amda
Acid Maltase Deficiency Association

August / 2026

AMDA Newsletter

Protected Together: Your August Immunization Awareness Issue

August brings long days, warm nights, and a few good reminders about staying prepared, connected, and cared for. This issue is full of ways to do just that. Join us for a candid conversation about cruising with Pompe disease at our next Talking With Your Pompe Peeps (TWYPP) session, hear directly from a leading Pompe diagnostics expert on what your test results really mean, and learn how the AMDA's Emergency Medical Information and Alert Card can offer real peace of mind. Wherever your summer is taking you, we're glad you're here with us.

This Month's Highlights

Immunization Awareness Month: What Pompe Families Should Know

August is National Immunization Awareness Month, a good reminder that vaccines matter, and even more so for our community — respiratory muscle weakness in Pompe disease raises the risk of severe illness from flu, RSV, and pneumonia.

This guidance, reviewed by Pompe specialists at Duke, is clear: Stay current on the standard vaccine schedule (flu, pneumococcal, COVID-19, RSV). For infants with infantile-onset Pompe (IOPD), ask about Synagis (palivizumab) during RSV season. **There is an important exception**: People undergoing immune tolerance induction (ITI) should avoid live vaccines during treatment and recovery. Talk to your care team about timing.

Cost concerns? The Vaccines for Children and Vaccines for Adults programs offer no-cost vaccines for uninsured and underinsured families; find options near you at www.vaccines.gov.

Read the Full Article

AMDA Updates

The AMDA Showed Up, Did You?

It was wonderful seeing everyone at the 2026 Duke Pediatric Conference on July 11. Our patient advocate, Marsha Zimmerman, was there representing the AMDA and connecting with families, clinicians, and researchers from across the Pompe community. Events like this are a reminder of how much stronger we are together; they are a chance to build relationships, ask questions, and stay current on the latest in Pompe research. We hope to see even more of you at the next one.

Talking With Your Pompe Peeps (TWYPP) Session 17 — Setting Sail with Pompe Disease

WEBINAR • FRIDAY, AUGUST 14, 2026 • 1 p.m. CT / 2 p.m. ET

Cruising can be one of the most accessible ways to travel with Pompe disease, but a little planning goes a long way. Join us Friday, August 14, at 1 p.m. CT / 2 p.m. ET for our next TWYPP session, where we'll hear a firsthand account of cruising with Pompe, from requesting accommodations before departure to navigating boarding and port excursions, and managing daily energy levels at sea. If you've ever wondered what a cruise could look like with Pompe disease, this conversation is for you.

Note: This discussion is for informational and community support purposes and is not medical advice.

Learn More

Register Today

What Do Your Pompe Test Results Really Mean?

WEBINAR • THURSDAY, AUGUST 20, 2026 • 1 p.m. CT / 2 p.m. ET

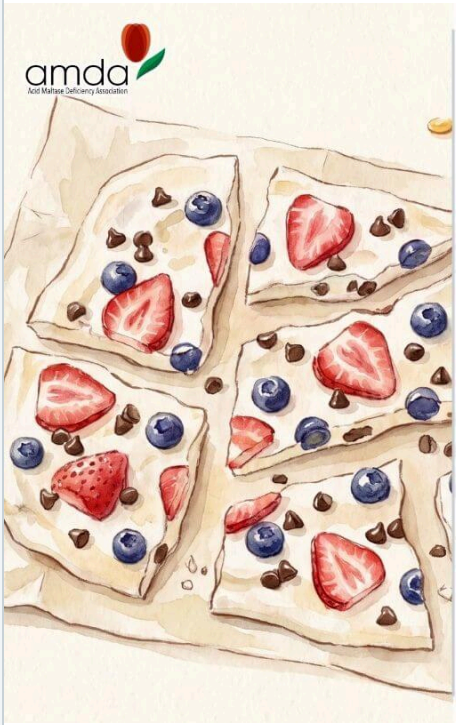
What do your Pompe test results actually tell you? How has that answer changed over time? Join us Thursday, August 20, at 1 p.m. CT / 2 p.m. ET for a webinar with Deeksha Bali, PhD, FACMG, from Duke University, exploring the evolution of Pompe diagnostics from newborn screening to today. We'll look at how CRIM testing, GAA enzyme and mutation analysis, and biomarker testing come together to support early, accurate diagnosis, and what's still needed to close the gaps for newly diagnosed families.

Learn More

Register Today

Pompe Kitchen — Greek Yogurt Berry Bark with Chocolate

Beat the August heat with a no-bake treat that's as easy as it is refreshing. Our latest Pompe kitchen recipe — "Greek Yogurt Berry Bark with Chocolate" — combines creamy yogurt, honey, fresh berries, and a sprinkle of chocolate chips for a frozen snack the whole family can enjoy. It takes 10 minutes to prep, then a few hours in the freezer does the rest. See the full recipe card below.



GREEK YOGURT BERRY BARK WITH CHOCOLATE

Servings: 6-8 | Prep Time: 10 minutes | Freeze Time: 3 hours (or overnight)

Ingredients

- 3 cups plain Greek yogurt
- 1 tsp vanilla
- ⅓ cup honey
- 1 cup sliced strawberries (or berries of choice)
- 1 cup blueberries (or berries of choice)
- ⅓ cup mini chocolate chips
- Extra honey for drizzling (optional)

Instructions

1. Line a baking sheet with parchment paper.
2. Mix Greek yogurt, honey, and vanilla in a bown until smooth.
3. Top with strawberries, blueberries, and chocolate chips.
4. Drizzle with extra honey, if desired.
5. Freeze for at least 3 hours, or overnight, until fully set.
6. Break into pieces and serve.

Tips: Use plain, unsweetened Greek yogurt to keep protein high and added sugar low. Reduce honey to 2-3 tbsp for a lower-sugar version, and swap standard chocolate chips for a dark or sugar-free variety. Add unsweetened nuts or a low-sugar granola for extra crunch and protein.

Community & Events

WORLDFair 2026: A Gathering for the Lysosomal Disease Community

Mark your calendar for the 12th annual WORLDFair 2026 Annual Meeting, bringing together patients, families, health care providers, and researchers from across the lysosomal disease community. The event offers education on lysosomal disease and current treatments, along with a chance to connect with others navigating similar journeys and learn about the latest advancements in research.

Date: September 18, 2026

Time: 9:30 a.m. – 4:00 p.m. CT

Venue: University of Minnesota Landscape Arboretum, 3675 Arboretum Drive, Chaska, MN 55318

Can't attend in person? You can register to join remotely via Zoom. A box lunch will be provided for in-person attendees.

Note: This resource is shared for your information. It is provided by an independent organization and is not affiliated with or endorsed by the AMDA.

Register Now

Understanding Medical Nutrition and Insurance Coverage Challenges

WEBINAR • WEDNESDAY, AUGUST 19, 2026 • 12 p.m. CT / 1 p.m. ET

Medical nutrition, meaning medical foods and formulas, is one of nine policy areas NORD evaluates on its State Report Card, and the nationwide grade currently sits at a C, with no state earning an A. Join the NORD Rare Action Network on Wednesday, August 19, from 1 to 2 p.m. ET for a webinar exploring medical nutrition, the insurance coverage challenges families face, and how NORD is advocating for rare disease patients to receive comprehensive medical nutrition coverage for any condition where medical nutrition is a medically necessary component for effective treatment. Speakers will cover what counts as a "medically necessary nutrition product," the coverage barriers affecting the rare disease community, and how medical nutrition coverage factors into the state report card.

Note: This resource is shared for your information. It is provided by an independent organization and is not affiliated with or endorsed by the AMDA.

Learn More and Register

Muscular Dystrophy Association (MDA) Durable Medical Equipment Grant Program

Durable medical equipment — things like wheelchairs, lifts, and canes — can be costly and difficult to access. The MDA's Durable Medical Equipment Grant Program is working to change that, helping people living with neuromuscular diseases secure funding for equipment that supports greater independence, safety, and mobility at home, school, work, and play. If you or someone you care for has been diagnosed with a neuromuscular disease covered under MDA's program, is a U.S. citizen or legal permanent resident, and is (or becomes) an MDA member, you may be eligible to apply.

Note: This resource is shared for your information. It is provided by an independent organization and is not affiliated with or endorsed by the AMDA.

Learn More

Advocacy & Science

Free Rare Disease Curriculum for Patients, Caregivers, and Providers

Rare diseases affect an estimated 30 million Americans — roughly 1 in 10 people — yet many health care professionals receive little formal training in recognizing and managing them. That gap can mean years of delay before an accurate diagnosis. We wanted to share a resource that's working to close it: the Rare Disease Curriculum from Global Genes. The curriculum is a free, accredited, seven-module course built in collaboration with the Rare Disease Diversity Coalition. It's designed for patients, caregivers, health care professionals, caseworkers, and anyone who wants a deeper understanding of the rare disease landscape, and it's available at no cost.

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Learn More

FDA Launches Rare Connections Newsletter

Staying informed about what's happening at the FDA just got easier. The agency's Rare Disease Innovation Hub has launched Rare Connections, a new quarterly newsletter covering rare disease programs and initiatives, including press releases, guidance documents, approvals, upcoming events, and personal stories from across the FDA. We're grateful to see this kind of regular, direct communication with our community, and we wanted to make sure you knew about it.

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See the First Edition

Observances

Monthly Observances

MedicAlert Awareness Month: For many in our community, preparation is its own quiet form of care. Knowing that if an emergency ever arises, the people helping you have the information they need before you can explain it yourself can be very beneficial. This month is a good moment to make sure that piece is in place. The AMDA's Emergency Medical Information Alert Card was built with exactly that in mind.

National Immunization Awareness Month: Staying current on vaccines is one of the quieter ways our community protects itself, season after season. We covered what that looks like for Pompe disease above; consider this your gentle nudge to check in with your care team if you're due.

Daily Observances

National Book Lovers Day | Aug. 9: A good book can be its own kind of rest, a place to go when energy is limited but curiosity isn't. Today is a small invitation to pick one up.

National Patient Advocacy Day | Aug. 19: Advocacy often looks quieter than people expect: a phone call to an insurer, a story shared at the right moment, a seat at the table nobody thought to save for a rare disease family. Today is a small nod to everyone in our community who has ever spoken up, for themselves, for a loved one, or for all of us.

Eat Outside Day | Aug. 31: There's something restorative about a meal outdoors, even a short one on a porch or a park bench. If the heat allows, take a moment this week to eat somewhere with a little more sky.

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