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December 2025

AMDA Newsletter

Reflecting, Resting, and Rekindling Hope Together

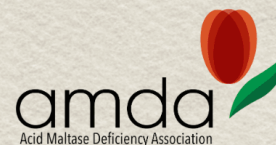
A Christmas Message From the AMDA:

As the year draws to a close, the Pompe community reminds us of the true meaning of courage and connection. Every shared story, act of advocacy, and word of encouragement reflects the quiet strength that unites us, even across distance and time.

This season, we pause to remember those who are no longer with us. As we light candles, hang ornaments, or gather with loved ones, we carry their memories forward, honoring them not with silence but through continued purpose, compassion, and kindness.

May we find gratitude in the simple moments that give life meaning — a shared laugh, a kind message, a day of comfort. With hope for better treatments and, one day, a cure, the AMDA remains steadfast in its mission to serve the Pompe community with care and dedication.

From all of us at the AMDA,
Merry Christmas and Happy Holidays.



Artwork: watercolors
created for the AMDA by
Annic Kolbrück.
www.annickolbrueck.de

Featured Story

Burnout, Creativity, and Rest

By Lucas Garrett, AMDA Editor & Community Contributor

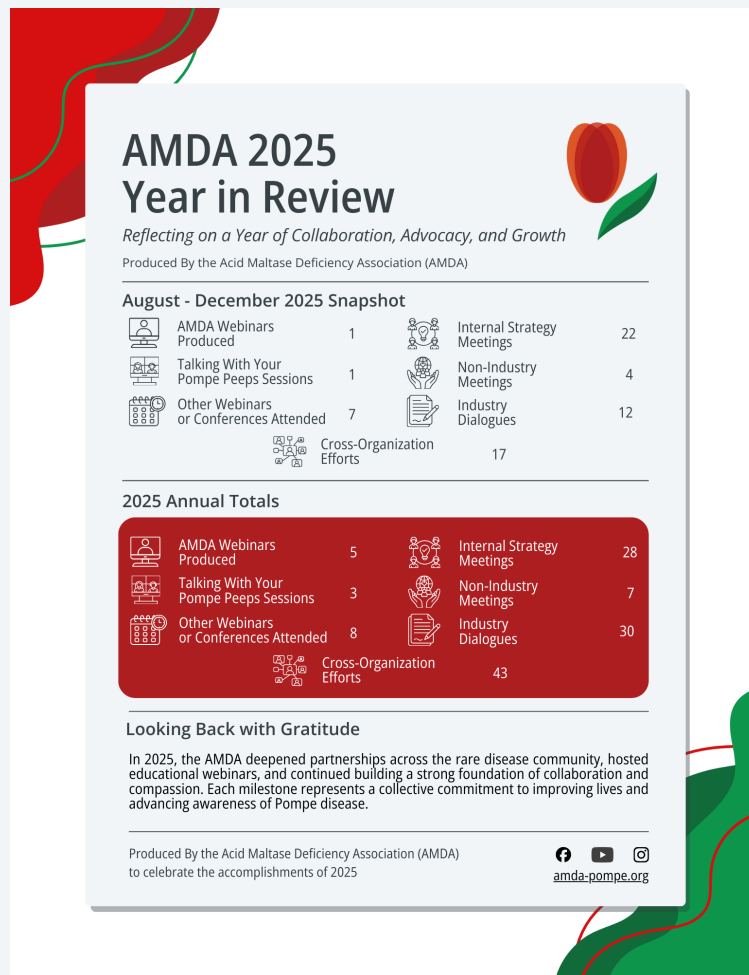
In this month's featured story, AMDA's new editor and community contributor Lucas Garrett — a musician, writer, and lifelong member of the Pompe community — explores the importance of rest as a source of creativity and healing.

His piece, "Burnout, Creativity, and Rest," reflects on how pausing to recharge can help restore balance and renew perspective, reminding us that self-care is both an act of strength and a foundation for creativity.

Read the full article

AMDA Updates

2025 Year in Review



In spite of the tragic loss of our president Tiffany House this year was one of steady growth, resilience, and collaboration for the AMDA. Tiffany's leadership and compassion continue to guide our work, reminding us that every effort in advocacy, education, and connection carries her legacy forward.

Throughout 2025, the AMDA strengthened partnerships across the global Pompe community by producing new webinars, participating in international conferences, and engaging with clinicians, researchers, and advocacy organizations. These collaborations ensured that the patient

perspective remained central to ongoing discussions about care, treatment, and research.

This year also reflected a renewed sense of unity. From community forums to multiorganization initiatives, each partnership represented a shared determination to inform, empower, and uplift the Pompe community. The progress achieved through these efforts will continue to build a stronger foundation for years to come.

[Download the full 2025 Summary Report](#)



Clinician Education Program

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New CME Course: Patient-Centered Care in
Late-Onset Pompe Disease

Join experts Drs. Tahseen Mozaffar, Benedikt Schoser, and Natalie Goedecker, DNP, CPNP, for insights on recognizing late-onset Pompe disease (LOPD). Learn how to apply biomarkers and genetic testing for earlier diagnosis and initiate treatment strategies that improve long-term outcomes.

[Watch Now & Earn CME](#)



Rare Disease Day 2026 — “More Than You Can Imagine”

The National Organization for Rare Disorders (NORD) has announced the 2026 Rare Disease Day theme: *More Than You Can Imagine*.

The AMDA is proud to join the Global Chain of Lights campaign, working to illuminate landmarks across Los Angeles, San Antonio, and Austin on February 28, 2026.

We invite you to help spread the light by reaching out to local landmarks, sharing your story, and participating in a global movement that shines hope worldwide.

[Learn More](#)

Advocacy & Science



Sanofi Global Rare Impact Awards

At Sanofi's inaugural *Global Rare Impact Awards* in Vienna, three exceptional leaders were recognized for their lifelong dedication to rare disease advocacy, including two from the Pompe community:

Tiffany House, the AMDA's late president, was celebrated as a visionary leader in patient advocacy whose compassion and dedication set a lasting example for collaborative leadership.

Maryze Schoneveld van der Linde, of the International Pompe Association, was honored for her tireless commitment to improving access to care and strengthening rare disease networks across developing countries.



Their compassion, advocacy, and leadership continue to inspire progress across the Pompe community and beyond.

Tiffany's recognition at this global event serves as a meaningful tribute to her legacy and a reminder of the lasting impact she made on behalf of all those living with Pompe disease.

[Read More](#)



Tiffany House Named a 2025 RareVoice Awards Finalist

The EveryLife Foundation for Rare Diseases has named Tiffany House among the 2025 *RareVoice Awards* finalists, recognizing advocates who amplify the rare disease voice in state and federal policy.

Awardees will be announced during Rare Disease Week on Capitol Hill, February 24–26, 2026.

Tiffany's nomination is a reflection of a lifetime of advocacy, especially for newborn screening (NBS) and Texas. Tiffany played a key role in the Texas NBS House Bill 2478: on August 18, 2025, Texas DSHS (finally) launched newborn screening for Pompe, MPS I, MPS II, and Krabbe. To read more about Tiffany's NBS advocacy, check out these links

- [Texas Adds Pompe Disease to Newborn Screening Panel — A Historic Milestone Coinciding with the AMDA's 30th Anniversary](#)
- [Closing the Gaps: Pompe Disease Newborn Screening and the Importance of RUSP Alignment](#)

[Learn More](#)

National Influenza Vaccination Week — Protecting the Pompe Community

For people living with Pompe disease, respiratory health is always a priority. Because Pompe disease weakens the muscles that help with breathing, even a mild case of the flu can lead to serious complications. Annual influenza vaccination remains one of the most effective ways to prevent severe illness and protect the Pompe community.

Why it matters:

- Weakened respiratory muscles increase the risk of severe flu complications.
- Studies show flu vaccination reduces ICU admissions by up to 82% and lowers flu-related deaths.
- Annual vaccination helps maintain immunity as new flu strains emerge each season.
- The International Pompe Association advises scheduling flu shots around enzyme replacement therapy (*Myozyme® infusions*) to optimize timing.
- Getting vaccinated helps protect not only individuals with Pompe disease, but also caregivers and family members.

Learn more:

- [International Pompe Association — Influenza Vaccinations and Pompe Disease](#)
- [CDC — Benefits of Flu Vaccines](#)

Community & Events



Duke Pompe Patient Meetings 2026 — Save the Date

The Duke Pompe Disease Clinical & Research Program and Pompe Alliance have announced the dates for their upcoming 2026 Pompe Patient Meetings:

- Adult Conference: March 28, 2026 (Virtual)
- Pediatric Conference: July 11, 2026 (Hybrid)

Both events will bring together families, clinicians, and researchers to share updates and insights for the Pompe community.

Agenda and registration details coming soon.

Celebrating Creativity

Be Well — Comfort Meets Care



Finding comfort during infusion days can make a world of difference. Orchid, daughter of Juls Williams, AMDA Liaison, recently received a *Be Well Arm IV hoodie* designed with discreet zip-access sleeves for infusion sites.

The thicker, softer fabric offers warmth without interfering with treatment, making long infusion days a little easier.

[Learn More](#)

The AMDA does not receive any compensation for sharing this product. We simply want to highlight a thoughtful resource that may benefit our community.

Observances



Monthly Observances

[National Volunteer Month](#): December recognizes the generosity of volunteers who give their time and heart to make a difference. Whether supporting a local rare disease organization, joining awareness campaigns, or helping illuminate landmarks for Rare Disease Day 2026, every effort matters. Share how you're giving back this month using #NationalVolunteerMonth.

Daily Observances

[Candle Day](#) | [December 3](#): Candle Day reminds us that even a single light can dispel darkness. Take a quiet moment to light a candle for someone who inspires you or to honor loved ones within the Pompe community.

[National Influenza Vaccination Week](#) | [December 6-12](#): This week spotlights the importance of flu prevention and respiratory health — especially for individuals with Pompe disease. Schedule your annual flu shot, encourage others to protect themselves, and share why vaccination matters to you.

[Make Good Today Day](#) | [December 14](#): Make Good Today Day is a reminder to turn good intentions into positive action. Do one thoughtful thing — help a friend, reach out to a neighbor, or share encouragement with the Pompe community.

[Look on the Bright Side Day](#) | [December 21](#): Falling near the winter solstice, this observance invites us to focus on light and gratitude. Reflect on the bright spots of your year and share one that brought hope or joy.

[Make Up Your Mind Day](#) | [December 31](#): As we reach the final day of the year, Make Up Your Mind Day encourages us to look ahead with purpose.

Decide how you'll continue to support the Pompe community, advocate for awareness, or care for yourself in the year ahead.

As we reflect on 2025, the AMDA recognizes the many moments, large and small, that shaped our shared journey. From community discussions and educational events to advocacy and collaboration, each effort strengthened the Pompe community and reinforced the value of connection.

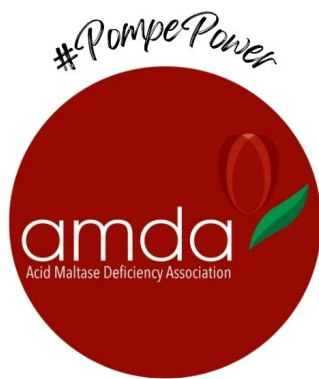
This has been a year of progress and perseverance, built through compassion and shared purpose. The AMDA extends heartfelt gratitude to everyone who contributed their time, energy, and creativity to advance our mission.

Your involvement and trust have made a lasting impact. Together, we continue to build the foundation for a brighter future for all those affected by Pompe disease.

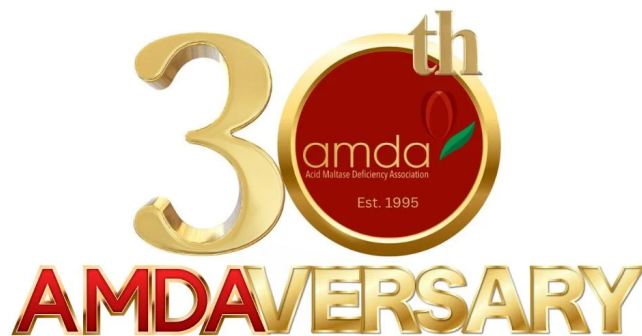
With appreciation and gratitude,
The AMDA Team

We look forward to welcoming 2026 with you, continuing our shared journey of learning, advocacy, and hope.





passionate
On
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