October 2025

AMDA Newsletter

Enroll Now: *Breathing Muscle Weakness 101* (access through Nov. 15). Limited spots, first-come, first-served. - https://forms.gle/dtsJTsj1YMZ9Y3KH6

Oct. 10-12: Grant's Giants Family Retreat

Oct 22: *Talking With Your Pompe Peeps* "Spooky Soirée Part 2" - Register Now!

Disclaimer:

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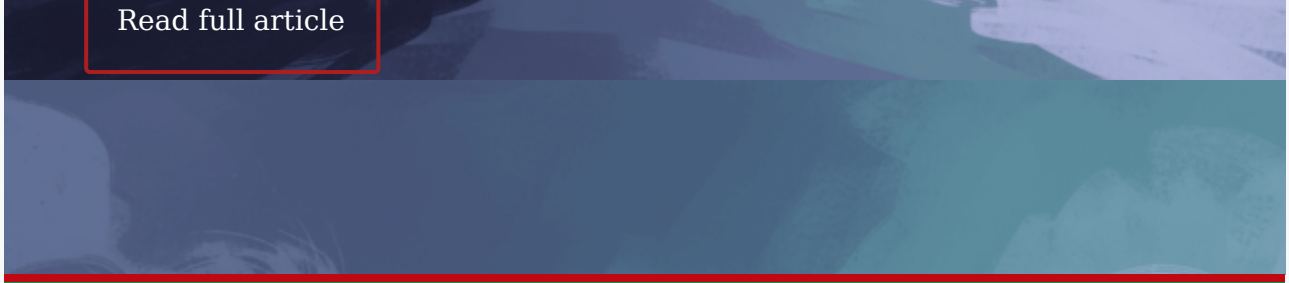
Featured Article: Grief and Rare Disease - Recognizing Loss and Building Grief Literacy

Grief is part of every rare disease journey. Whether it's the loss of ability, opportunity, or someone we love, learning to name and understand those emotions can help us heal. This month's article explores how grief shows up in the Pompe community and how we can build "grief literacy" — the shared language and understanding that help us support one another through change and loss.

Our latest piece reflects on the many forms of grief in the rare disease world and offers insight, compassion, and hope for moving forward together



CELEBRATING PHYSICAL THERAPY MONTH & HALLOWEEN

Exercise Recommendation for LOPD with Keyuna “Coach K” Milam

Speaker: Keyuna (Coach K) Milam — Owner, Wanna Go Fit LLC

In celebration of **National Physical Therapy Month**, we’re spotlighting a wonderful session from Coach K focused on **exercise recommendations for adults living with LOPD**. The guidance is practical and encouraging, with adaptable options so you can choose what fits your day. If you’re looking for a friendly place to start—or fresh ideas to keep you moving—this is a great watch.

About Coach K: Keyuna Milam (aka *Ms. Wanna Go Fit*) is the owner of **Wanna Go Fit LLC** and a certified personal trainer with a therapeutic background. She blends rehab-minded coaching with real-world training to help clients reduce pain and improve mobility. Her experience includes supporting people with Pompe disease, cerebral palsy, Ehlers-Danlos syndrome, and fibromyalgia.

AMDA/IPA International Pompe Patient & Scientific Conference 2024

Exercise Recommendation for LOPD

With:
Keyuna (Coach K) Milam

Aquatic Exercise — Applications for Pompe Disease

Speaker: Dr. Kendra Lucas, PT, DPT — Aquatic Physical Therapist, Kettering Health (Ohio)

Water can be a powerful ally in maintaining strength and mobility. Its buoyancy supports your body, easing joint pressure and allowing greater freedom of movement with less effort. In this engaging webinar, **Dr. Kendra Lucas** explores how aquatic therapy can benefit individuals facing muscle weakness, balance issues, or respiratory challenges — offering a safe and refreshing way to stay active.

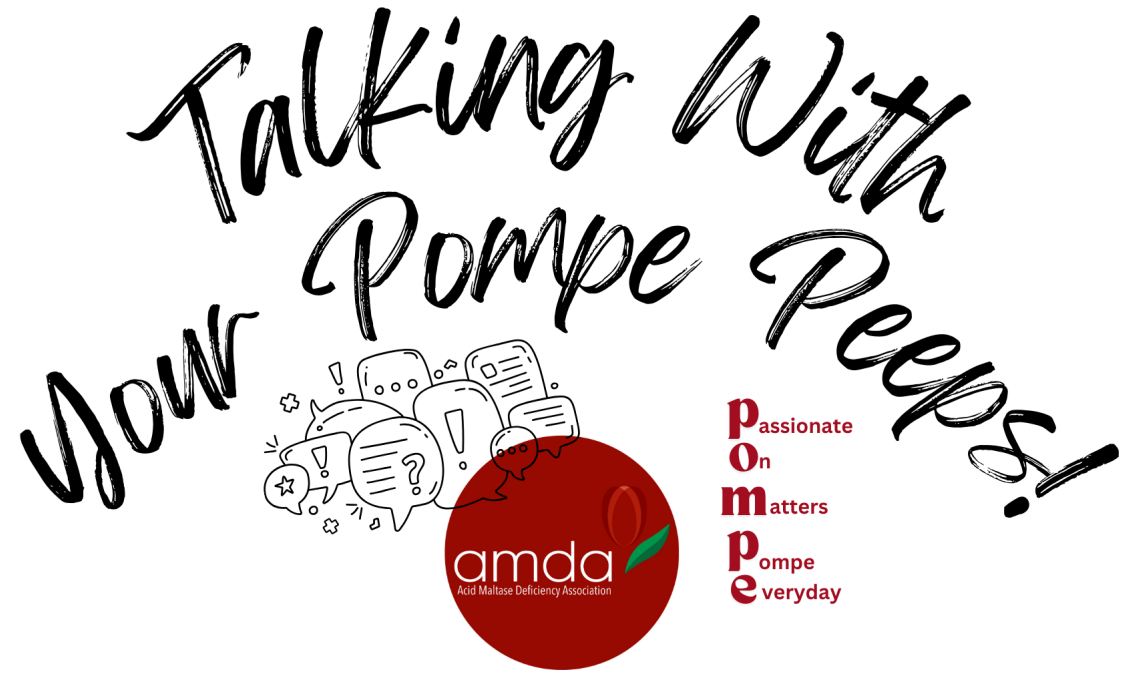
AMDA Webinars

Aquatic Exercise: Applications for Pompe Disease

With:
Dr. Kendra Lucas

Aquatic Exercise PDF Download

Slide Deck PDF Download



Spooky Soirée: Enjoying Halloween with PD for You and Your Kiddos Part 2

Calling all Pompe Parents! Are you stuck thinking up costume ideas? Have you made an awesome one that you would like to

share? This is your chance to share and help each other. Halloween can be a challenging time for many parents when it comes to finding the right costumes. For our Pompe kiddos, there can be added challenges when mobility issues are involved. Do you need help? Do you have suggestions? Join us and share! Please share your past costume photos!

Also related to Halloween… have you found creative ways to deal with the massive candy haul? None of us want our kiddos to miss out on these experiences, but how can we modify when needed?

***This session will be recorded and posted on the AMDA YouTube Channel, by attending, you are giving the AMDA permission to post your image on it's channel.**

EVENT DETAILS:

Title: Spooky Soirée – Enjoying Halloween with PD for You and Your Kiddos Part 2

Date: Wednesday, October 22, 2025

Time: 1 PM CST / 2 PM EST

Moderator:
TBD

Register Now

SCIENCE AND YOU

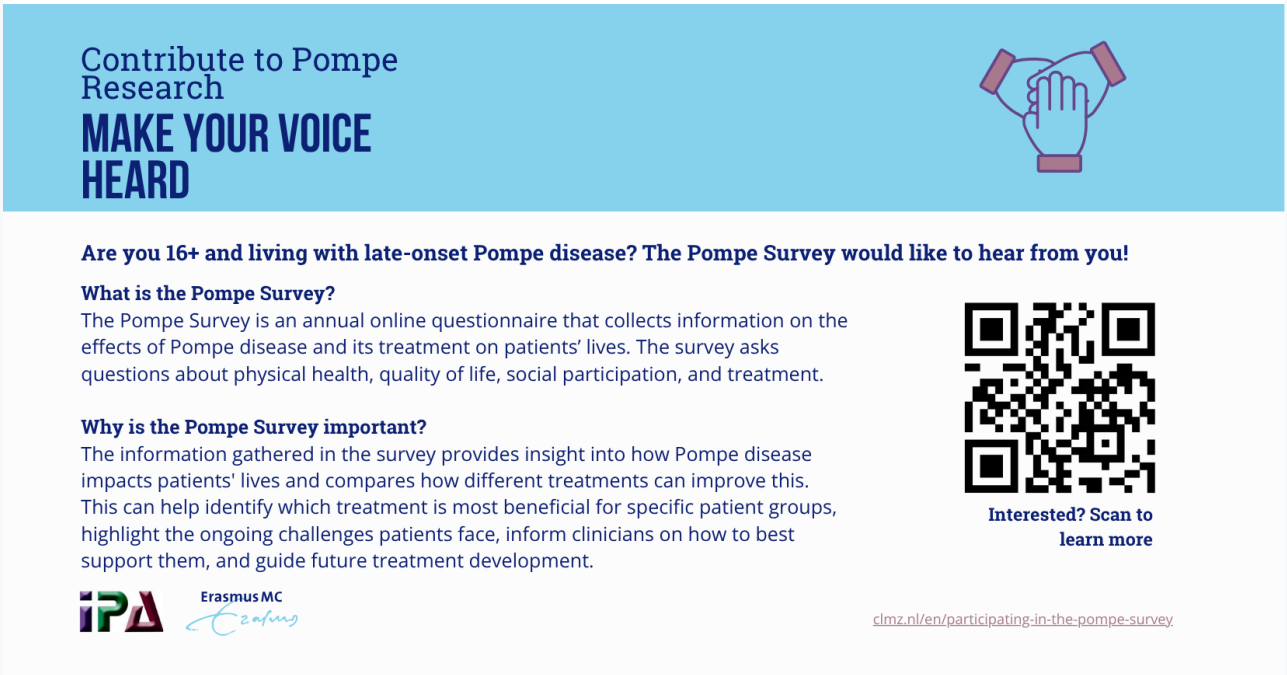
Helen Walker Research Grant Award Winners

The AMDA is excited to announce a new section on our website dedicated to the **Helen Walker Research Grant**. This page will showcase all past award recipients, organized by year, and highlight publications or research outcomes that resulted from their funded projects.

By sharing this information, we hope to celebrate the important contributions of our grantees and keep the Pompe community

informed about the progress being made toward improved treatments and care.

Stay tuned for the official launch!



Erasmus MC Pompe Survey — Sign Up and Complete Your Baseline

The Erasmus MC Pompe Survey is building a clearer picture of life with Pompe disease. Your voice helps researchers and clinicians understand needs, track changes over time, and improve care.

Why participate

- Contribute real-world insights that guide future research and support
- Establish your **baseline** now so your future answers have context
- Add to a growing community resource that benefits patients and families

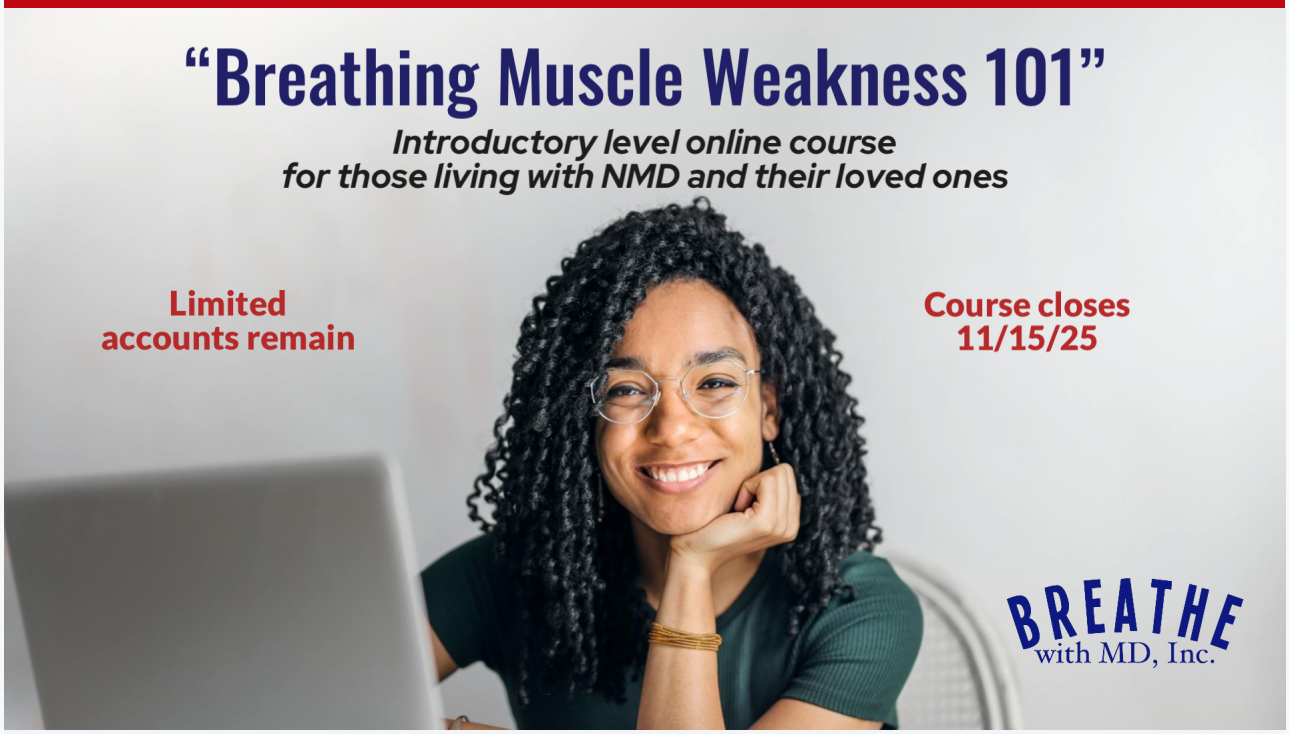
What to do

1. **Sign up** for the survey.
2. **Complete the baseline** questionnaire. It sets the foundation for future check-ins.
3. Keep your login handy for follow-ups later in the year.

How to join
Scan the **QR code** in the image to enroll and get started.
Prefer a link? **Sign up here:** https://clmz.nl/en/participating-in-the-pompe-survey

Join the Pompe Survey

TOOLS FOR YOUR CARE



Breathing Muscle Weakness 101 — Online Course (Ends Nov. 15)

In September, **Andrea Klein**, founder and president of **Breathe With MD, Inc.**, joined us for a webinar on understanding breathing muscle weakness. If you want to go deeper, her **self-paced online course, *Breathing Muscle Weakness 101***, is open now — with enrollment closing **November 15**.

Spots are limited and first-come, first-served, so it's a great time to sign up.

Average completion time is about **two weeks**.

Enroll now; self-paced access available through **Nov. 15**.

Enroll now

AWARDS SPOTLIGHT

Honoring the 2025 Sanofi TORCH Award Pompe Recipients

This year, the Sanofi TORCH Awards recognized several outstanding advocates who have made lasting contributions to rare disease awareness. Two of the honorees are part of the Pompe community: **McKenzie Barker** and **Alison Breitbarth**.

Their recognition at the 2025 TORCH Awards is a reminder of the strength, resilience, and advocacy within the Pompe community.

In Memoriam
During the ceremony, Sanofi displayed a photo of **Tiffany House** (AMDA/IPA leader) to honor her memory. In addition, patient organizations around the world, including the IPA and Erasmus MC, published tributes in May and June 2025 reflecting on her decades of service, leadership, and dedication to the Pompe community. Her legacy continues to guide and inspire the next generation of advocates.

Meet McKenzie Barker

McKenzie Barker — A young patient from Maine living with infantile Pompe disease. Diagnosed at six weeks, she has received weekly enzyme replacement therapy (ERT) since infancy. Despite long hospital visits, McKenzie has grown into a bright, resilient child. She even authored *I Am a Pompe Warrior* to help other children feel less alone. Local coverage has noted that she is the only child in Maine with Pompe disease, and she has become a symbol of courage for others.

Meet Alison Breitbarth

Alison Breitbarth — From Indiana, Alison founded **Grant's Giants** after her son, Grant, was diagnosed with infantile

Pompe disease through newborn screening in 2021. Her family's journey quickly became one of advocacy. Alison now serves as a Newborn Screening Ambassador and the Indiana parent representative for the Unite Newborn Screening Learning Community. As shared on the Grant's Giants website, she is dedicated to supporting families and expanding newborn screening programs so that other children can benefit from early detection and timely treatment.

COMMUNITY CORNER

Infusion Role-Play Kits from Grant's Giants

Grant's Giants is providing **Infusion Role-Play Kits** to Pompe children who are currently receiving enzyme replacement therapy (ERT) or are about to begin ERT. Each kit includes a stuffed animal with a port or IV access and all the supplies needed for kids to practice and normalize the infusion process. These kits are available **worldwide**.

> “When a child is able to engage in role-playing an infusion, it helps normalize the process and makes it feel much less intimidating. Currently, enzyme replacement therapy, delivered via IV infusion, is the only treatment for Pompe disease. That’s why it’s crucial to normalize this lifelong treatment for children, helping them feel more at ease with it.” — **Alison Breitbarth, Grant’s Giants**

Request Play Kit

Safety note: For children **under age 3**, an adult must supervise at all times due to **small pieces and strong magnets**.

Grant's Giants Family Retreat (Oct. 10-12)

Happening in a few days. Join Pompe families for a weekend of connection, community, and fun in southern Indiana.

Who: Families affected by Pompe disease, including **IOPD** and **LOPD**. Preference given to pediatric families, all families welcome.

What: A weekend of community building for Pompe families.

When: **October 10–12, 2025**

- **Check-in:** Friday, Oct 10 at 3:00 PM
- **Check-out:** Sunday, Oct 12 at 3:00 PM

Where: **Camp Pyoca**

886 E County Rd 100 S
Brownstown, IN 47220

Accessibility: Venue is **wheelchair accessible**.

Email Questions

Monthly Observances

National Physical Therapy Month: Movement looks different for everyone, and that's okay. This month is a reminder to celebrate small, sustainable steps—gentle stretches, posture work, breath practice, or aquatic exercise—whatever supports your goals and comfort. We're sharing resources all month, including adaptable routines from Coach K and a refresher on aquatic therapy, so you can choose what fits your day.

Organize Your Medical Information Month: A little prep goes a long way. Start by updating a **one-page summary** with medications and doses, key diagnoses, allergies, current care team with contacts, and infusion or respiratory settings. Save it as a **PDF on your phone** and share a copy with a caregiver. When you're ready to go further, build a simple medical information binder using our **Printable Binder Template**

Daily Observances

World Mental Health Day | Oct 10th: Caring for mental health is part of caring for your whole self. Today's a good moment to check in with your stress level, set aside a little quiet

time, or reach out to someone who understands the rare-disease journey. If you're supporting a loved one, a quick "How are you holding up?" can mean a lot.

National I Love You Day | Oct 14th: Say it out loud or in a quick text—tell someone they matter. Partners, parents, kids, friends, infusion nurses, care coordinators… a simple "thank you, I love you" can lift the whole day.

National Pumpkin Day | Oct 26th: Lean into the cozy. Carve a pumpkin, paint one, or set out a few mini pumpkins on the table. Pumpkin muffins, soup, candles—pick your vibe and enjoy the season.

#PompePower

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