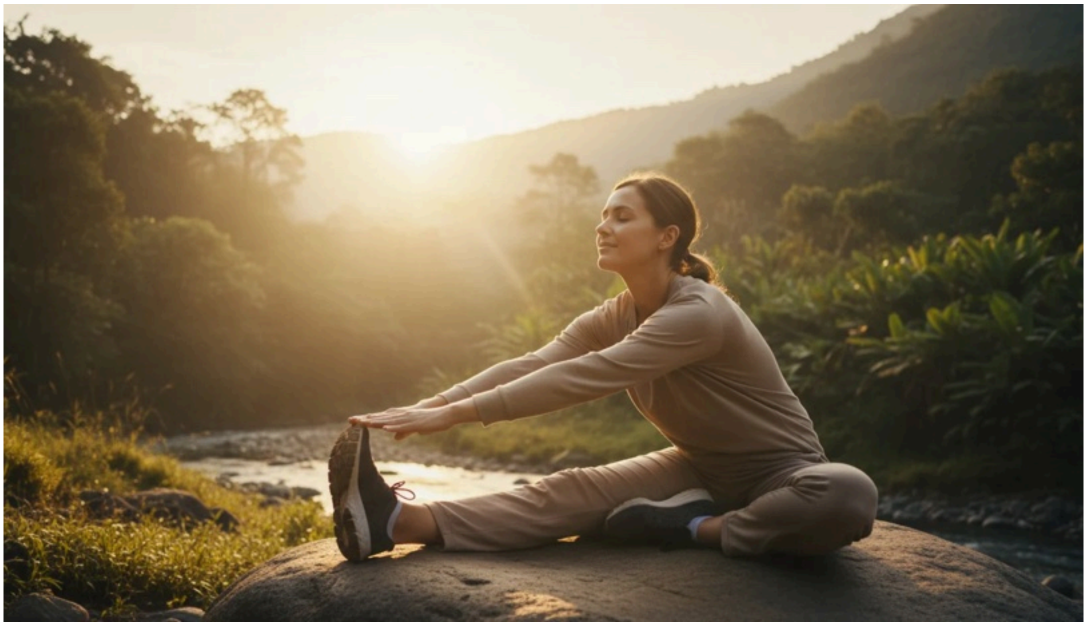
April / 2026

AMDA Newsletter

Living Well with Pompe

April is a month of awareness, movement, and community. This issue, we are focusing on health in three areas: the mind, the body, and the connections that sustain us. From understanding our energy to celebrating International Pompe Day, we hope this newsletter offers something meaningful for wherever you are in your journey.

Featured Story



Move How You Can, Rest All You Need

By Lucas Garrett, AMDA Editor and Community Contributor

Living well with Pompe disease does not always look the way health advice assumes it will. Sleep gets interrupted by nighttime treatments. Exercise happens with pulleys, an auto elliptical, and hand movements through sand. Rest is not laziness; it is medicine. And movement, in whatever form is accessible, is one of the most powerful tools we have.

In this month's article, AMDA contributor Lucas Garrett reflects honestly on his own routines around sleep and exercise, what the research says about both, and why physical activity may be one of the best defenses against the kind of stress so many in this community carry every day. He also offers a reminder that is easy to forget: it is OK not to have it all figured out. What matters is that we keep trying and extend ourselves the same grace we would give to anyone else.

Whether you are currently hitting your goals or rebuilding from scratch, this article is for you.

Read the Full Article

AMDA Updates

AMDA April Webinar: Immune Responses to AAV Gene Therapy

WEBINAR • FRIDAY, APRIL 10, 2026 • 12 p.m. CST / 1 p.m. EST

Gene therapy has long represented one of the most promising frontiers in Pompe disease research, and the science is advancing faster than ever. One of the key hurdles in gene therapy is the body's immune response to AAV gene therapy vectors. Researchers are working on finding a way to overcome this obstacle. Join us to learn about the exciting progress being made to solve this challenge and what it could mean for the future of treatment.

Immune Responses to AAV Gene Therapy: Challenges and Emerging Solutions

Immune responses to AAV gene therapy remain a major barrier to its access and effectiveness. This talk will highlight key immune challenges and emerging strategies to overcome them, including antibody-cleaving enzymes and novel capsids designed to evade pre-existing immunity.

Speaker: Abigail Benkert, MD, cardiothoracic surgery resident and research fellow at Duke University Medical Center.

Disclaimer: *The content provided in this webinar is for informational purposes only and does not constitute an endorsement by the AMDA.*

Learn More and Register

Talking With Your Pompe Peeps Session 13: Home Infusions

TWYPP • WEDNESDAY, APRIL 29, 2026 • 7 p.m. CST / 8 p.m. EST

Are you considering a transition to home infusions, or already receiving them and looking for guidance? Whether the idea feels exciting, overwhelming, or somewhere in between, you are not alone. Join us for an open, practical conversation about what home infusions really look like day to day.

Home Infusions

Home infusions can feel overwhelming at first. Join Ashley Lloyd, BSN, RN, for a practical discussion on how to prepare, what to expect, and ways to make infusion days run more smoothly. Whether you are new to home infusions or looking to fine-tune your routine, this conversation will offer helpful insights and real-world guidance.

Moderator: Ashley Lloyd, BSN, RN, a home infusion nurse with over 15 years of experience and a specialization in rare disease care, including Pompe disease.

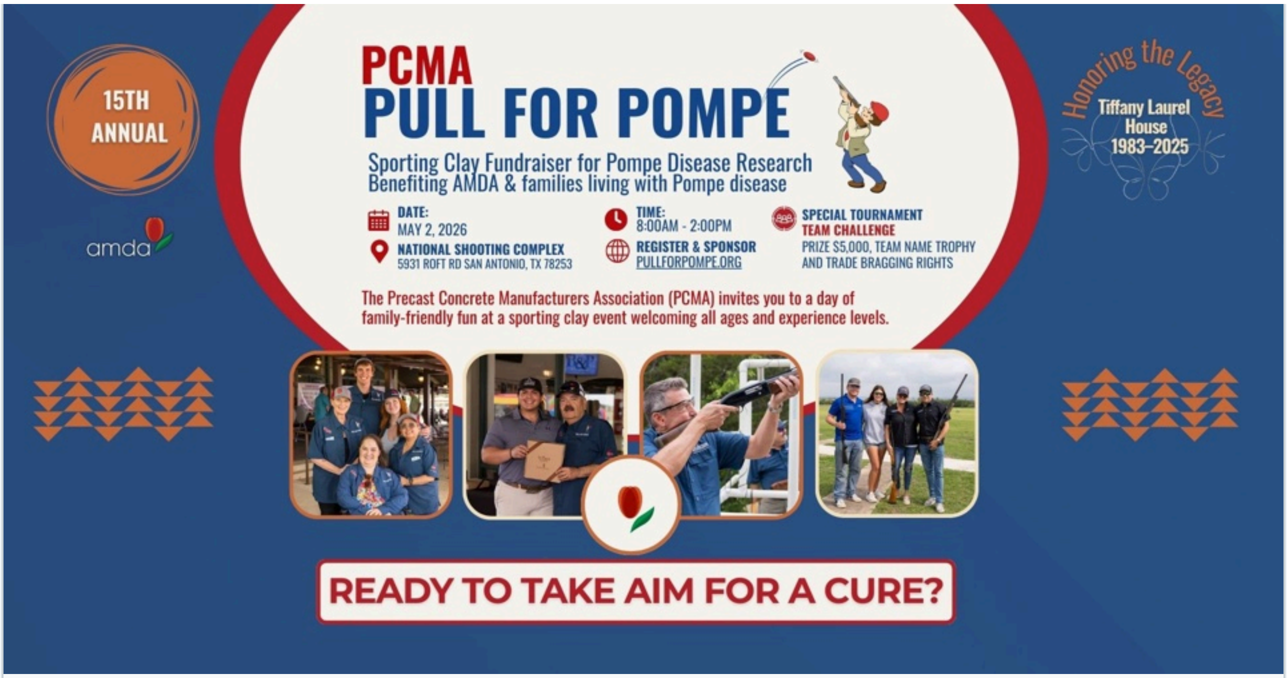
Note: *This discussion is for informational and community support purposes and is not medical advice.*

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

15th Annual Pull For Pompe — Coming May 2, 2026



The 15th Annual PCMA Pull for Pompe is just around the corner! Join us on Saturday, May 2, 2026, from 8 a.m. to 2 p.m. CST at the National Shooting Complex in San Antonio, Texas. This family-friendly clay shooting fundraiser is open to all ages and ability levels. All proceeds support the AMDA's 2026 Pompe Disease Research Grant.

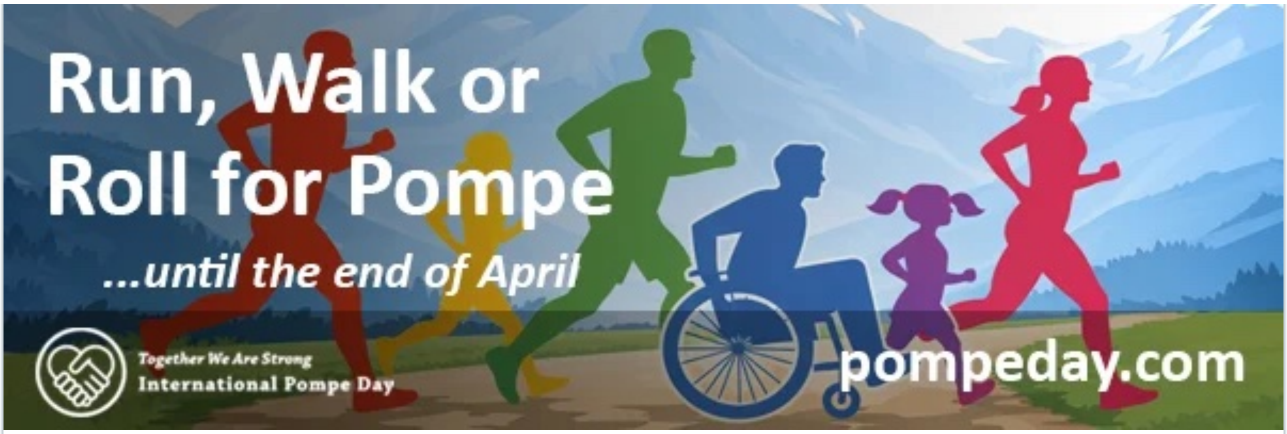
Register and Support

AMDA Emergency Medical Alert Card

Does your emergency contact information clearly communicate your Pompe disease diagnosis and treatment needs? The AMDA Emergency Medical Alert Card is a free, printable resource designed to help first responders and emergency room staff understand your condition quickly.

Order Your Free Card

Community & Events



International Pompe Day: Run, Walk, or Roll 2026 — Every Move Counts!

VIRTUAL EVENT • APRIL 1-30, 2026 • PARTICIPATE FROM ANYWHERE IN THE WORLD

International Pompe Day falls on April 15. This year, the global Pompe community is celebrating with a month-long virtual event. Whether you run a marathon, take a gentle walk, or roll through your neighborhood, every move you make raises awareness for Pompe disease.

Here’s How to Get Involved

1. Register at pompeday.com
2. Log your distance. Every step and roll counts!
3. Track the leaderboard and cheer on fellow participants.
4. Share your journey on social media and inspire others.

Post your photos and videos and tag the International Pompe Association (IPA). Let’s flood social media with awareness and unity!

#RunWalkOrRoll #PompeDay2026 #EveryMoveCounts #PompeAwareness #InternationalPompeDay #RareDisease #Pompe

Register Today!

Donate to Support the Cause

Advocacy & Science

Ohio Families: Your Voice Can Shape Newborn Screening

A meaningful advocacy opportunity has come to our attention for families in Ohio, and we want to make sure it reaches those who may be eligible. Cincinnati Children's Hospital Medical Center, in partnership with the Ohio Department of Health, is recruiting parents and caregivers to serve on a Newborn Screening Family Advisory Committee — a statewide effort to improve newborn screening systems and make care more family-centered.

If your child received a positive newborn screening result in Ohio since 2016 for a genetic disorder (endocrine or metabolic), sickle cell disease, congenital heart defect, or early hearing disorder, you may be eligible to participate. This includes families in the Pompe community.

About the Committee

Six regional committees are being established across the state, covering Cincinnati, Cleveland, Columbus, Dayton, Toledo, and Akron. The project is expected to run through 2028, and participants are welcome to stay involved for as much of that time as they choose.

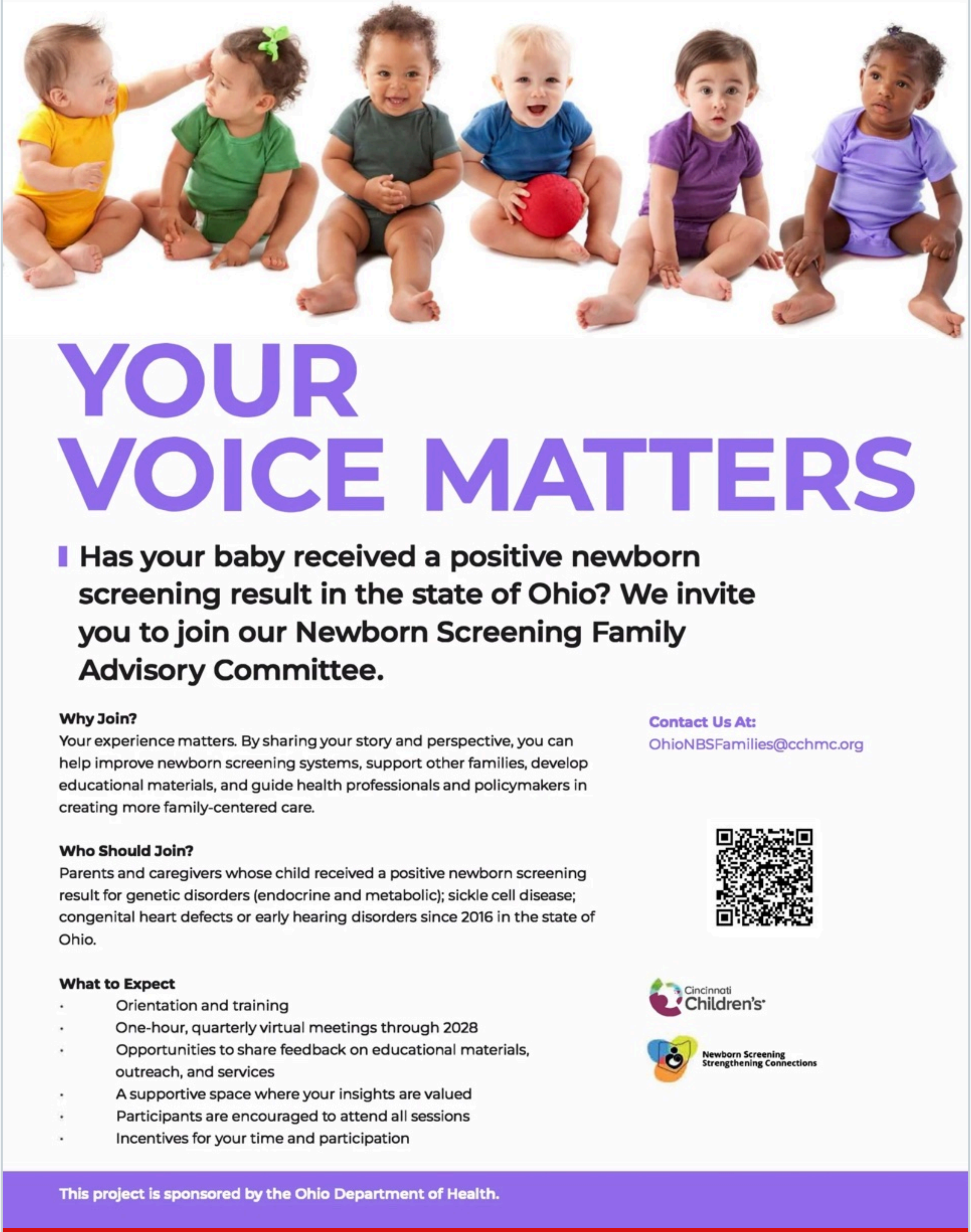
What participation looks like:

- A virtual orientation and training to get started
- One-hour quarterly committee meetings held online
- Opportunities to review and provide feedback on educational materials, outreach, and services
- A supportive space where your experience and insights are genuinely valued
- Compensation for your time and participation

By participating, families help guide health professionals and policymakers toward more informed, compassionate, and family-centered care — work that benefits not only future families navigating a positive newborn screening result, but the broader rare disease community as well.

For more information or to express interest, contact the project team directly at OhioNBSFamilies@cchmc.org.

Note: This opportunity is open to Ohio residents only. This is a third-party initiative. Inclusion does not constitute an endorsement by the AMDA



YOUR VOICE MATTERS

Has your baby received a positive newborn screening result in the state of Ohio? We invite you to join our Newborn Screening Family Advisory Committee.

Why Join?

Your experience matters. By sharing your story and perspective, you can help improve newborn screening systems, support other families, develop educational materials, and guide health professionals and policymakers in creating more family-centered care.

Who Should Join?

Parents and caregivers whose child received a positive newborn screening result for genetic disorders (endocrine and metabolic); sickle cell disease; congenital heart defects or early hearing disorders since 2016 in the state of Ohio.

What to Expect

- Orientation and training
- One-hour, quarterly virtual meetings through 2028
- Opportunities to share feedback on educational materials, outreach, and services
- A supportive space where your insights are valued
- Participants are encouraged to attend all sessions
- Incentives for your time and participation

Contact Us At:

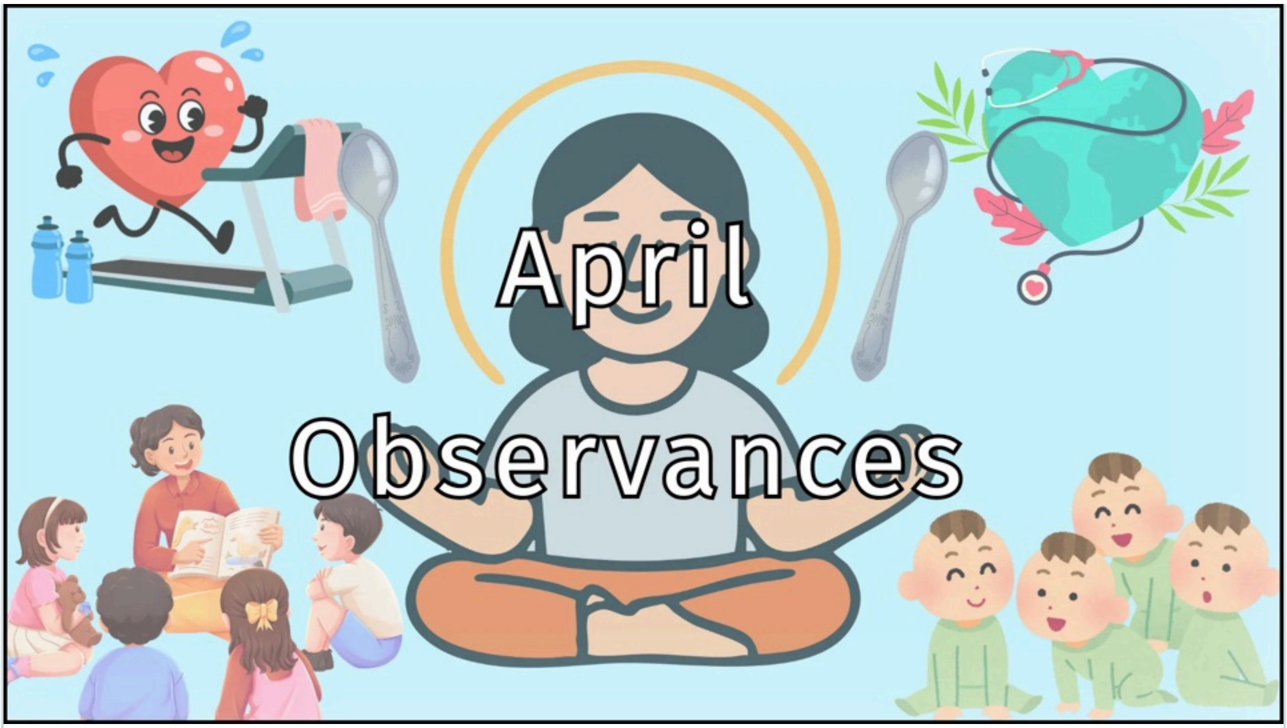
OhioNBSFamilies@cchmc.org

Cincinnati Children's

Newborn Screening Strengthening Connections

This project is sponsored by the Ohio Department of Health.

Observances



Monthly Observances

Stress Awareness Month: April is Stress Awareness Month, a timely reminder that mental and emotional health is just as important as physical health. For those living with Pompe disease and other chronic conditions, stress often takes forms in ways that others cannot see — such as the weight of a body that requires more effort for everything, navigating a complex health care system, and being perceived as healthy when you are not. This month, the AMDA encourages our entire community — patients, caregivers, and families alike — to acknowledge that rest is not indulgence, asking for help is a sign of strength, and personal well-being matters.

Living With Limited Spoons: Spoon Theory and Pompe Disease

What does it feel like to start every day knowing that your energy is finite and that each task brings you one step closer to empty? It is something that people living with Pompe disease and other chronic conditions know all too well. It is the daily reality that Spoon Theory helps put into words.

Spoon Theory was created in 2003 by Christine Miserandino, a writer and chronic illness advocate, to explain the limited energy experienced by people living with lupus and other chronic conditions. The metaphor is straightforward: spoons represent units of physical and mental energy needed for daily activities. Most people wake up with an unlimited or easily replenished supply. People living with chronic illness do not.

For someone living with Pompe disease, a typical day might begin with just five spoons: getting out of bed, showering and dressing, attending an appointment or therapy session, preparing meals, and completing basic daily tasks. Once those spoons are gone, energy is depleted. Recovery involves managing muscle weakness, breathing effort, and brain fog. Energy used today affects tomorrow.

Why Spoon Theory Matters

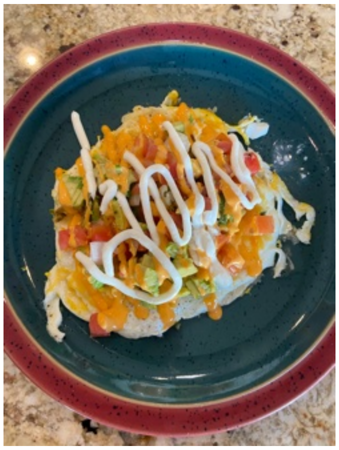
Many people living with Pompe disease do not appear sick on the outside. Because others cannot see fatigue, muscle weakness, breathing effort, or pain, these individuals are sometimes misunderstood. Spoon Theory gives patients a framework to explain what is otherwise difficult to articulate. It helps others understand that energy limitations are real, valid, and medically significant. They are not excuses, not exaggerations, and not choices. Understanding Spoon Theory encourages compassion and flexible thinking across every setting — for example, workplaces, medical environments, and families. Most importantly, it gives people living with Pompe disease and other invisible disabilities a way to communicate their experience and be heard.

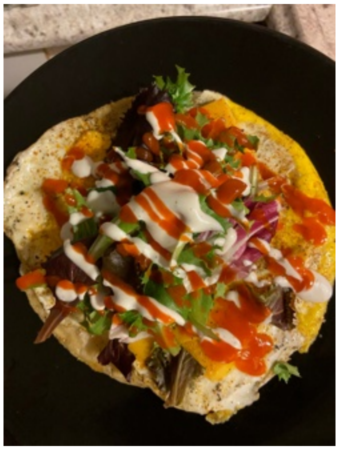
Daily Observances

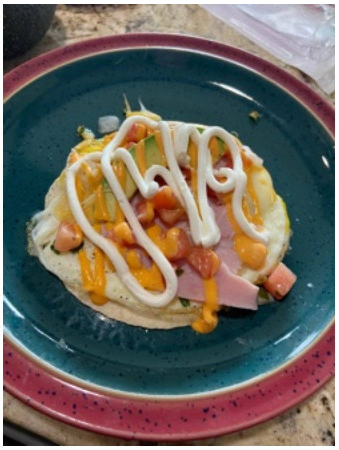
World Health Day | April 7: Established by the World Health Organization in 1948, World Health Day is a global call to action to build a healthier, fairer world for everyone. For our community, it is a moment to reflect on what health truly means, not only the absence of disease, but access to care, quality of life, and the right to be seen and supported. Take a moment today to celebrate the steps you take each day to care for yourself and those you love

Recipe from the Community — Egg Flat Bread (Low Carb, High Protein)

Submitted by Morgan Burroughs in the spirit of World Health Day. This is a simple, nutritious, and endlessly customizable recipe the whole community can enjoy.







Egg Flat Bread (Low Carb, High Protein)

Ingredients

- 1 tortilla (any kind, any size)
- 1–3 eggs (see tips below)
- Your favorite cheese
- Toppings of your choice (e.g., lettuce, avocado, Pico de Gallo, grilled onions and peppers, bacon, shredded chicken, beans)
- Salt and pepper
- Spices of your choice (e.g., onion powder, chives)
- Condiments of your choice (e.g., mayonnaise, sour cream, Sriracha)

Directions

1. Spray a small pan with oil or use butter and heat over low–medium heat.
2. Crack egg(s) in the center of the pan and place the tortilla over the egg(s). Push the tortilla into the egg(s) to break the yolk underneath, making sure the bottom of the tortilla is coated with egg. Flip the tortilla so the egg-coated side is facing up. Season with salt and pepper.
3. As the egg cooks underneath, use a spatula to keep the edges neat. The egg can overlap a little, but don't let it go too far.
4. Cook longer before flipping for crispy edges or turn off the stove to keep the egg soft. When the egg has cooked through, flip it so the tortilla is on the bottom. Season again. Add spices of your choice.

5. Add shredded or sliced cheese, then cook for another 1–2 minutes until the tortilla reaches your desired texture.
6. Place on a plate and add toppings, condiments, and sauces of your choice. Enjoy!

Tips

- Use 1 egg for a 4-inch tortilla, 2 eggs for a 6-inch tortilla, and 2–3 eggs for an 8-inch tortilla.

Experiment with topping combinations! Keep it simple with lettuce and ranch dressing, or go bold with cumin, chili powder, black beans, salsa, and guacamole. The options are endless.

National Siblings Day | April 10: National Siblings Day is a moment to celebrate one of life's most enduring bonds. For many in our community, siblings are not just family; they are first advocates, early supporters, and lifelong companions in navigating Pompe disease. Whether they push a wheelchair, sit with you at appointments, or simply show up, siblings often carry their own quiet kind of love. Today, we honor them.

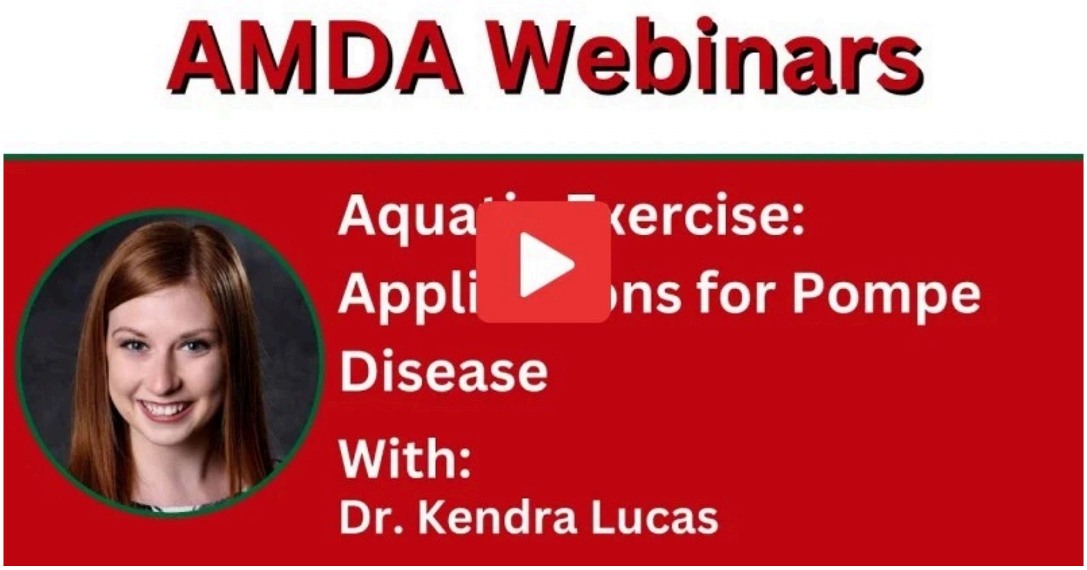
International Pompe Day | April 15: International Pompe Day is a global movement to raise awareness for Pompe disease and celebrate the strength of the community that has grown around it. This year, we invite you to participate in the Run, Walk, or Roll virtual event (see Community & Events above), share your story on social media, and use the day to connect with someone who understands this journey.

National Exercise Day | April 18: Movement looks different for everyone, and for those living with Pompe disease, finding safe and sustainable ways to stay active is both a challenge and a lifelong practice. National Exercise Day is a reminder that physical activity, in whatever form is accessible to you, supports respiratory function, muscle maintenance, and overall well-being. Always work with your care team to find the approach that is right for you.

Resources for Exercise and Pompe Disease

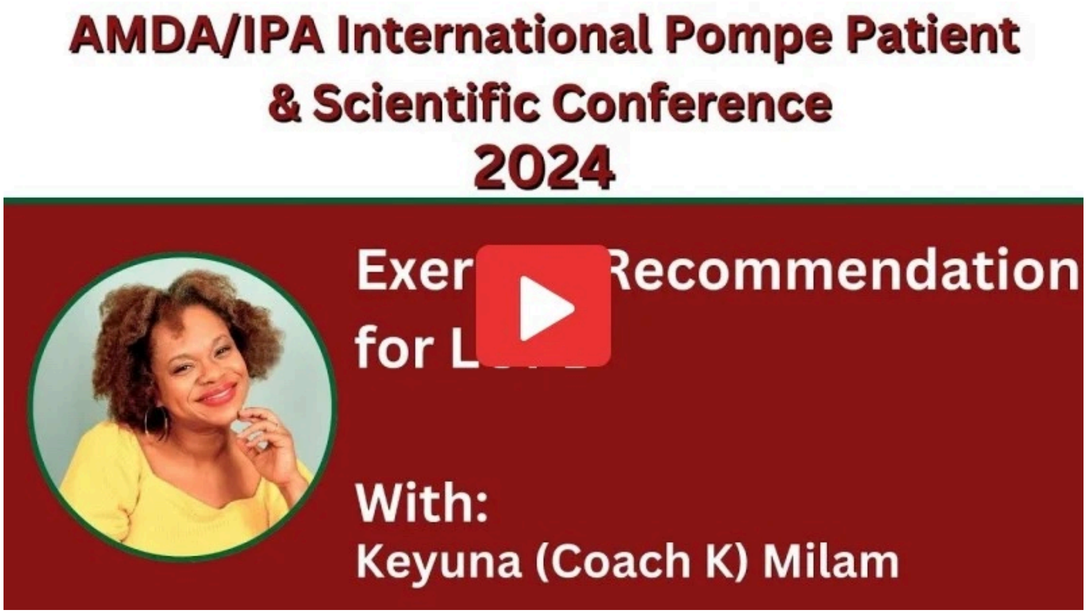
AMDA Aquatic Physical Therapy Webinar

Aquatic exercise can offer significant benefits for individuals with neuromuscular conditions. In this AMDA webinar, experts discuss how water-based therapy supports strength, mobility, and respiratory health for people living with Pompe disease.

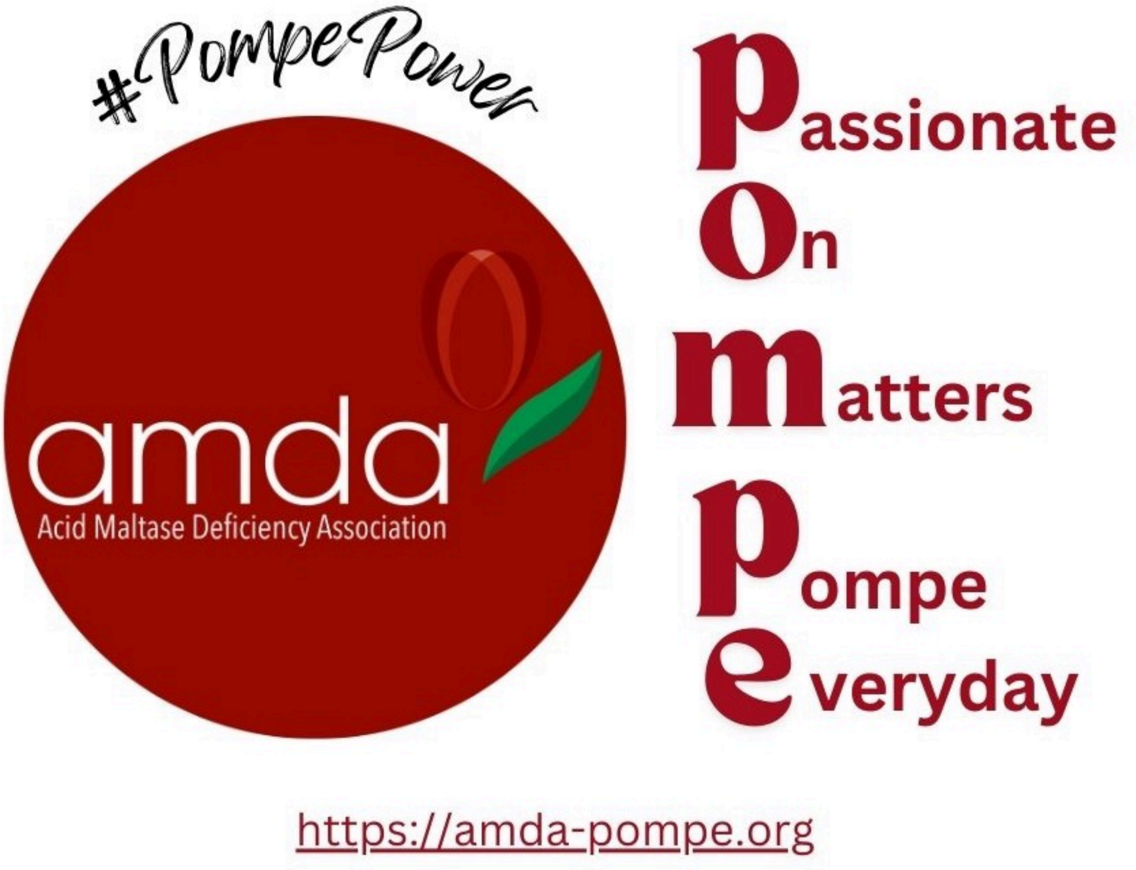


AMDA 2024 Conference: Exercise Recommendations for Late-Onset Pompe Disease

This session from the 2024 AMDA/IPA International Pompe Patient and Scientific Conference reviews the latest evidence-based exercise recommendations for adults living with late-onset Pompe disease (LOPD), covering both aerobic activity and resistance training adapted to individual ability.



National Tell a Story Day | April 27: Every person in this community carries a story worth telling. National Tell a Story Day is an invitation to share, whether through a social media post, a conversation with a friend, or a message to someone newly diagnosed. Stories break isolation. They build understanding. And in the rare disease community, they have the power to change lives. We encourage you to share yours today, in whatever way feels right.



AMDA

PO Box 700248, San Antonio
TX 78270 United States