



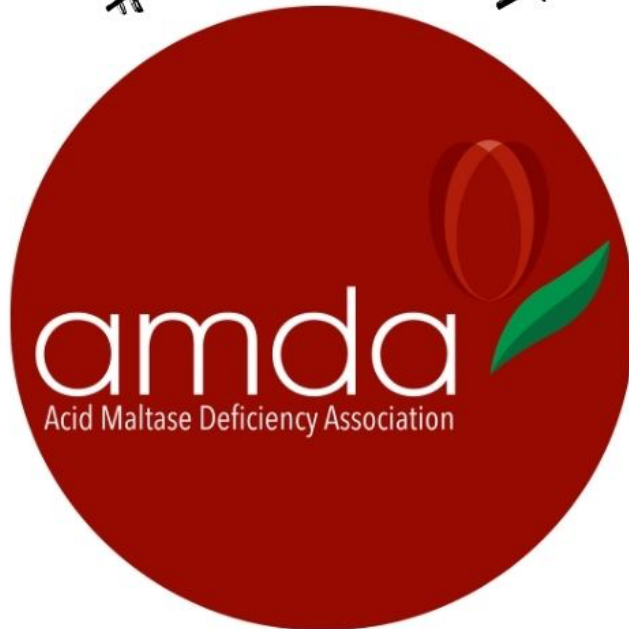
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AMDAVERSARY

March 2025

AMDA Newsletter

Upcoming Webinar

The Pompe Survey: Past Insights and Future Goals

Join us, **Tuesday, March 25, 2025** at **11 AM CT / 12 PM ET** for an update on the IPA/Erasmus MC Pompe Survey presented by **Lauren Dobischok** and **Michelle Kruijsaar** from Erasmus Medical Center, in Rotterdam, the Netherlands. With second-generation ERT entering the market and other novel therapies on the horizon, insights from patients' perspectives are more relevant than ever.

In this webinar, you will learn about the history of the Pompe Survey, key findings from the survey, and the continued importance of patient participation in achieving future goals. There will be a Q&A session following the presentation.

Register Now!

Webinar Details

Title: The Pompe Survey: Past Insights and Future Goals

Date: Tuesday, March 25, 2025

Time: 11 AM CT / 12 PM ET

Speakers:

Lauren Dobischok, MSc

Michelle Kruijsaar, PhD

Webinar Overview:

Launched in 2002, the IPA/Erasmus MC Pompe Survey collects information on the impacts of Pompe disease on patients' lives, and how these impacts may change with treatment. Pompe patients from around the world provide this information through an annual questionnaire. The information collected in the Pompe Survey provides insights on the effect of different treatments and particular issues that Pompe patients may face in daily life. With second-generation ERT entering the market and other novel therapies on the horizon, insights from patients'

perspectives are more relevant than ever. Learn about the history of the Pompe Survey, key findings from the survey, and the continued importance of patient participation in achieving future goals in this webinar.

Speaker Biography

Lauren Dobischok, MSc

Lauren Dobischok is the coordinator of the Pompe Survey at Erasmus Medical Center in Rotterdam, the Netherlands. She received her BSc in Health Sciences with a concentration in Population and Quantitative Health from Simon Fraser University in 2020 and her MSc in Epidemiology from the Netherlands Institute for Health Sciences in 2022. Lauren works closely with representatives from Pompe patient organizations around the world to maintain and expand the Pompe Survey, with the aim of creating an international network of patients whose perspectives inform future research. She is passionate about community-engaged research and hopes to connect and empower people living with Pompe disease through their participation in the survey.



Speaker Biography

Michelle Kruijshaar, PhD

Michelle Kruijshaar is a senior scientist (epidemiologist) at Erasmus MC, Rotterdam. In 2012 she joined the center for Lysosomal and Metabolic Disorders (CLMD), where her



work has focused on investigating the effects of enzyme replacement therapy, in patients with Pompe disease. Two key cohort studies at Erasmus MC are the basis for this work: the Dutch Pompe registry and the International Pompe Survey.

Michelle studied medical biology in Amsterdam and has a master's degree in epidemiology from the Netherlands Institute for Health Sciences in Rotterdam. In 2004 she obtained a PhD for her research on summary measures of population health from the department of Public Health of the Erasmus MC.

SAVE THE DATE!!!

Grant's Giants' 2025 Pompe Family Meet Up

[Grant's Giants](#) is hosting their Third Annual Pompe Family Meet Up on October 10-12, 2025. If you or your kiddo

have Pompe disease and want to spend a weekend of fun and community building at Camp Pyoca, located on Lake Pyoca and the beautiful hills of southern Indiana. Email grantsgiants@gmail.com for more information.

***Note: As space is limited, priority will be given to pediatric Pompe families.**

2025 POMPE FAMILY MEET UP

Pediatric Pompe patients (IOPD & LOPD) and their families are invited to join us for a weekend of fun and community building



Location:
Camp Pyoca
886 E County Rd. 100 S
Brownstown, IN 47220

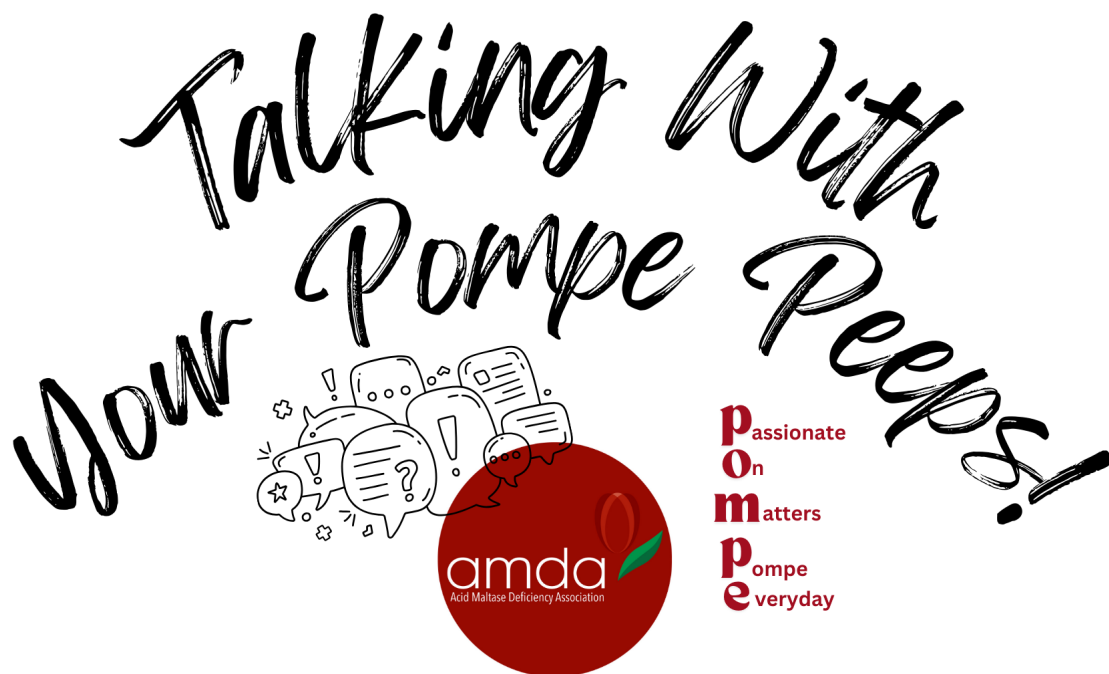
**OCTOBER
10-12**



VENUE IS WHEELCHAIR ACCESSIBLE

2025 AMDA Quarterly Review:

- AMDA Hosted Webinars: 3
 - Other Webinars Attended: 1
 - *Talking With Your Pompe Peeps Series* Sessions: 2
 - Non-Industry Meetings: 1
 - Meetings with Industry: 8
 - AMDA Meetings: 4
 - Panels/Working Groups Collaboration: 17
-



Join Us For Our *Talking With Your Pompe Peeps Series*—Because We Are Stronger Together!

At the AMDA, we know that living with Pompe disease comes with challenges—but we also know that no one has to face them alone. Our community is built on shared experiences, support, and the strength we draw from one another. That's why we launched the *Talking With Your Pompe Peeps Series*—a space where we can connect, learn, and grow together.

This series is more than just a conversation—it's about **building a stronger Pompe community**. It's about sharing our victories, discussing our struggles, and lifting each other up. But for this to work, **we need YOU!** Your voice, your perspective, and your experience matter.

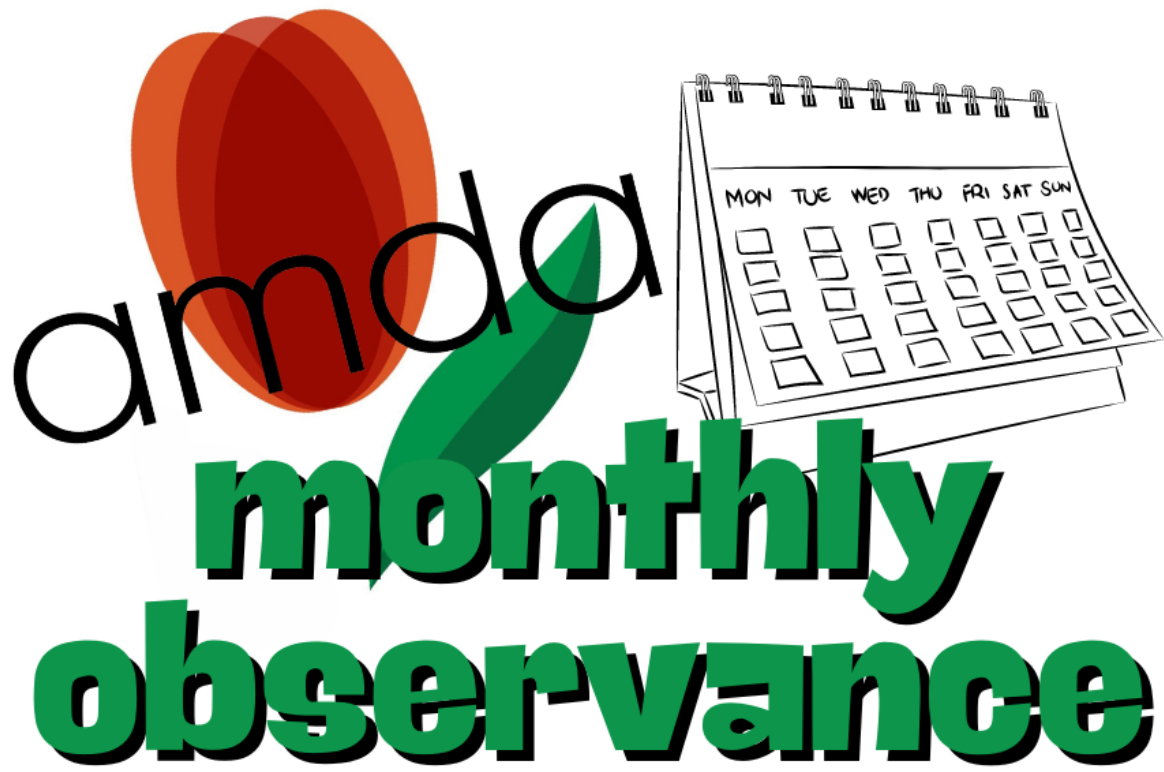
How can you get involved?

- **Join the discussion**—Attend as many sessions as possible to get the most out of this initiative!
- **Suggest topics**—What do you want to talk about? Traveling tips? Daily life hacks? Mental health? Let us know!
- **Volunteer as a moderator**—Help guide conversations and make sure everyone feels heard.

And here's a little incentive: The person who attends the most sessions will win a **special prize**—but you'll have to stay tuned to find out what it is!

Let's make something truly impactful. Join us in strengthening the Pompe community, one conversation at a time.

Send your suggestions for topics or let us know your interest in moderating a session by emailing: info@amda-pompe.org.



March Observances



Monthly Observances

Listening Awareness Month: Despite being a crucial communication tool, it is often undervalued. Truly hearing and understanding what others convey can enhance the quality of your relationships and boost your effectiveness in the workplace. Therefore, listening is undeniably a vital skill to develop. Listening is more than just a soft skill—it's a powerful tool. We, at the AMDA, hear you: If you are interested in talking to someone or if you are struggling, please contact us at support@amda-pompe.org; we have an awesome Patient Advocate, other patients, or family members who are ready and willing to listen and talk to you— you don't have to feel alone! Listen to our experts and other patients in a variety of past [Webinars](#), [Talking With Your Pompe Peeps Series sessions](#), and [YouTube videos](#).

National Nutrition Month: Our overall health relies on a delicate balance of diet, exercise, rest, and hereditary factors. While heredity is beyond our control, we have the power to influence the other three. Among these, nutrition plays a pivotal role in determining our well-being. In today's world, we are constantly exposed to a multitude of diet programs promising

improved health and weight management, which can make navigating these options overwhelming. Nevertheless, research consistently supports that a nutritious diet includes fruits, vegetables, whole grains, lean meats, and proteins; serve smaller portion sizes, eat smarter snacks, or try a meal kit program. Consult your provider and/or fitness trainer for guidance and check out these resources:

- <https://www.myplate.gov/>
- <https://www.myplate.gov/resour...>

National Physicians Week (Mar. 25 - 31): During National Physicians Week, we have the perfect opportunity to express our deep gratitude and appreciation for doctors who dedicate themselves to our well-being. Let's show them the recognition they truly deserve! Physician appreciation is also symbolized by a red carnation, so be sure to bring one to your favorite doc during this week!

Daily Observances

National Write Down Your Story Day, March

14th: Everyone has a story! Your courage, resilience, and openness in sharing your stories make a world of difference—it highlights the importance of mutual support and sharing experiences to reduce feelings of isolation. Stories are a reminder that **YOUR** voices matter and empowers you and others with similar stories to advocate for your needs. If you are interested in sharing yours or to update yours already on our website, please contact us at info@amda-pompe.org. Refer to our website for inspiration:

- [Patients - AMDA Pompe](#)

National Awkward Moments Day, March 18th: This is the perfect occasion to embrace all those cringe, quirky, and hilariously uncomfortable moments we all encounter. It's a day to celebrate the charm in awkwardness and remind us that nobody's perfect—and that's okay! From accidentally waving back at someone who wasn't greeting you to enduring an overly long handshake, these moments connect us as humans. On this day, let's laugh at the awkwardness, let go of embarrassment, and maybe even share some funny stories. After all, life's imperfections often make for the best memories! Share your moments with us and our community on our socials!

National Virtual Vacation Day, March 30th: This day highlights the idea that everyone can experience the joy of travel, regardless of physical, financial, or logistical constraints. For individuals with disabilities, virtual vacations provide an accessible way to explore iconic landmarks, serene landscapes, and bustling cities through tools like virtual reality, online travel videos, and interactive tours—all from the comfort of home. These experiences not only reduce barriers but also foster adventure and offer therapeutic benefits, such as relaxation and inspiration. Immersive experiences such as beach relaxation apps, virtual nature walks, or cultural tours can bring peace, joy, and inspiration to individuals who may not otherwise have access to such environments. Let's use this day to celebrate technology's ability to make the world more inclusive and accessible for all. Share your travel videos or favorite go-to sites and apps with us and our community on our socials!

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AMDA

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