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March / 2026

AMDA Newsletter

March is a month of movement — new seasons, new research, and new reasons to connect. This month the AMDA is sharing exciting updates on an upcoming gene therapy webinar and a home infusion session coming in April, a patient-reported outcome study seeking your voice, and a free resource from the American Society of Gene & Cell Therapy to help you navigate the science. We're also celebrating creativity with a spotlight on one of our team members, honoring National Craft Month with a look at the many ways our community makes things, and pausing to recognize the caregivers, the nappers, and the laughs among us. Read on for everything happening in and around the Pompe community this March.

AMDA Updates

Talking With Your Pompe Peeps (TWYPP)
Session 12: A Personal Look at the Benefits of
Having a Portacath

2026
TALKING WITH YOUR
POMPE PEEPS



**SESSION #12:
A PERSONAL LOOK AT
THE BENEFITS OF
HAVING A PORTACATH**

**MODERATED BY:
LUCAS GARRETT**



 THURSDAY
MARCH 19, 2026
1 p.m. CST
/ 2 p.m. EST

 **OPEN
DISCUSSION**

 **SHARE YOUR
STORY**

 [HTTPS://AMDA-POMPE.ORG](https://amda-pompe.org)

REGISTER NOW

Date: Thursday, March 19, 2026 • 1 p.m. CST / 2 p.m. EST

Moderator: Lucas Garrett

The concept of IV enzyme replacement therapies is not foreign to the Pompe community. For many patients, having a portacath makes the infusion process easier. We invite you to take part in this TWYPP that offers personal insight into the advantages of having a portacath. The session is being led by Lucas Garrett of the AMDA, a longtime user of portacaths.

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.

Recording or reposting AMDA TWYPP sessions is prohibited without the AMDA's prior express written permission. Unauthorized use may result in takedown demands and legal action.

[Learn More and Register](#)

Coming in April:

AMDA Webinar on
New AAV (Duck-
Derived) Vector &
Gene Therapy
Redosing in Pompe

We are excited to announce that Dr. Abigail Benkert from Duke University will present preclinical work on an immune-evasive, duck-derived AAV vector and what it may enable for gene therapy redosing in Pompe disease.

Read the [related article](#) in *Cell Reports Medicine*.

TWYPP Session 13 —
Home Infusions



Join us in April for a special TWYPP session focused on home infusions. Ashley, RN, will go over a lot of information: what families can expect, how to prepare, common challenges, and practical tips to help infusion days run smoothly. Whether you're new to home infusions or looking to fine-tune your routine, this conversation will offer

helpful insights and real-world guidance.

The dates and registration details are coming soon. Follow us on [Instagram](#) and [Facebook](#), and watch for our email announcement. If you have not already, add us to your VIP sender list so you are the first to know.

Patient-Centered Care in Late-Onset Pompe Disease (LOPD) Continuing Medical Education (CME) Course



Clinician Education Program

CME
1.0

Optimizing Respiratory & Motor Outcomes in LOPD



NOW AVAILABLE ON-DEMAND

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Education that empowers



NORD[®]
National Organization
for Rare Disorders

amda

LOPD presents unique diagnostic and treatment challenges. This program reviews clinical clues, evaluates evidence on emerging

therapies, and highlights team-based approaches that improve motor and respiratory outcomes.

Watch Now and Earn CME

Advocacy & Science

The Pome Disease Health Index Study (POMPE-HI): Phase 1



WANT TO PARTICIPATE IN AN ONLINE RESEARCH STUDY IN POMPE DISEASE?

COMPLETE AN ONLINE INTERVIEW WITH THE UNIVERSITY OF
ROCHESTER STUDY COORDINATORS

- Participate in a 30 to 60-minute, audio-only, interview discussing the symptoms of Pompe disease that are most important to you



For more information, please contact

Study Coordinator:

Charlotte Engebrecht

Charlotte_Engebrecht@URMC.rochester.edu

OR

Karnavaal Al-Rubayie

Karnavaal_AlRubayie@URMC.Rochester.edu



RSRB Approval Date: 12/8/2025

Development of a patient-reported outcome measure for Pompe disease.

What: Researchers at the University of Rochester are interested in creating a patient-reported outcome measure that will assess the

health, symptoms, and disease burden of individuals with Pompe disease. This study is being conducted by Dr. Chad Heatwole from the University of Rochester's Department of Neurology. This study aims to identify the symptoms that have the greatest impact on quality of life for individuals with Pompe disease and will help guide future research.

What's involved: As a participant in this study, you will participate in a Zoom interview with a study coordinator, where you will talk about the symptoms of Pompe disease that you experience and that have the greatest impact on your daily life. This interview will take approximately 30-60 minutes and will be audio recorded, transcribed, and data analyzed. All responses will be coded and identifying information will be strictly confidential with access limited to research staff.

Who can participate: Individuals with Pompe disease ages 18 years and older who live in the United States and speak, read, and understand English.

How to participate: Interested participants can reach out to a study coordinator:

Charlotte Engebrecht

Phone: (585) 275-8605

Email: Charlotte_Engebrecht@URMC.rochester.edu

Karnavaal Al-Rubayie

Phone: (585) 275-8586

Email: Karnavaal_Alrubayie@URMC.rochester.edu

Any questions or comments can be directed to the study coordinators.

A Resource Worth Bookmarking: American Society of Gene & Cell Therapy (ASGCT) Patient Education Hub

When you're living with Pompe disease or caring for someone who is, staying informed about emerging treatments can feel both exciting and overwhelming. That's why we wanted to share a free resource we think our community will love: the ASGCT [Patient Education website](#).

The site was built with patients and families in mind, and the language is clear and approachable. Most importantly for our community, there's a dedicated page on Pompe disease and gene therapy that explains how the disease affects the body, how gene therapy could help, and where current research stands.

Beyond Pompe, the site covers how cell and gene therapies work, how clinical trials are structured, and what to expect if you ever consider participating in one. There are also videos, webinars, and a glossary to make the science more accessible.

Knowledge is empowering, especially when navigating a rare disease. We hope this becomes a go-to resource for you and your family.

[Explore the Pompe Disease Page](#)

Community & Events

Duke Virtual Adult Pompe Conference 2026 — Registration Now Open!



Registration for the 2026 Duke Virtual Adult Pompe Conference is now live!

Name: Duke Adult Pompe Conference 2026

Date: Saturday, March 28, 2026

Time: 7 a.m. CST / 8 a.m. EST

Have photos you'd like to include in the patient slideshow or questions about this event? Send them to dukepompe@duke.edu.

Register Now!

Celebrating Creativity

Meet the Artist — Lucas Garrett



Photo credit: Stephani J. Bartik

Lucas Garrett, aside from being the AMDA's Editor and Community Contributor, works primarily as a musician in the Capital Region of New York. A musician living with Pompe disease, Garrett has embodied resilience throughout his career.

Diagnosed at five months old, Pompe disease has been a part of Garrett's life from the beginning, yet his songs convey a well of material far outside his diagnosis. Tackling topics such as love, regret, and joy — all paved with a thematic sense of nostalgia — Garrett's songs are boosted by his unique vocal stylings.

With a voice described as a "rumbling baritone," Garrett "churns out smart, catchy rock tunes that growl in some places, jangle in others." (Amy Biancolli, *Times Union*).



Lucas Garrett

Michigan



The lead single, "Michigan," from his latest record, [Bad Karma](#), has been met with praise:

"Michigan" has a lovely way of addressing the positives and negatives that come along with having a special person in your life... The song ends with the lyric "There's no point in lying, It would've never happened without you." — which perfectly wraps up what the song is about. It's the full circle moment when we can accept how we've changed after the relationship has come to an end." - Lauren Hunter, NYS Music.

"Michigan" has also been nominated for Record of the Year at **Capital Region Thomas Edison Music Awards**.

The independent film "Deb & Seth Save the World" by Dirty Sweater Productions features Garrett's instrumental track, "Loosey Goosey."

Garrett is currently promoting his latest record, *Bad Karma*, while continuing to actively pursue projects on and off the stage all around New York's Capital Region.

You can hear *Bad Karma* on all popular streaming platforms. Be sure to visit the [artist's](#) website to stay up-to-date with his latest projects.

National Craft Month: A Look at What Our Team Makes

National Craft Month feels like the perfect time to celebrate something we don't always talk about: the creative lives our team members carry outside of their advocacy work. From painting on canvas and hand-decorating ornaments to the quiet focus of diamond dot pictures and

the satisfying precision of cross-stitching, our team finds joy and restoration in making things. Some of us bedazzle, some fold and cut and layer through paper crafts, and some do a little of everything depending on the season or mood. Creativity looks different for everyone, and that variety is part of what makes it so meaningful. This month, we'd love to know: what do you make?

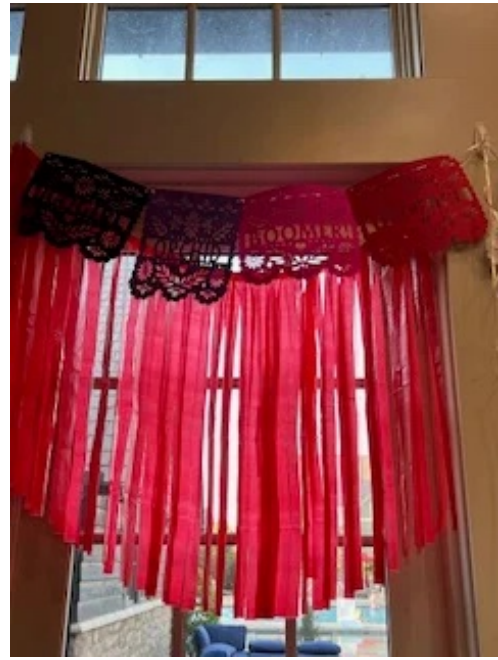
Paintings By Andrea Faris





Crafts by Juls Williams





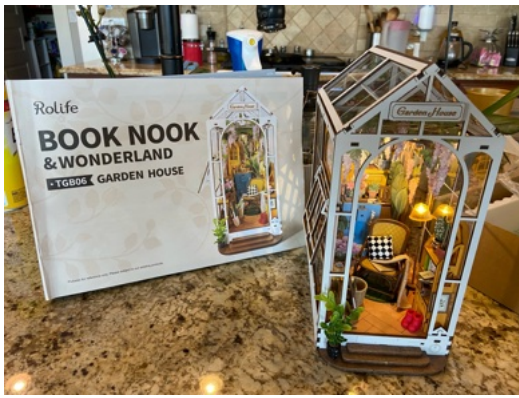
**Diamond Dot Paintings by Marsha
Zimmerman**



Cross-Stitching by Matt Zimmerman



Crafts by Morgan Burroughs



Paintings by Orchid Williams (daughter of Jul's Williams)





Observances



Monthly Observances

[National Craft Month](#): There is something quietly powerful about making something with your hands, a project that begins as an idea and slowly takes shape through patience and small, deliberate steps. Craft invites us to slow down, stay present, and find meaning in the process, not just the finished product. If our Celebrating Creativity feature this month inspired you, consider this your nudge to pick up something new or return to something you love.

Daily Observances

[Caregiver Appreciation Day](#) | [March 3](#): Caregiving is one of the most consistent and often invisible acts of love, showing up day after day in ways both big and small. Today is a moment to pause and acknowledge those who hold others steady, who ask the questions, remember the details, and make hard things a little more manageable. To every caregiver in this community: you are seen, and your presence matters more than words can say.

[National Napping Day](#) | [March 10](#): Rest is not a reward for finishing everything else possible. Today offers a simple, well-timed reminder that honoring your body's need for rest is not indulgence; it is a form of good stewardship. If there is ever a day to listen to what your body is asking for, let it be today.

[National Let's Laugh Day](#) | [March 19](#): Laughter has a way of surfacing even in the most unexpected moments: a shared joke, an absurd inconvenience, a story that somehow becomes funnier with time. It does not minimize the hard things; it simply reminds us that lightness can coexist with them. Today is permission to find the humor where you can and let it linger a little longer than usual.



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<https://amda-pompe.org>

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AMDA

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