



Insights from the MNT4P Program

Medical Nutrition Therapy for Prevention



Rani H Singh, PhD, RDN, LD Professor Department of Human Genetics

Message from the Director

MNT4P was created to build on the mission and vision of leading with excellence in the field of genetic metabolic nutrition within an academic environment — carrying it forward to some degree by ensuring that both patients and providers have greater access to nutrition care, resources, and support. It was built through partnerships with HRSA, the Georgia Department of Public Health, Emory University, and families themselves — all working together to expand access and strengthen care. And it continues to grow through the dedication of our team, whose commitment makes this mission a reality.

The future of MNT4P is about growth expanding our research, broadening our education programs, and deepening our community outreach—so that every patient with a genetic disorder has access to the nutrition care they deserve.

To bring all aspects of the program together, we've launched a new and improved website: www.mnt4p.org. We hope it showcases the work we do and highlights opportunities for collaboration.

News & Updates

MCADD Registry

MNT4P Program at Emory University has partnered with **Minutes Matter** to create a registry of families managing **Medium-Chain Acyl-CoA Deficiency (MCADD).** This registry aims to create a robust database with the MCADD family to support medical researchers to find therapeutics for MCADD as part of HRSA -funded newborn screening research project lead by Rani Singh, PhD, RD in the department of Human Genetics. Please be on the lookout for further information in near future.

MNT4P Website

Check out our new and improved MNT4P Website, incorporating research, education, and community outreach. Hope you like it!

Georgia CTSA TL1 Grant

Under the mentorship of Rani H Singh, PhD, RDN, LD, MNT4P's Post Doctoral Fellow, Jessica Strosahl, PhD, RDN, LDN, has been awarded a highly competitive NIH-funded Georgia Clinical TL1 Postdoctoral Training Grant for her research project titled, "Defining Protein Requirements in Adults with PKU: Impact of Genotype and Medical Food Intake". Her application received the highest possible score (10 on the NIH scale). Dr. Singh, believes this research will have a huge impact on advancing translational science activity in the field genetic metabolic nutrition.



Spotlight

Emory's Impact on Genetic Metabolic Nutrition

MNT4P Celebrated 20th Anniversary of Founding of GMDI at Emory

On October 24, 2025, Emory University's MNT4P team, led by Rani H. Singh, PhD, RD, hosted a special scientific conference marking the 20th anniversary of the founding of Genetic Metabolic Dietitians International (GMDI) at Emory.

The hybrid conference brought together healthcare professionals, researchers, and leaders in the field of nutrition and genetic disorders for a day of insightful discussions and collaborative learning. The program honored the organization's founders and highlighted Emory's pivotal role in advancing the field of genetic metabolic nutrition therapy.





Dr. Leanne Redman, PhD, RD, LDN, LPFA Endowed Chair and Executive Director at Pennington Biomedical Research Center, delivered the keynote address. Leading NIH-funded research in human metabolism, energy balance, and precision nutrition, Dr. Redman emphasized how translational nutrition science connects discovery to clinical practice -aligning with MNT4P's mission to integrate research and care for improved outcomes in individuals with inherited metabolic disorders.

73

I personally believe in the power of community, and GMDI grew out of a desire to bring us together, share knowledge, and give this specialty a strong professional identity... something Emory helped make possible.

"

Rani H Singh GMDI Founding President





Honoring GMDI Founders

Amy Cunningham, Barbara Marriage, Barbara S. Goss, Carol Hartnett, Cristine M. Trahms, Dianne M. Frazier, Elaina Jurecki, Fran Rohr, Helen McCune, Kathleen Huntington, Kathryn Camp, Laurie Bernstein, Linda Tonyes, Rani H Singh, Sandy Van Calcar, Sharon L. Ernst, Shideh Mofidi, Steven Yannicelli, Ulrike Reichert

Southeast Integrative Newborn Screening & Long-Term Follow-Up (SE INBS-LTFU) Consortium Corner

Pilot Project- Caremapping

Seeing the Whole Picture

As part of HRSA activities under the SE INBS LTFU Consortium, the MNT4P program introduced a caremapping activity during the annual Metabolic Camp held at Emory University in June. The primary objective of this activity was to help campers aged 13 and older identify and understand the full spectrum of their care team, including healthcare providers, family members, schools, and others involved in managing complex rare diseases through a participant generated graphic organizer. The goal was to empower campers to communicate their care needs more clearly to their healthcare providers.

More than 30 campers, primarily diagnosed with PKU and MSUD, participated in the caremapping sessions. A key takeaway was the realization among campers of the many individuals who play a role in their care—some of whom they had never considered before. This reflection proved to be a meaningful step toward strengthening their self-advocacy and care coordination, especially during the transition of care in adulthood.



At first I didn't know what type of idea I should do in order to make my care map. But the more I thought of my life and the past experience that people have helped me with my MSUD, I thought of my map as a "Long Journey" about how over the years I've grown and changed and most importantly, health

A 19-year-old camper with MSUD

Feature

Healthy Mom, Healthy Child

Managing PKU During Pregnancy with Palynziq

Pregnancy with Phenylketonuria (PKU) can be challenging, as maintaining safe phenylalanine (Phe) levels is vital for mother and baby. Palynziq (pegvaliase) often helps achieve this without the burden of a strict diet. While not officially approved for use during pregnancy, there have been reported success stories.

In a recent study of 14 pegvaliase-treated pregnancies, mothers maintained safe blood phe levels on average, with no major complications or congenitial anomalies reported. Some pregnancies were delivered preterm (1). Although more research is needed, current findings provide hope for families planning pregnancy. Real-world data from the BioMarin registry and clinical experience show that, with close monitoring and dietitian support, women on Palynziq can maintain safe Phe levels and achieve healthy pregnancies. Tyler, a patient at Emory Genetics Clinic shared that Palynziq helped her keep Phe levels in range before conceiving, easing fears of maternal PKU syndrome.

Her story, along with growing BioMarin registry data, continues to offer encouragement to women with PKU on Palynziq as they plan for healthy, well-supported pregnancies.



"With my first pregnancy, I was not on Palynziq and felt helpless on a very strict diet. Starting on Palynziq changed everything. I could eat enough real food to keep both me and my baby healthy. Instead of starving or stressing over every meal, I finally had options. My levels stayed stable, and I had the confidence to enjoy being pregnant."

Tyler, a mother with PKU



MNT4P Recipe Corner

Charred Carrots with Orange and Balsamic



This recipe has been adapted for individuals with Long-Chain Fatty Acid Oxidation Disorders (VLCAD,LCHAD,CPTII Deficiency) and is also lower in protein and can support individuals who require a protein restriction. Patients on a protein restriction, can use regular olive oil to roast carrots and can omit MCT oil.

Ingredients

1½ pounds rainbow carrots, scrubbed (about 8 large or 15 medium carrots)

3 tablespoons vegetable broth or water (for roasting) *if amino acid disorder or organic acid disorder can use 3 tablespoons olive oil instead*

1 ½ teaspoons minced fresh thyme leaves

½ orange, zested and juiced

1 tablespoon aged balsamic vinegar

1½ teaspoons salt

½ teaspoon freshly ground pepper

1 tablespoon medium chain triglyceride(MCT) oil (added after roasting) * for amino acid disorder or organic acid disorders, omit MCT oil*

Sea salt, optional for finishing

Nutritional analysis for entire recipe (with MCT oil and without Olive Oil)

Metabolic Pro# 78948

Recipe (4 servings): Per Serving (around 1/4 of the roasted carrot mixture)

Calories: 425 kcal 106 kcal Carbohydrate: 64 gm 16 gm Fat: 19.6 gm 4.8 gm

Medium Chain Triglycerides (MCT):

13.75 gm 3.4 gm

Long Chain Triglycerides(LCT):

5.80 gm 1.4 gm
Protein: 5.7 gm 1.4 gm
Phenylalanine (Phe): 355 mg 88 mg
Leucine (Leu):585 mg 146 mg

Recipe from Ina Garten, Featured on the New York Times Cooking

Preparation

Step 1

Preheat the oven to 425 degrees Fahrenheit.

Step 2

Cut the carrots crosswise into 4-inch lengths. Cut the larger pieces lengthwise in half or quarters so the sticks are roughly $\frac{1}{2}$ inch wide.

Step 3

Place the carrots on a sheet pan. Sprinkle with the thyme, $1\frac{1}{2}$ teaspoons salt, and $\frac{1}{2}$ teaspoon black pepper. Add 2-3 tablespoons of vegetable broth or water *amino acid disorders and organic disorders can add olive oil instead*. Toss with your hands until coated, then spread the carrots out in an even layer.

Step 4

Roast for 25-35 minutes, flipping halfway until brown and tender.

Step5

Immediately after removing from the oven, top the carrots with orange zest, orange juice, MCT oil *if amino acid disorder or organic acid disorder can skip MCT oil*, and balsamic vinegar. Sprinkle with sea salt and toss to coat. Taste for seasonings, then serve warm or at room temperature.

MNT4P LPMF Offer

Promin Low Protein Foods

MNT4P has partnered with **Zoia Healthcare** to give you access to more low protein modified foods (LPMF) options from the UK brand **Promin**. As part of this partnership, you can place <u>one order per month per person</u> up to \$50 in **November and December 2025**—at no cost to you!

This offer is in addition to the MNT4P's current \$150 LPMF allowance from Cambrooke.

Upcoming Events

- MNT4P Annual Enrollment (January 1, 2026) Check your email for enrollment links
- Emory eGNA's Genetic Nutrition ECHO Traineeship Cohort 11 (January 15-April 16, 2026) eGNA
- Rare Disease Day February 28, 2026
- Emory Metabolic Camp (June 9-13, 2026): www.metcamp.net
- SERGG Annual Meeting (July 16-18, 2026) <u>www.sergg.org</u>

Contact Us

Have additional questions or comments? <u>Contact us!</u>



Department of Human Genetics Visit our website: www.mnt4p.org

