January / 2026

AMDA Newsletter

New Year Letter from the AMDA

As we begin a new year, we want to share a message from the AMDA to our community.

Welcoming a New Year of Hope and Progress

As the calendar turns to a new year, the AMDA looks ahead with gratitude and optimism. The Pompe community continues to inspire us with its strength, compassion, and unwavering determination to make a difference — for today and for the future.

A new year brings new possibilities: advancing research, expanding newborn screening, improving access to care, and building stronger connections across the globe. Through ongoing initiatives like the Helen Walker Research Grant and our commitment to education and advocacy, we move forward together — united by hope and purpose.

May this year bring renewed energy, meaningful progress, and moments of joy to everyone touched by Pompe disease.

WITH APPRECIATION AND HOPE — HAPPY NEW YEAR FROM ALL OF US AT THE AMDA!

Make Space for What Refuels You

Hobbies can be more than a pastime. They can offer calm, connection, and a sense of progress, especially when life includes ongoing care. This month, we're focusing on starting the year strong with a fresh perspective and new AMDA resources.

Inside this issue: Webinar: Grief Happens in Rare Disease, TWYPP Infusion Day Playbook, organizing tools, and updates from the AMDA.

A Fresh Start for the Year Ahead

January can come with pressure to make big changes fast. But life does not always follow a tidy calendar, and progress often comes in waves. This month, we're thinking of a "fresh start" as something gentler: a chance to pause, breathe, and begin again in whatever way feels right.

A reset might look like a small shift in routine, a renewed commitment to self-compassion, or a fresh conversation with your care team. And for caregivers and care partners, a reset counts too. Your well-being is not an afterthought. It's part of what helps everything else hold together.

Featured Story

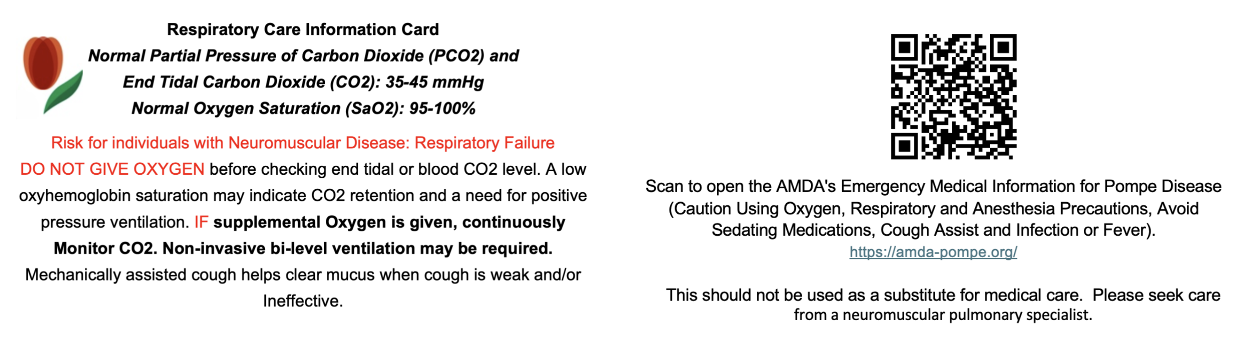
New Year's Resolutions and Hobbies

Are New Year's resolutions already starting to feel heavy? Lucas, the AMDA's community contributor, explores why we put so much pressure on ourselves and why breaking a resolution can spiral into guilt. His gentler reset is simple: pivot to a hobby, and if it does not bring you joy, you can stop without feeling bad about it. He also points to research linking hobby engagement with mental health and well-being

Read the full article

AMDA Updates

Medical Alert Card Now Available



Respiratory Care Information Card
Normal Partial Pressure of Carbon Dioxide (PCO2) and
End Tidal Carbon Dioxide (CO2): 35-45 mmHg
Normal Oxygen Saturation (SaO2): 95-100%

Risk for individuals with Neuromuscular Disease: Respiratory Failure
DO NOT GIVE OXYGEN before checking end tidal or blood CO2 level. A low oxyhemoglobin saturation may indicate CO2 retention and a need for positive pressure ventilation. IF **supplemental Oxygen is given, continuously Monitor CO2. Non-invasive bi-level ventilation may be required.** Mechanically assisted cough helps clear mucus when cough is weak and/or Ineffective.

Scan to open the AMDA's Emergency Medical Information for Pompe Disease (Caution Using Oxygen, Respiratory and Anesthesia Precautions, Avoid Sedating Medications, Cough Assist and Infection or Fever).
https://amda-pompe.org/

This should not be used as a substitute for medical care. Please seek care from a neuromuscular pulmonary specialist.

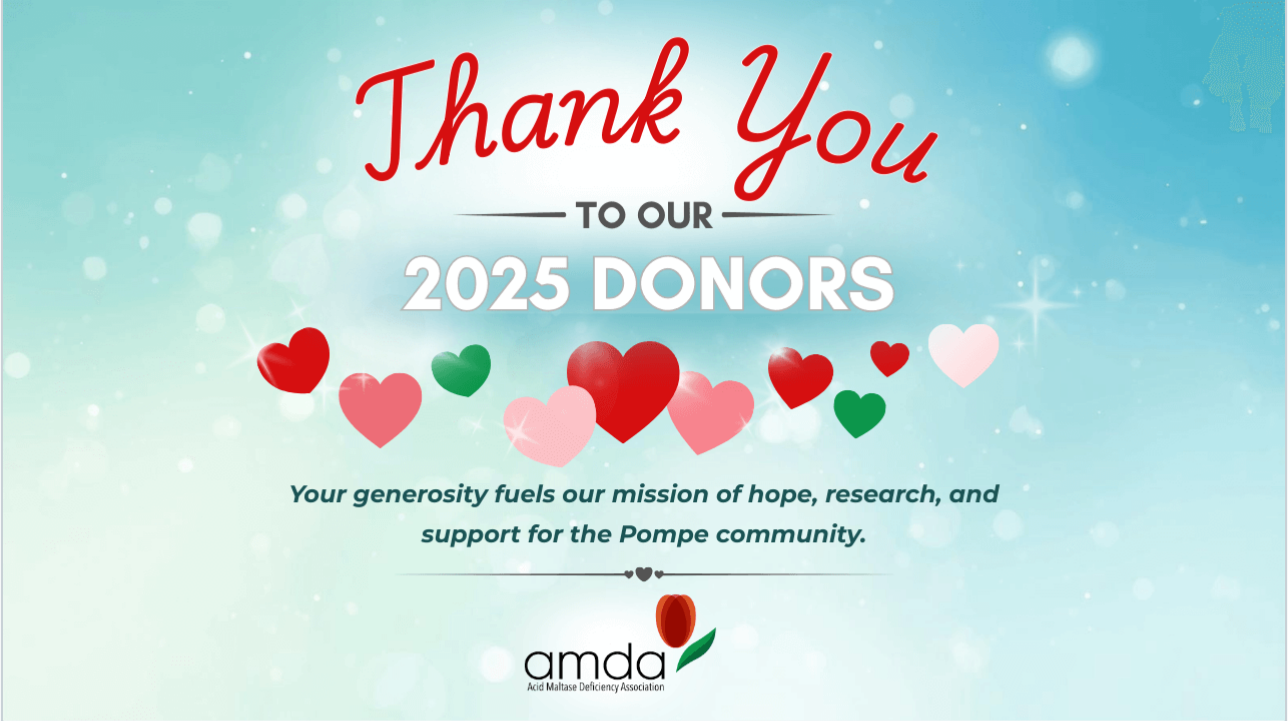
The AMDA's Medical Alert Card is now available on our website. This resource is designed to help people living with Pompe disease share key safety considerations quickly in urgent situations and during medical care.

Get the Medical Alert Card

New Resource: New Year, New Routines: Organizing Your Pompe Care Plan

A new year often brings a "fresh start" mindset, and one small step can make a big difference: having your medical information organized and easy to access. The AMDA has prepared a simple, practical resource to help you gather key details in one place, so you feel more prepared for appointments, travel, emergencies, and day-to-day care.

Organize your medical information



As we look ahead, we also want to pause and say thank you. Your generosity helps the AMDA fund research, expand education, and support the Pompe community throughout the year.

Thank you to our 2025 donors

Community & Events

2026
AMDA
WEBINAR

GRIEF HAPPENS IN RARE DISEASE: LET'S TALK ABOUT IT ALREADY

WITH
LISA KEEFAUVER, MSW

THURSDAY
JAN 15, 2026
1 PM CT /
2 PM ET

WWW.AMDA-POMPE.ORG

REGISTER NOW

Upcoming Webinar: Grief Happens in Rare Disease: Let's Talk About It Already

Date: Thursday, January 15, 2026 • 1 PM CST / 2 PM EST

Speaker: Lisa Keefauver, MSW

Grief touches all of us, and in rare disease communities it can show up in layered and unexpected ways, including the losses that don't always get named. Join us Thursday, January 15, 2026 at 1 PM CST / 2 PM EST for our first webinar of 2026! In this webinar, Lisa Keefauver will draw on both professional experience and personal insight to help us build "grief literacy" and better understand how grief impacts our bodies, relationships, work, and daily life.

With a mix of metaphor, science, storytelling, and humor, Lisa will offer a more expansive framework for grief, along with practical ways to reduce the unnecessary suffering that can come from a grief-illiterate culture. Lisa is a narrative therapy–trained social worker, grief advocate, and the author of Grief Is a Sneaky Bitch: An Uncensored Guide to Navigating Loss.

Learn more and register

Talking With Your Pompe Peeps Session 10: Infusion Day Playbook: Stories, Tips, and Support

Date: Thursday, January 29, 2026 • 7 PM CST / 8 PM EST

Moderator: Alison Breitbarth (Grant’s Giants)

Infusions can feel overwhelming at first, and then, over time, they become part of life. In this Talking With Your Pompe Peeps session, Alison Breitbarth, President and Co-founder of Grant's Giants, will help us talk openly about what it can look like to normalize infusion day for kids and families, while keeping the conversation welcoming for anyone navigating infusions at any age.

We’ll swap first-infusion stories, share what helped (and what we wish we’d known), and trade practical tips for making the day smoother, from comfort items and routines to mindset shifts that build confidence. Alison will also share ideas behind her Infusion Play Kit, designed to bring playfulness into a day that can otherwise feel stressful.

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

Recording notice: *This session will be recorded for internal review and possible educational use. If we share a recording publicly (including YouTube), we will post an edited version focused on general information and community tips, and we will remove participant personal stories and identifying details when possible. If you prefer not to be recorded, you're welcome to keep your camera off, change your display name, and/or participate via chat. If you have concerns, please contact us in advance.*

Learn more and register

Save The Date

Mark your calendar for these upcoming events:

- Rare Disease Day: February 28, 2026. A global day to raise awareness and build support for the millions of people living with rare diseases, including Pompe disease.
- International Pompe Day: April 15, 2026. A day to unite the global Pompe community, share stories, and highlight the progress and needs of those affected by Pompe disease.
- Pull for Pompe Fundraiser: May 2, 2026, in San Antonio, Texas. Join us for our annual fundraiser to support research, education, and community initiatives.

Observances

Monthly Observances

National Hobby Month: Hobbies can be more than a pastime. They can offer calm, connection, and a sense of progress, especially when life is busy or unpredictable. Adaptable hobbies can support mental well-being, provide a creative outlet, and fit different energy levels and abilities

Daily Observances

National Hat Day | Jan. 15: Whether it’s a beanie, a baseball cap, a floppy sun hat, or something delightfully over the top, hats can be pure fun. Today is a playful reminder that self-expression matters. Even a small pop of personality can brighten a day.

National Compliment Day | Jan. 24: Encouragement goes a long way, and it doesn’t have to be complicated. A sincere compliment can strengthen connection, reduce isolation, and remind someone they are seen. It’s a small gesture that can linger in the best way.

National Hot Chocolate Day | Jan. 31: Consider this your official excuse to lean into cozy. Hot chocolate is a small celebration in a mug, topped with marshmallows, whipped cream, cinnamon, or whatever makes you smile. Sometimes comfort is as simple as something warm in your hands.

As we start a new year, we’re grateful for everyone who helps make this work possible. Your support fuels research progress, education, and practical resources for people living with Pompe disease and their families.

Support the AMDA

#PompePower

amda
Acid Maltase Deficiency Association

passionate
On
matters
pompe
everyday

https://amda-pompe.org

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The content provided in this newsletter is for informational purposes only and does not constitute an endorsement by the AMDA, unless explicitly stated.

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