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Videos Conferences News AMDA Publications Webinars
Talking With Your Pompe Peeps

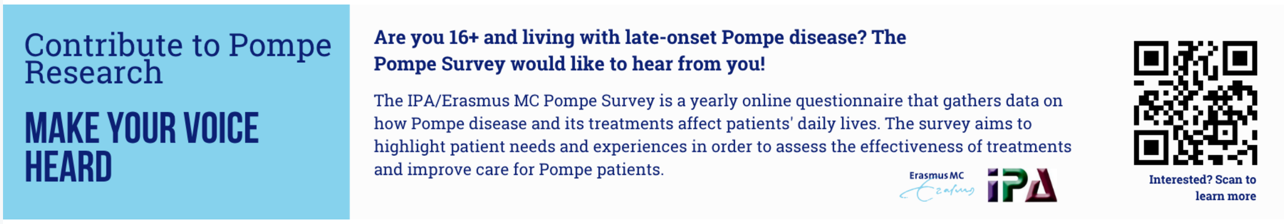
June 2025

AMDA Newsletter

Don't miss out! Register for our next webinar NOW!

Join us **Monday, June 9, 2025** at **2 PM CT / 3 PM ET** for our next webinar all about genetic counselors presented by **Erin Huggins**— a board certified genetic counselor with extensive experience working with the Pompe disease community. Register using the button below.

REGISTER HERE



Contribute to Pompe Research

MAKE YOUR VOICE HEARD

Are you 16+ and living with late-onset Pompe disease? The Pompe Survey would like to hear from you!

The IPA/Erasmus MC Pompe Survey is a yearly online questionnaire that gathers data on how Pompe disease and its treatments affect patients' daily lives. The survey aims to highlight patient needs and experiences in order to assess the effectiveness of treatments and improve care for Pompe patients.

Interested? Scan to learn more

Help contribute to patient centered research and make your voice heard!

The IPA/Erasmus MC Pompe Survey is actively seeking US participants living with late-onset Pompe disease.

What is the Pompe Survey?

The Pompe Survey collects information on the effects of Pompe disease on patients' lives, and how these effects may change with treatment. Patients themselves provide this information through an annual online questionnaire. Launched in 2002, the Pompe Survey is a collaboration of the International Pompe Association (IPA) and Erasmus MC. The questionnaire can be completed online and takes approximately half an hour to complete.

Why is the Pompe Survey important?

The information collected in the Pompe Survey helps us understand what happens to patients over time. Each year, patients report on their physical health, quality of life, social participation, and the treatments they receive. This information is key in studying the effects of treatment on patients' lives and to assess the effectiveness of new treatments. It also helps to inform physicians about the changing needs of patients. Patient reported information from the Pompe Survey is especially valuable as new ERT and other therapies are now being offered to patients.

We are specifically focusing on highlighting international patient experiences in 2025, which is why we would greatly appreciate your participation.

How can I participate?

Are you interested in sharing your patient perspective? Visit the Pompe Survey website and complete the contact form. The study team will mail you a participation package containing information about the survey and the informed consent documents. Once you have read through the survey information and have decided you want to participate, simply sign the informed consent documents and mail them back to the study team using the prepaid mailing envelope. The survey will then be sent to your email. No more paper or mail required!

Questions? Contact your national representative (for the United States: Marsha Zimmerman) or pompe.survey@erasmusmc.nl

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Rare Artist 2025 is now Open for Submissions

Enter through July 9th at RareArtist.org

The Rare Artist program, powered by the EveryLife Foundation for Rare Diseases, was established in 2010 to showcase the talents of those impacted by rare diseases. The annual contest provides a national platform for artists to advocate through music, poetry, and visual artwork.

This year we are introducing a **new medium: MUSIC!** Music has the power to move hearts and activate change. Now, it’s another way to raise your voice for rare disease advocacy. Whether it’s a song about your personal journey or an anthem for our community, your music can help others feel seen, heard, and understood.

The contest is open to anyone in the U.S. who has a rare disease or is connected to someone who does. **For a full list of guidelines visit** ***RareArtist.org***

Monthly Observances

Audiobook Appreciation Month: For those living with Pompe disease, symptoms like muscle weakness, fatigue, or limited mobility can make traditional reading difficult. Audiobooks offer an accessible, hands-free way to enjoy stories, learn new skills, or simply relax—whether during treatments, while resting, or on the go. This month, celebrate by exploring audiobooks that uplift, educate, or entertain. What will you listen to first?

National PTSD Awareness Month: PTSD Awareness Month is a time to recognize that trauma isn't always visible. For many living with Pompe disease, the long diagnostic journey, invasive procedures, and uncertainty about the future can lead to medical trauma and emotional distress. It's important to acknowledge the mental health challenges that come with managing a rare disease. Supporting the Pompe community means addressing not only physical needs, but also emotional resilience and access to mental health care.

National Fresh Fruit and Vegetable Month: Celebrate National Fresh Fruit and Vegetables month with these colorful and tasty foods. Fruits and vegetables provide a variety of nutrients, vitamins, minerals, and fiber — while remaining naturally low in calories, fat and sodium. In addition, they lower your risk of developing certain chronic diseases — and help you maintain a healthy weight. Whether you fancy a market, or just grow the fruits and veggies at home, enjoy any combination of these delectable delights to kick off your summer right.

Daily Observances

New Year's Resolution Recommitment Day | June 1: New Year's resolution Recommitment Day is a perfect midpoint check-in on the goals we set at the start of the year. With six months behind us, it's a great time to pause, reflect on the progress you've made, and make a plan to keep—or restart—your momentum. Many resolutions fade quickly after January, but this day offers a fresh chance to realign and re engage. Want some inspiration to stick with it? Check out our *"Talking With Your Pompe Peeps"* session, where we explore how the Kaizen approach—making small, steady changes—can make your resolutions more sustainable and less overwhelming. Let's keep moving forward together, one step at a time!

Talking With Your Pompe Peeps Series

National Start Over Day | June 5: National Start Over Day is a reminder that it's never too late to begin again. For those living with Pompe disease, this day can symbolize a fresh start after diagnosis, a new treatment plan, or renewed hope in the face of ongoing challenges. Whether it's rebuilding strength, finding support, or redefining goals, every day offers a chance to start over. The Pompe community embodies resilience, proving that new beginnings are always possible.

Family Health and Fitness Day | June 12: Family Health & Fitness Day, observed the second Saturday in June, is a perfect opportunity to celebrate the importance of staying active and healthy together. For families affected by Pompe disease, movement might look different—but it's still powerful. Whether it's stretching, adapting exercise, or simply sharing nutritious meals, small steps can make a big impact. Health is a family journey, and every bit of movement matters. Check out this video featuring Coach K for some exercise recommendations for LOPD.

International Being You Day | June 22: International Being You Day honors the courage it takes to be authentically yourself. For those living with Pompe disease, embracing your uniqueness is a daily act of strength. Rare disease doesn't define who you are—it's just one part of your incredible story. Today, we celebrate every individual in the Pompe community for exactly who they are.

#PompePower

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PO Box 700248, San Antonio
TX 78270 United States

Contact Us