

Welcome To MNT4P Family Newsletter 2024!

Advancing Newborn Screening and Care Across the Southeast

MNT4P is pleased to announce a significant new initiative funded by the U.S. Health Resources and Services Administration (HRSA). We are leading the development of the **Southeast Integrative Newborn Screening – Long-Term Follow-Up Consortium**, the only nationally funded, multi-state collaboration of its kind. This consortium unites public health departments from Georgia, Florida, Louisiana, and Mississippi alongside partners across the Southeastern Regional Genetics Group (SERGG).



MNT4P remains committed to working collaboratively with families and healthcare providers at every stage of the newborn screening system.

By fostering meaningful involvement and prioritizing patient-centered care, this effort will help build a more effective, equitable system that benefits families across the Southeast and beyond.



Newborn screening improves infant outcomes by providing timely results and is further enhanced by the swift initiation of therapeutic interventions, including medical nutrition therapy in many disorders, based on diagnoses

Rani H Singh, PhD, RDN, LD

Patient -Provider Education Summit

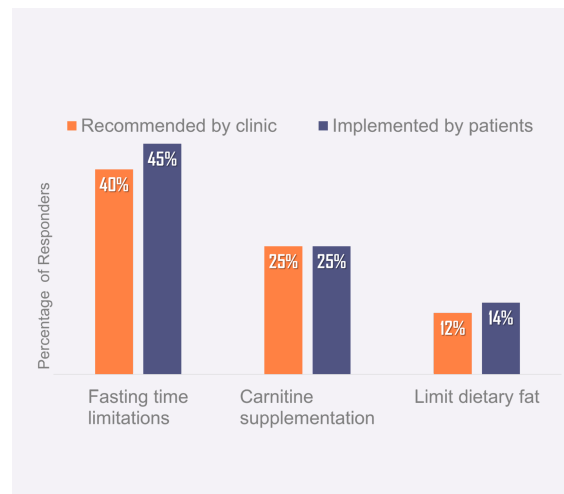
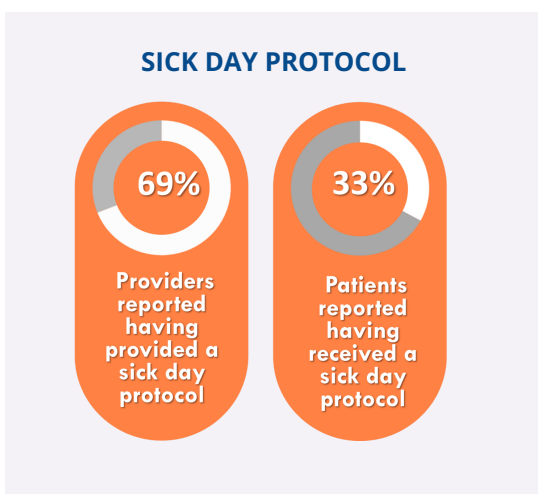
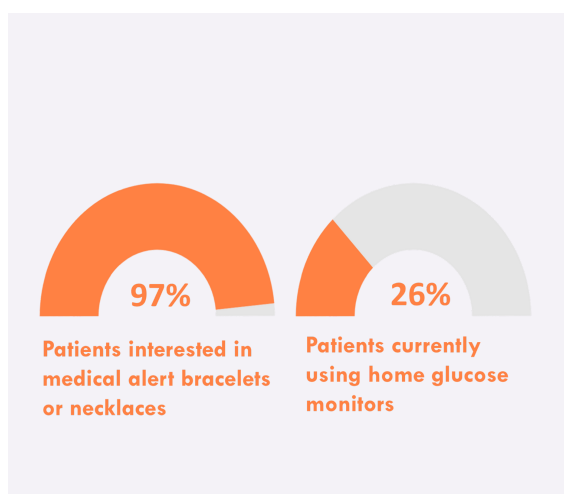
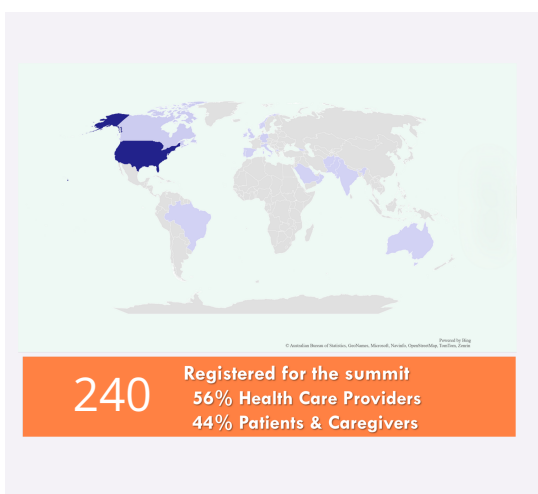
MNT4P prioritizes research, education, and community outreach to better understand the needs of the rare genetic disorders community. A notable example of this commitment is the patient and provider summit on medium-chain acyl-CoA dehydrogenase deficiency (MCADD), hosted by MNT4P in February 2023.

This virtual event gathered patients, caregivers, and healthcare providers from the United States and around the world to share insights and address the unmet needs within the MCADD community through open discussions and evidence-based research findings.

Thanks to the Salley Family for their financial contribution to support this event.

“Great event! Would love to see similar summits for other inborn error of metabolism. Super helpful to learn from fellow providers and patients/families.”

Through registrations, surveys, and polling, we gained insights from patients and providers in the MCADD community.



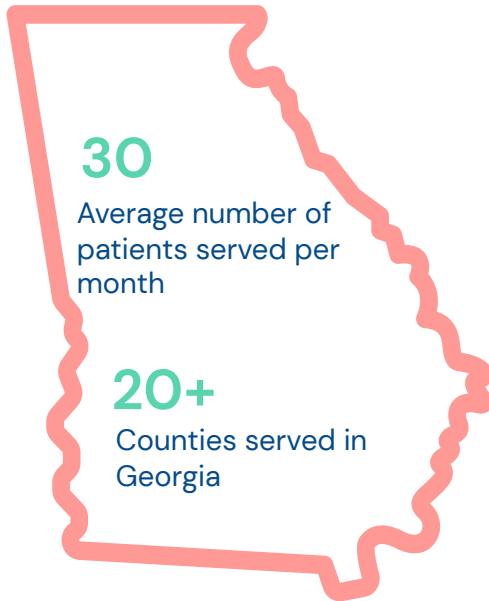
We intend to organize similar events in the near future to advance knowledge in the field of rare genetic disorders. Stay tuned!

MNT4P Partnership with Georgia WIC

Strengthening community outreach

MNT4P has continued its partnership with Georgia's WIC Program since it started. The WIC Program helps low-income women who are pregnant or have recently given birth, as well as infants and children up to five years old who are at risk of poor nutrition.

The MNT4P team, which consists of registered dietitians and program coordinators, ensures that eligible women and children with diagnoses of inherited metabolic disorders have proper access to medically necessary nutrition, including medical foods, through WIC.



To check your eligibility for WIC, go to:
[WIC Eligibility Assessment](#)

MNT4P Services

Referrals

MNT4P helps new patients find WIC clinics and ensures they have the necessary prescriptions. Any updates are noted and followed up on.

Compliance

MNT4P ensures that WIC participants are placing orders every month. If they are not, we will coordinate with providers to ensure compliance.

Instructions

MNT4P offers families handouts or email instructions for ordering monthly supply of medical foods. Shipping information available upon request.

MNT4P Visits

MNT4P offers in-person or telemedicine visits for families needing guidance on medical nutrition management. Language interpreters available as needed.

Meet the MNT4P Family

MNT4P offers the MNT4P visit, where registered metabolic dietitians provide timely disease and nutrition education, including formula mixing, and guidance for families with positive newborn screening results.

Recently, we conducted such MNT4P visit for Murchland Family whose son was screened positive for Ornithine transcarbamylase (OTC) deficiency through NBS program. Here is a summary of their experience with us!

How MNT4P services have impacted your family

MNT4P helped our son get a jump start out of the NICU and he is growing, developing, and exceeding all expectations!

Any lasting improvements since accessing our services from the MNT4P

Our son is home and thriving! He is in the 90th percentile with his weight gain and doing very well!

Any memorable experiences you've had with us

Dr. Singh and Amber were fabulous to work with, and we will take our son back to visit them in the near future!

Thoughts on how we could improve

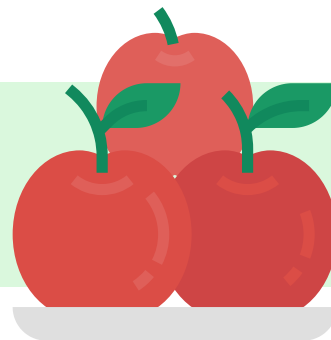
Ryan and I had a great experience with the program, and would recommend to a family like us who needed that extra support!

Kendall Murchland
Mother of an infant with OTC deficiency



Holiday Recipe:

Baked Apples



4 Servings



75 Minutes,
plus cooling

Ingredients

4 large baking apples, like Rome Beauty
2 lemon wedges
3 dried apple rings, cut into bits
4 teaspoons honey
1 tablespoon unsalted butter
1 cup apple cider or juice
Cinnamon, for dusting (optional)
1 cup So Delicious Coconut Milk Ice Cream
Vanilla, for serving

Nutritional Analysis

Metabolic Pro# 73317

<u>Recipe (4 apples):</u>	<u>Per Serving (1 apple):</u>
Calories: 1079 kcal	270 kcal
Protein: 4 gm	1 gm
Carbohydrate: 228 gm	57 gm
Fat: 29 gm	7 gm
Phe: 138 mg	34 mg
Leu: 252 mg	63 mg

Source: Recipe adapted from NewYork Times Cooking;
<https://cooking.nytimes.com/recipes/1020471-baked-apples?smid=ck-recipe-iOS-share>

Preparation

Step 1

Center a rack in the oven and heat to 375F. Line a baking sheet with parchment paper or foil, and set a 9- or 10-inch glass pie dish on top.

Step 2

Cut a small cap off the top of each apple, and set aside. Using a paring knife or corer, core the apples, making sure not to go all the way to the bottom. Cut away and reserve about ½ inch of peel around the tops of the apples. Rub the peeled portions of the apples with the lemon, squeezing a little juice into each opening.

Step 3

Fill each apple with an equal amount of dried apple and ginger, if using, pressing down lightly as needed to push bits into the opening. Pour ½ teaspoon honey over the dried fruit in each apple. Cut the butter into 4 pieces, and top each apple with a pat. Pop the caps back on the apples. (It's O.K. if they teeter). Transfer the apples, lemon wedges and a few of the reserved peels into the pie dish; pour in the cider or juice, and stir in 1 to 2 teaspoons honey. (The honey won't blend evenly into the cider, and that's fine.)

Step 4

Bake the apples, basting occasionally with the cider and honey, until you can poke them with a skewer or the tip of a knife and not meet much resistance, 50 to 70 minutes. Since apples are so variable, check early and often, as you might need more or less time.

Step 5

Let them cool for at least 15 minutes before serving moistened with a little pan sauce, and if you want, top with coconut milk ice cream and dust with cinnamon. The apples are good warm or at room temperature. They'll keep, covered, for 2 days in the refrigerator and can be reheated in a microwave.

Upcoming Events



- **Annual open enrollment for Medical Insurance** (November 1- December 15, 2024)
- **PKU Awareness Day** - December 3, 2024
- **Rare Disease Day** - February 28, 2025
- **MNT4P Annual Enrollment** (January 1, 2025)
Check your email for enrollment links.
- **Emory Metabolic Camp** (June 9-14, 2025):
www.metcamp.net
SERGG Meeting(July 17-19, 2025):
www.sergg.org

Contact Us

Have additional questions or comments? [Contact us!](#)



Department of
Human Genetics

Visit our website:
www.mnt4p.org



"Wishing you joy, peace, and all the festive cheer this holiday season!"