amda
Acid Maltase Deficiency Association

July / 2026

AMDA Newsletter

Together We Thrive

July is a month that reminds us how much we need each other. In recognition of Social Wellness Month, this issue of the AMDA newsletter is filled with opportunities to connect, learn, and show up for the Pompe community. The newsletter highlights a Talking With Your Pompe Peeps peer session designed for students navigating college life with Pompe disease, the Duke Pediatric Pompe Conference, and a family meet-up weekend that takes care of everything once you walk through the door. We are also proud to share a special reflection from our editor on the 36th anniversary of the Americans with Disabilities Act, a milestone that belongs to all of us. However you choose to engage this month, we are glad you are here.

This Months Highlights

The ADA at 36: What the Law Did, and What Only We Can Do

By Lucas Garrett

36 years after the Americans with Disabilities Act became law, our editor Lucas Garrett reflects on what the legislation accomplished and what it

could never do on its own. Drawing from his own experiences navigating a world still catching up to the ADA's promise, Lucas makes the case that dialogue is what carries us the rest of the way. It is a timely read for Social Wellness Month and beyond.

Read the Article

Talking With Your Pompe Peeps Session 16 — Campus Ready: Two Perspectives on College Life with Pompe Disease

TWYPP • WEDNESDAY, JULY 29, 2026 • 7 p.m. CT / 8 p.m. ET

College is a major transition for anyone. When you are managing enzyme replacement therapy schedules, navigating campus accessibility offices, and learning to advocate for yourself in a new environment, the stakes feel that much higher. The 16th TWYPP session brings together two community members who know that experience firsthand: one preparing to start college, and one who recently graduated. Together they will share what they wish they had known, the questions worth asking before you are on campus, and the practical realities of building a life at college with Pompe disease. After their discussion, they will open the floor to those in attendance.

Date: Wednesday, July 29, 2026 **Time:** 7 p.m. CT / 8 p.m. ET

Moderators: Haley Hayes and Margaret Koehler

Learn More **Register Today**

Duke Hybrid Pediatric Pompe Conference — July 11, 2026

Each year, the Duke Pediatric Pompe Conference brings together families, clinicians, and researchers for a day centered entirely on the Pompe Community. The 2026 conference, hosted by the Duke Pompe Disease Clinical and Research Team and the Pompe Alliance, will be held in person at the Hilton Durham with a virtual option available. No matter where you are, you can be part of the conversation. Whether you are a longtime attendee or joining for the first time, this is one of the most meaningful gatherings in the Pompe community.

Date: Saturday, July 11, 2026

Format: Hybrid — In Person (Hilton Durham) and Virtual

Register Today

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.

AMDA Updates

The Card That Speaks For You

In an emergency, seconds matter, and so does having the right information in the right hands. The AMDA Medical Alert Card puts essential anesthesia and respiratory guidance directly in your wallet, available the moment emergency personnel or hospital staff need it. Each card includes a QR code linking to the AMDA's Emergency Medical Information page, giving care teams immediate access to the most current, evidence-based recommendations for Pompe disease care.

When one of our community members experienced a severe cardiac episode, she did not have to find words for a fast-moving medical team. She reached into her purse and handed them her card.

> *"I simply reached into my purse, handed the Respiratory Care Information Card to the staff, and said, 'Please read this.'"*

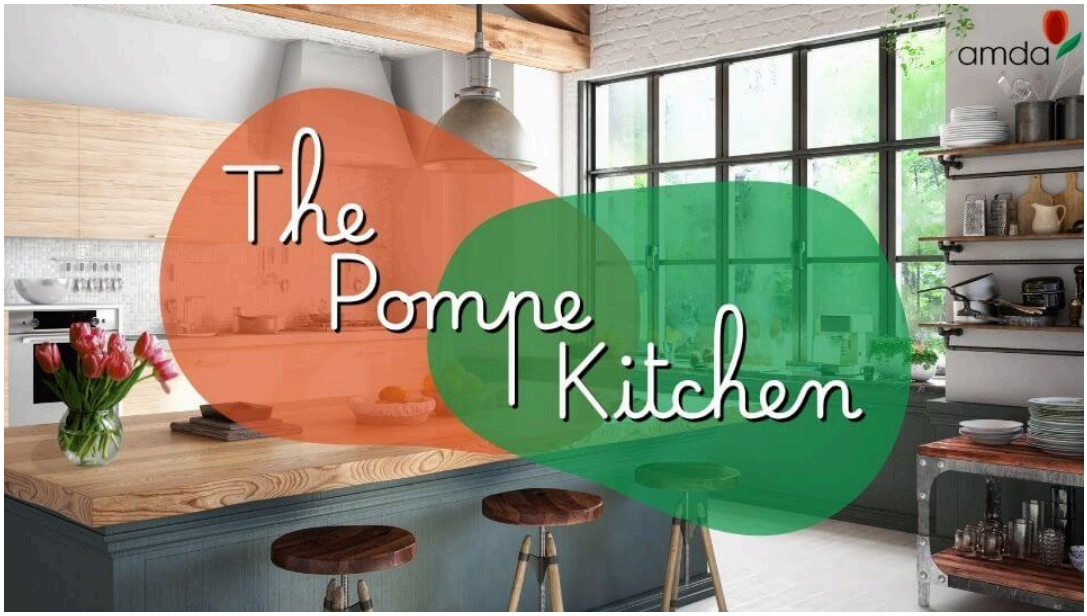
> *— Rebecca Brooks, Pompe community member*

That small card ensured her care team understood the respiratory considerations that come with Pompe disease.

The AMDA Medical Alert Card is free for all Pompe community members in the United States. An international printable version is also available for families outside the U.S.

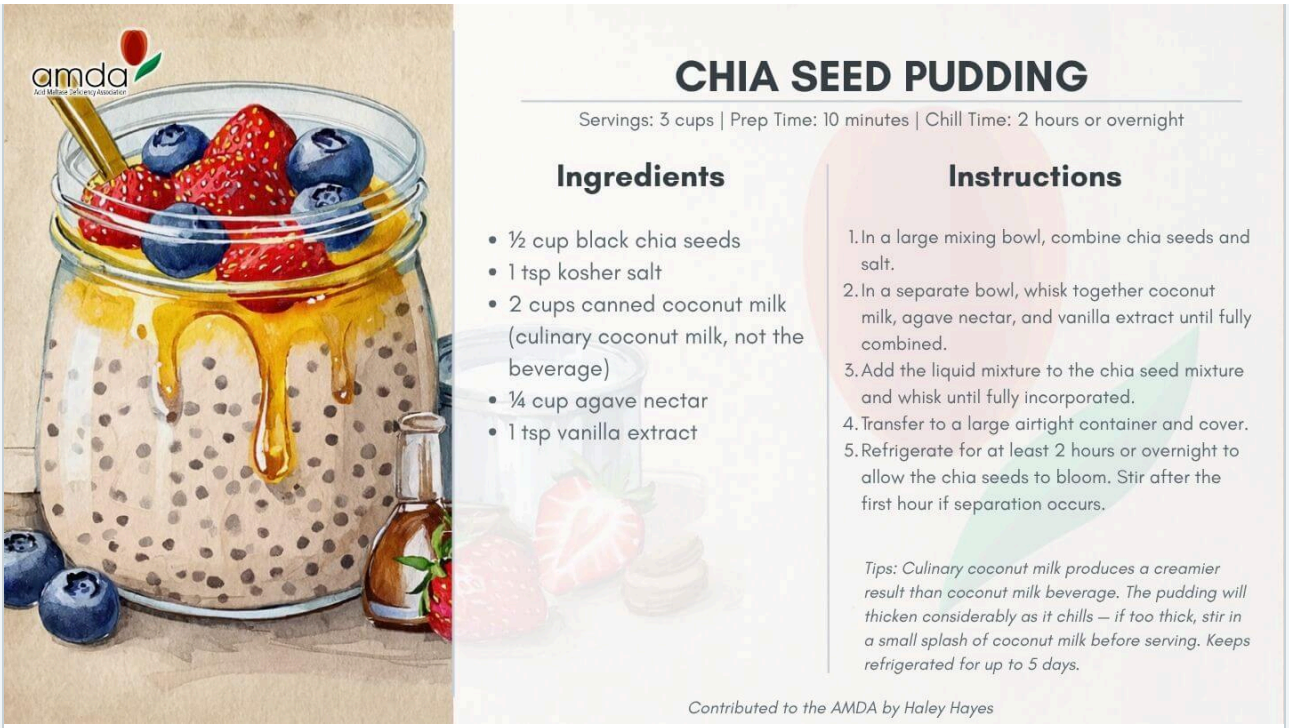
Get Your Card Today!

Read Rebecca's Testimonial



The Pompe Kitchen: Chia Seed Pudding

This month's Pompe Kitchen features a simple, nourishing recipe from community member Haley Hayes. Chia seed pudding is easy to prepare ahead of time, gentle on the body, and endlessly customizable, making it a perfect addition to any routine.



Share Your Recipe with the Pompe Community

The Pompe Kitchen is a space where our community shares what nourishes them, and we want your recipes in it. Whether it is a weeknight staple, a family favorite, or something you adapted to fit your nutritional needs, we would love to feature it in an upcoming issue.

Submissions are open to all Pompe community members. Send your recipe to matt.zimmerman.amda@gmail.com and you may see it featured right here.

Submit Your Recipe

Advocacy & Science

A New Clue About the Brain in Pompe Disease

Researchers at Duke University have identified a blood biomarker called GFAP (Glial Fibrillary Acidic Protein) that may help doctors detect and monitor brain involvement in people with infantile-onset Pompe disease.

Current enzyme replacement therapies have dramatically improved survival for children with Pompe disease, but they do not cross the blood-brain barrier. As children with Pompe disease live longer and healthier lives, evidence of neurological involvement has become increasingly apparent, and the field has been searching for reliable ways to measure it.

The biomarker GFAP is a protein released by specialized support cells in the brain. Elevated levels in the blood can signal injury or stress within the central nervous system. The Duke team found that GFAP levels appear to correlate with signs of brain involvement in Pompe disease, that some patients showed increasing white matter changes on MRI scans over time, and that the biomarker may help identify children at higher risk for developing central nervous system complications.

While this discovery does not change current treatment recommendations — GFAP is not yet a routine clinical test for Pompe disease — it represents an important step forward: toward better understanding brain involvement, identifying patients who may benefit from closer neurological monitoring, and providing a measurable tool for evaluating future brain-targeted therapies once they become available.

Learn More

Community & Events

2026 Newborn Screening Bootcamp — Washington, D.C.

Registration is now open for the 2026 Newborn Screening Bootcamp, a full-day event bringing together advocates, experts, and members of the newborn screening community to learn, discuss, and connect. Cohosted by the EveryLife Foundation for Rare Diseases and Expecting Health, the bootcamp features developments in newborn screening policy, ways advocates can interact with the newborn screening system, and steps to navigate the broader overview of this topic. There will be panels and expert speakers; a reception concludes the day's events.

Date: Wednesday, September 24, 2026

Time: 10 a.m.-4 p.m. ET | Reception: 4 p.m.-5 p.m. ET

Location: Faegre Drinker, 1500 K St NW, Suite 1100, Washington, D.C.

Limited travel stipends are available.

Register Here

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Grant's Giants Pompe Family Meet Up — October 2-4, 2026

Social Wellness Month is a fitting time to share this one. Grant's Giants is hosting its 2026 Pompe Family Meet Up, open to individuals with IOPD and LOPD and their families. The meet-up takes place at Bradford Woods in Martinsville, Indiana. Once you arrive, Grant's Giants takes care of the rest. Lodging, meals, and activities are all provided so you can focus entirely on what the weekend is for: connecting with people who understand.

Travel assistance is available to help families attend.

Date: October 2-4, 2026

Location: Bradford Woods, 5040 State Road 67 N, Martinsville, IN 46151

Register Here

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Celebrating Creativity

RareArtist 2026 — A New Category Is Here

The 2026 RareArtist Contest, powered by the EveryLife Foundation for Rare Diseases, is open for submissions, and this year brings something new. Short-Form Video has been added as a category, joining 2D Art, 3D Art, Digital Art and Photography, Poetry, and Music as ways to share your story and advocate through creativity.

Ten awardees will have their work showcased at Rare Disease Week on Capitol Hill in 2027, receive a cash prize, and more. If you have a story to tell, this is a meaningful way to tell it.

Submissions close July 20, 2026.

Learn More and Enter

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Observances

Monthly Observances

Social Wellness Month: Connection is not a luxury; it is part of what keeps us well. Social Wellness Month is an invitation to be intentional about the relationships that sustain us: the friends who check in, the community members who understand without explanation, the peers who show up on a Zoom call on a Wednesday evening just to share space. For those living with Pompe disease, that kind of connection can be harder to find and all the more valuable when you do. This month, we hope you find a moment to reach toward it.

Disability Pride Month: Every July, Disability Pride Month marks the anniversary of the Americans with Disabilities Act and honors the full, complex lives of people with disabilities. For many in the Pompe community, disability is part of a larger identity shaped by resilience, creativity, advocacy, and an intimate knowledge of what it means to fight for the care you deserve. This month is a reminder that pride and Pompe can share the same breath.

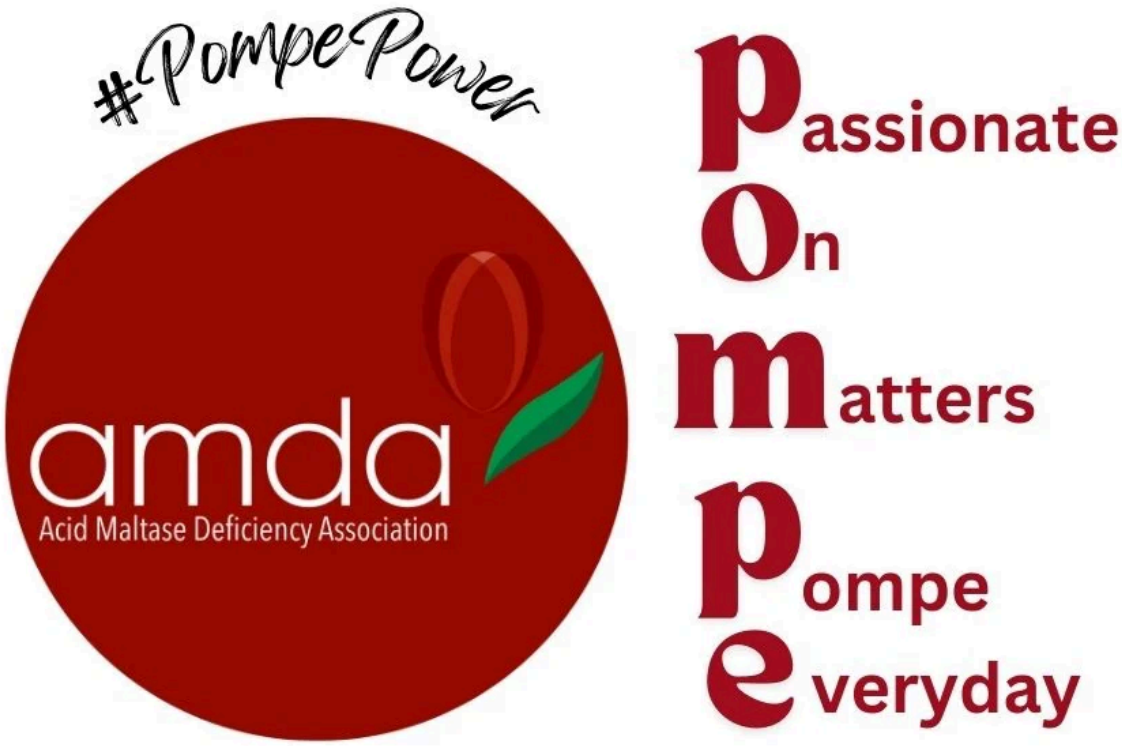
Daily Observances

America's 250th Birthday (Independence Day) | July 4: Two hundred and fifty years is a long time to carry a story. On the 4th of July, communities across the country pause to mark that milestone: with fireworks, with family, with food, and with the particular warmth that comes from gathering together. However you spend the day, we hope it brings you rest, joy, and good company.

National Mac and Cheese Day | July 14: Few dishes carry the kind of comfort that a well-made bowl of macaroni and cheese does. It is the food of celebrations, of hard days, of childhood kitchens, and of the meals that somehow taste better when shared. Today, we give it the appreciation it has always deserved.

Americans with Disabilities Act — 36th Anniversary | July 26: Thirty-six years ago, the Americans with Disabilities Act (ADA) became law and the world changed. Access, inclusion, and the right to full participation in public life became not just ideals but legal guarantees. For the rare disease community, the ADA's promise is personal. There is still work to do, and there always will be. But today, we mark how far that work has already carried us.

National Challenged Champions and Heroes Awareness Day | July 29: Some of the most remarkable people in our community never sought recognition. They simply kept going. Today is set aside to acknowledge those who face extraordinary challenges with quiet strength, and the people who stand alongside them. We are surrounded by both types of folks in the Pompe community. On this day, we honor them.



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AMDA

PO Box 700248, San Antonio
TX 78270 United States