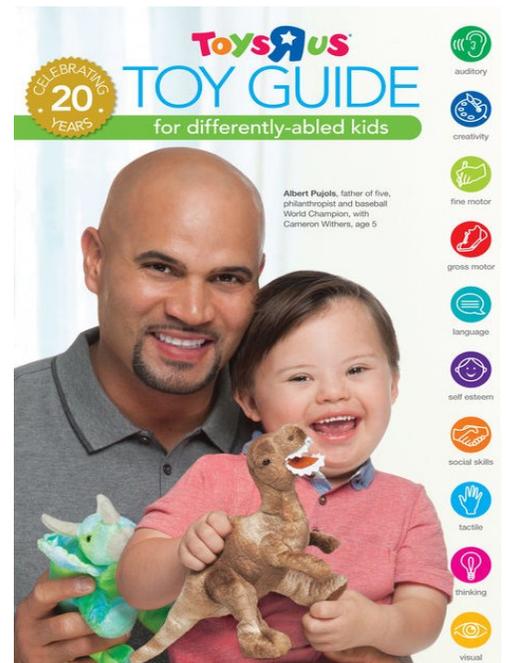
How to Make your Holiday Shopping a Little Happier

Finding an educational and enjoyable gift for your child can be a challenge during the holiday season. To help make your shopping experience a little happier and easier Toys “R” Us has released a [Toy Guide for Differently-Abled Kids](#). This is an easy-to-use resource featuring specially selected toys that encourage play for children with physical, cognitive or developmental disabilities. The *Parenting Special Needs Magazine* also has a great [Holiday Gift Guide](#) (Pages 37-47) that will help ease the stress of holiday shopping and inform you of some fantastic gift options!

Note: The University of Michigan does not endorse the products mentioned in this newsletter. The purpose of this newsletter is to provide resources that might interest you/your family.

Inside this Issue:

Welcome to the Second Issue	1
Happy Holiday Shopping	1
Current Research Opportunities at the University of Michigan	2
A Crowd-Pleasing, Nutritious Recipe	3
UM Clinical Studies.org	3
Additional Resources to Stay Active this Winter	4
Unique Opportunities to Beat the Ice and Snow	4
Meet our Fantastic Faculty	5
Office Contact Information	6
What’s new with the CP Registry?	6



RESEARCH OPPORTUNITIES at the UNIVERSITY of MICHIGAN

2

Currently the [Department of Physical Medicine and Rehabilitation](#) at the University of Michigan is conducting six research studies focusing on cerebral palsy. To determine if you or your child is eligible to participate in any of these studies, please contact the research team of the specific study.

Outcomes After Rhizotomy (HUM00070864)

Adults with cerebral palsy, ages 18-35: We are studying how a surgical procedure called a rhizotomy has affected people as they age. You can participate in the study even if you haven't had the surgery! We are looking for adults with CP to answer questions about pain, fatigue, and function. The survey is online, and can be completed from home in about 30 minutes. You'll receive \$5.00 for your time.

If interested or for more information: Contact the researchers at 734-764-5217 or PMR-CPresearch@med.umich.edu

Brain-Computer Interface (HUM00012968)

Researchers are looking for individuals with cerebral palsy age 8 years and up for a very unique study. This study is exploring how a person can control a computer and even take tests to show their capabilities, by using **ONLY** their brain waves – no talking and no hands!

If interested or for more information : Contact the researchers at 734-936-7178 or umdbi-recruit@umich.edu

Health Self-Management (HUM00081812)

Teens and young adults , ages 13-29 years, with cerebral palsy are invited to take part in this study. Participants will complete standard paper/pencil or computer tests, so researchers can measure thinking and motivational factors. The study will take 3 hours and participants will receive \$50 for their participation.

If interested or for more information : Contact the researchers at 734-936-6023 or PMR-UMACAL@med.umich.edu

Working Memory (HUM00055681)

Researchers are interested in learning more about how children with cerebral palsy remember information. We invite children, ages 6-16 years, to take part in this study and try computerized tests of working memory. The study will take approximately 3 hours and participants will receive \$50 for their time and effort.

If interested or for more information : Contact the researchers at 734-936-6023 or PMR-UMACAL@med.umich.edu

Measure of Pain (HUM00085574)

We invite people with cerebral palsy, ages 13 years and up, who can speak, sign, or use a communication board to tell us their own pain level. Responses will be videotaped during a medical doctors exam. The videotape will be shown to raters and we ask them to guess the pain level and see how close they get to what the pain level really is. This study will take about 5 to 10 minutes to fill out forms and consents and for the videotape.

If interested or for more information : Contact the researchers at 734-936-8613

Screening and Exercise Health (HUM00067890)

We invite adults with cerebral palsy who are ages 18-45 years and have NOT participated in exercise during the past 6 months to help researchers find new ways to identify general cardiovascular and metabolic health risks and utilize exercise participation to reduce these risks. Participants will receive an honorarium up to \$220 for full participation in the study.

If interested or for more information: Contact the researchers at 734-763-0692 or mdpeterz@med.umich.edu

A Crowd-Pleasing Nutritious Recipe: Gluten Free Vegan Lasagna (Serves 8-10)

Ingredients

1½ cups raw, organic cashews
Kosher salt
8 ounces **organic brown rice lasagna noodles**
3 tablespoons plus ¼ cup olive oil, divided use
1 white or yellow onion, diced
1 small eggplant, peeled and diced
1 pound mushrooms, cleaned and sliced
1 red bell pepper, seeded and chopped
4 cloves garlic, minced – divided use
1 (28 ounce) can chopped tomatoes
½ teaspoon black pepper
¼ teaspoon crushed red pepper flakes
2 teaspoons dried basil
2 teaspoons dried oregano
1 tablespoon fresh lemon juice
2 teaspoons nutritional yeast
1 cup fresh basil leaves



Directions

Place the cashews in a bowl and cover with filtered water. Let soak for at least 2 hours or up to 24 hours. Drain and set aside.

Bring a large pot of heavily salted water to a boil and cook the lasagna noodles according to the package directions. Drain, rinse with hot water, and drain again. Drizzle with 1 tablespoon olive oil and gently stir to coat the noodles. Set aside.

In a large skillet heat 2 tablespoons olive oil over medium-high heat. Add the onions, eggplants, mushrooms, and red peppers. Cook the vegetables, stirring occasionally, until they soften, brown, and any juices that the vegetables have released are cooked off, about 15 minutes. Add 2 garlic cloves and cook for 30 seconds. Lower the heat to medium, add the tomatoes, including the juice, 1 teaspoon salt, black pepper, the red pepper flakes, dried basil and oregano and cook until most of the tomato liquid has reduced and the mixture is thick and cooked through, about 20 minutes.

Preheat oven to 350 degrees.

Place the soaked cashews in a blender with about ¼ cup water, the remaining 2 garlic cloves, lemon juice, and the nutritional yeast. Blend until smooth, scraping down the sides of the blender as needed. If needed, add more water, a little at a time. Remove half the mixture and reserve. To the remaining cashew cheese add the fresh basil and remaining ¼ cup of olive oil and blend until smooth.

Ladle a little of the liquid from the tomato vegetable mixture on the bottom of a 9 by 12 inch baking dish then layer in half the lasagna noodles. Add half of the remaining tomato vegetable mixture and top with the basil cashew cheese. Layer on the remaining lasagna noodles, the rest of the tomato vegetable mixture and then drizzle the top with the reserved cashew cheese. Bake uncovered until hot and bubbly, 30 – 40 minutes. Let cool for a few minutes and serve.

Recipe notes: For the cashew cheese I use organic, raw cashews and I let them soak overnight in filtered water. You can get away with less soaking if pressed for time. The shortest I have soaked my cashews is 2 hours. The longest I let them soak is 24 hours, after that they seem to get a little funky for my tastes. I used **Pastariso organic brown rice lasagna noodles** for the noodle layer and I picked an assortment of veggies our family loves. Feel free to come up with your own assortment if you like. The mushrooms and eggplant give the lasagna a “meaty” taste and texture which the carnivores in my family appreciate.

Recipe by Carol Kicinski of *Simply Gluten Free Magazine*

Interested in participating in research opportunities NOT listed in this Newsletter?

... then check out [UMClinicalStudies.org](https://umclinicalstudies.org)

The UMClinicalStudies.org team wants to use their website to facilitate communication and partnerships between health researchers and volunteers.

Additionally, they hope to promote collaborations in which all are valued members of the health research team.

UMClinicalStudies.org

M UNIVERSITY OF MICHIGAN

Connecting YOU to Health Research

**DID YOU
KNOW
ABOUT...**

Additional Resources to Stay Active this Winter

1. For a great starting point on creating general fitness goals and compiling information to discuss with your physician, look at these [Quick Tips for Being Active with a Disability](#) from the US Department of Health and Human Services.
2. Think that your fitness is inhibited due to your wheelchair? The National Center on Health, Physical Activity and Disability (NCHPAD) has a guide to [Discovering Accessible Fitness](#). This guide is designed to help wheelchair users safely and effectively use equipment found in most fitness centers.
3. For children that utilize a wheelchair and are ages 3-8 years, the [Firefly Upsee Harness](#) is available to help change the way children with disabilities navigate the world. This device utilizes a specially designed harness and sandals that allows the child and adult to walk together, while leaving their hands free for other activities.
4. [United Cerebral Palsy of Michigan \(UCP\)](#) connects individuals with disabilities to opportunities and resources in the Michigan community. UCP believes that every individual with a disability has the right to be a full member of their community and provides information, advocacy and loans to help achieve this goal.



Unique Opportunities to Beat the Ice and Snow this Winter



Looking to increase your community involvement this Winter? Check out these awesome organizations for more information on how you can become more involved in sports and recreational activities:

1. The [Special Olympics Michigan](#) is an organization dedicated to providing athletic training and competition for adults and children with developmental disabilities. Special Olympics Michigan programs include 22 sports and divisions are based on an athlete's age, ability and gender. Additionally, competitions take place at the local, regional, state, national and international level.

For more information: contact your local area director by visiting Special Olympics Michigan's website and selecting your local county
2. [The Ann Arbor Rockets Hockey Team](#) provides an accessible opportunity for children with disabilities to participate in competitive ice hockey. They practice at the Veterans Arena in Ann Arbor, and this team allows the children to increase their confidence, teamwork, and sportsmanship.

For more information: contact Jacqueline Kaufman at 734-936-7066 or jaqk@med.umich.edu
3. [The Ann Arbor Figure Skating Club \(AAFSC\)](#) is located at the Ann Arbor Ice Cube and offers many learn to skate programs, which includes a therapeutic skating class! This class is designed for children with disabilities and will help improve your child's fitness, strength, balance, and flexibility.

For more information: contact the Mary Johanson at 734-660-4442 or escow33@yahoo.com

Meet Our FANTASTIC Faculty! Mark Peterson, PhD, M.S. 5

Dr. Peterson is passionate about movement, activity, and helping individuals with cerebral palsy (CP) to improve quality of life by making healthy lifestyle changes. Please see below for his responses on how exercise is a necessary component of making these changes in our lives.



Why is exercise important for individuals with CP? Many individuals with CP lead sedentary and inactive lifestyles, which can result in gradual losses of muscle mass, strength, and bone density. Exercise is one way that individuals with CP can increase their daily activity and counteract these effects because, after all, if we don't move it, we're going to lose it!

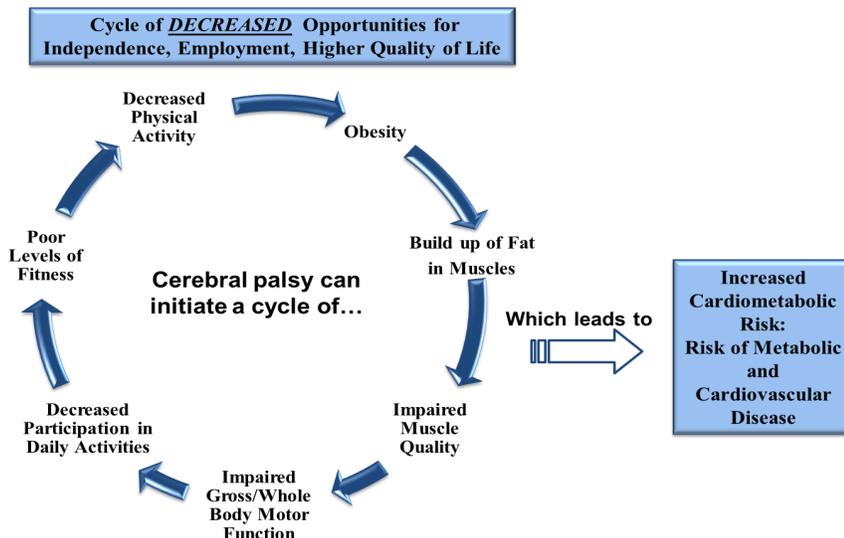
What is a sedentary lifestyle? An important distinction to make is that sedentary does not necessarily mean sitting! Sedentary means prolonged periods with no movement at all. However, even when sitting there are opportunities for movement, such as seated exercise, changing postures, and even periodically standing up with aides. This all counts as movement and can contribute to preservation of health!

What is the best way to increase my activity level? Resistance training is one of the best ways to increase your activity because it provides the most "bang for your buck". Not only is resistance training important for muscle and bone health, but it also contributes to positive cardiovascular and metabolic outcomes. Resistance training is beneficial due to the ability to perform the exercises intermittently, as well as to the noticeable functional increases compared to standard aerobic exercises.

Is going to the gym my only option for resistance training? Definitely not! A great way to ensure that you keep moving is to make things fun. This means that participating in outdoor recreation, going to a pool, or even playing on a jungle gym can be just as effective and worthwhile as going to the gym. Just make sure you are incorporating activities that will strengthen your muscles as you have fun.

How can parents/caregivers help individuals with CP make healthier lifestyle choices? The way we define exercise can significantly impact the likelihood that someone will integrate it into their lives and sustain it. Health-related physical activity does not need to be painful in order to be effective. In fact, encouraging individuals to participate in fun activities that ALSO incorporate health-related exercise is by far the best way to ensure that these positive lifestyles become a lifetime habit.

If I utilize a wheelchair or work long hours sitting all day, how can I increase my activity and make healthier choices? Remember that even while sitting there are opportunities for movement (basic activities count too)! Something as simple as standing up and sitting back down in your chair several times, every half hour, can be an effective activity. For many people, their own body weight is a heavy relative load, so by performing sit-to-stand movements, you are actually engaging in lower-body resistance training. The key is to start small and progress over time, as you see improvements. This will lead to more challenging and longer periods of exercises in the future, and of course more noticeable improvements in function and health. But always remember, any movement is better than no movement at all!





**The University of Michigan's
Adapted Cognitive Assessment Lab
houses
The Cerebral Palsy Research Consortium of Michigan**

Contact Information:

Phone: 734-936-6023

Or

Email: PMR-CPRegistry@med.umich.edu

What's New with the CP Research Registry?

Thanks to your continued support, we currently have over 300 registered participants! We look forward to continuing to see this number grow as we become more established and increase our representation of research studies occurring at the University of Michigan. Additionally, more University of Michigan faculty researchers have recently joined our office! We are very excited to welcome them to the Cerebral Palsy Research Consortium of Michigan, and check out Page 2 to learn more about the exciting research studies that they are currently conducting.

Our future is bright thanks to you: our registered participants, families and friends! Stay tuned for more great things and information to come from the Cerebral Palsy Research Consortium of Michigan!

*It is because of those who are willing to
volunteer in research that enables researchers to
find medical breakthroughs and improve quality
of life for individuals with cerebral palsy.*



**Cerebral Palsy Research
Consortium of Michigan
Cerebral Palsy
Research Registry**

