MNT4P™
Inherited Metabolic Disorders

# Welcome To The MNT4P Newsletter!

## What is the MNT4P Program?

Since 2016, the Medical Nutrition Therapy for Prevention (MNT4P) program has provided a platform for health prevention and promotion through services related to medical nutrition therapy for patients and families managing inherited metabolic disorders (IMD) in the state of Georgia.

This program is framed on 2009 research conducted by Emory University's Department of Human Genetics and Public Health Informatics Institute. This team identified the need for collaborative efforts to improve follow-up and care coordination for disorders identified through newborn screening.

MNT4P bridges gaps in access to medical foods, low protein modified foods, and/or dietary supplements, reflecting the program's core values of genetic nutrition research, education, and community outreach efforts.

Furthermore, the MNT4P program provides nutrition care services encompassing diagnosis-driven nutritional assessments, education, monitoring services, and insurance navigation for the IMD community, regardless of income status.

Under the leadership of Rani Singh, PhD, RD, and our dedicated team of registered dietitians and patient-care coordinators, MNT4P has worked relentlessly over the years to fulfill the program's mission and vision of equitable access to medical nutrition therapy and health-related quality of life improvement.

MNT4P receives primary funding through a grant from the Georgia Department of Public Health, in addition to other sponsors and donations.

## Family Feature:

"My name is Lilia, and I am the mother of five. My fifth child name Nehemiah was born with PKU, this is something completely new for me. All I knew was that this was a newborn screen for babies once they were born.

To my surprise a couple days after birth to be exact 7 days, I received a call from the pediatrician asking me to come in with Nehemiah immediately. As a parent it's hard to receive a call like that and not know what was going on. To my surprise Nehemiah has tested for a genetic disorder called PKU.

MNT4P was contacted by the pediatrician before I even made it to the office. I was so grateful because I had no idea of what I was doing. They shipped overnight formula and gave me instructions on what to do.

From the moment Dr. Singh, Saran and Jessica walked in to our lives, it made everything so much easier.

All this happened during Covid, but it didn't stop them from providing education through telemedicine, emails and phone calls.

It started with formula and all the tools needed like scale, formula mix bottles, prescriptions for the WIC program, taking Nehemiah for blood work, making sure I knew how to check his phe levels every week, later every two weeks and now making sure we give him low protein foods.

Because of the program we have been able to keep Nehemiah in the right direction.

We could not have done it without the guidance of MNT4P, they have and are still helping and guiding us through this new journey."

# MNT4P Program Highlights:

Due to the COVID-19 pandemic, the past two years have been difficult for all of us, including the MNT4P program. Thanks to a strong infrastructure and dedicated team members, MNT4P was able to navigate the challenges of virtual nutritional management, formula shortage crisis, and disruption of monitoring services.

## Transitioning Filter Paper Monitoring Interruptions

- Patients diagnosed with Phenylketonuria and Maple Syrup Urine disease rely on filter paper tests to monitor their disorders.
- When filter paper monitoring services were interrupted in September 2020 due to discontinuation of these tests by a local laboratory, MNT4P stepped up to collaborate with ARUP Laboratories to provide coverage of these tests.
- This prevented lapses in monitoring during a 4-month transition period.
- This pilot program between MNT4P and ARUP Laboratories laid the groundwork for Emory's in-house laboratory to develop a sustainable solution for filter paper monitoring.
- MNT4P continues to cover filter paper tests for uninsured patients.

95 Patients referred to MNT4P for filter paper tests during filter paper monitoring disruption

239 Filter paper tests covered by MNT4P during 4 months of filter paper disruption

## Bridging Gaps During Formula Crisis

- In March 2022, MNT4P collaborated with the Southeast Regional Genetics Network (SERN) to organize a meeting for dietitians from various states, representatives from formula companies, and individuals from patient advocacy groups.
- This group convened to address the disruption in metabolic formula supplies caused by Abbott Nutrition's temporary facility closure in Sturgis, Michigan.
- As a result of this collaboration, MNT4P utilized available resources to continue providing metabolic nutrition services, including medical foods, to patients and families in preventing hospitalizations and poor health outcome.

30% Increase in the number of patients served by the MNT4P Program since the formula crisis

## Implementing the MNT4P Care Model

- Inherited metabolic disorders management requires access to specialized medical foods and supplies, as well as education on how to utilize these resources, to implement diet for life.
- The MNT4P program provides nutritional education and instruction through telemedicine sessions to help patients ease the burden of managing their disorders

55 Average number of MNT4P visits conducted annually in the past 2 years

Children under the age of 18 served through MNT4P visits 54%

# Meet the MNT4P Team:

EMORY UNIVERSITY SCHOOL OF MEDICINE | Department of Human Genetics

*"The MNT4P program provides a platform for health prevention and promotion through nutrition interventions. Our program's approach has combined basic science, medical genetics, and public health to address nutritional needs and food insecurities through community outreach efforts exhibited by a bridge supply of medical foods, services and nutrition education associated with genetic disorders. We set MNT4P as a public health initiative to highlight medical foods as "food for medicine". We pride ourselves on the achievement so far, especially during the trying time in the pandemic, and hope to continue to provide the services to our community for years to come"*

Rani H. Singh, PhD, RD
Director, MNT4P Program

# Holiday Recipe:

## Simple Pumpkin Apple Soup

### Ingredients

Makes 7 cups, serving size 1/2 cup

- 3 tablespoons canola oil
- 1/2 medium onion, chopped (120 gm)
- 3 1/4 cups vegetable broth, canned or homemade
- 2 large tart apples, peeled and roughly chopped (400 gm)*
- 1 15-ounce can pumpkin (425 gm)
- 1/2 teaspoon ground cinnamon
- 1/4 teaspoon ground allspice
- 1/4 teaspoon ground ginger
- 1/4 teaspoon ground nutmeg or grated fresh nutmeg
- 1 tablespoon fresh chopped thyme or 1 teaspoon dried thyme (optional)
- 2 cups water
- Salt and black pepper
- Ground nutmeg and chopped fresh thyme for garnish (optional)

### Additional Information

*Examples of tart apples - Granny Smith, Pink Lady ®, Braeburn, Empire, McIntosh, Jonathan, Cortland

**Recipe source:** Schuett, Virginia and Dorothy Corry. Apples to Zucchini-A Collection of Favorite Low Protein Recipes. National PKU News, 2005.

**Other resources:**

- Safe Recipe Guide
- CDC Fruit & Vegetable Safety

### Instructions

1. After cleaning the food preparation area you will be using, gather the equipment and measure the ingredients you need for this recipe.

2. Wash your hands with soap and water.

3. In a large saucepan or stockpot, heat canola oil over medium heat. Reduce heat, add onions, and cook until tender but not brown, about 3-4 minutes.

4. Add vegetable broth, apple, pumpkin, spices and thyme if using. If using fresh thyme, wait to add until the end.

5. Simmer over low heat, covered, until apples are very soft, about 20 minutes.

6. Puree soup in food processor or blender in batches. Do not fill the blender more than ½ full.

7. Return the soup to the pot and add water. Add thyme if using, and salt and black pepper to taste.

8. Heat through. Sprinkle with ground nutmeg and thyme if desired

**Nutritional Analysis** (Metabolic Pro# 9981, 10/24/2022)

| Per Recipe: | Per ½ cup Serving: |
|---|---|
| Calories: 791 kcal | Calories: 57 kcal |
| Protein: 7.0 gm | Protein: 0.5 gm |
| Carbohydrate: 106.4 gm | Carbohydrate: 7.6 gm |
| Fat: 43.9 gm | Fat: 3.1 gm |
| Phenylalanine: 207 mg | Phenylalanine: 15 mg |
| Leucine: 312 mg | Leucine: 22 mg |

Nutritional analysis based on the products used at the time of analysis. Subject to change.

## Upcoming Events

- Annual open enrollment for Medical Insurance (November 1- December 15, 2022)
- MNT4P LPMF Program: Holiday special - order up to $300! (December 2022 only)
- PKU Awareness Day - December 3, 2022
- MNT4P Annual Enrollment (January 2023)
- Save the date: MCADD Education Summit (February 25, 2023)
- Save the date: Emory Metabolic Camp (June 2023): www.metcamp.net

## Contact Us

Have additional questions or comments? Contact us!

Visit our website: www.mnt4p.org