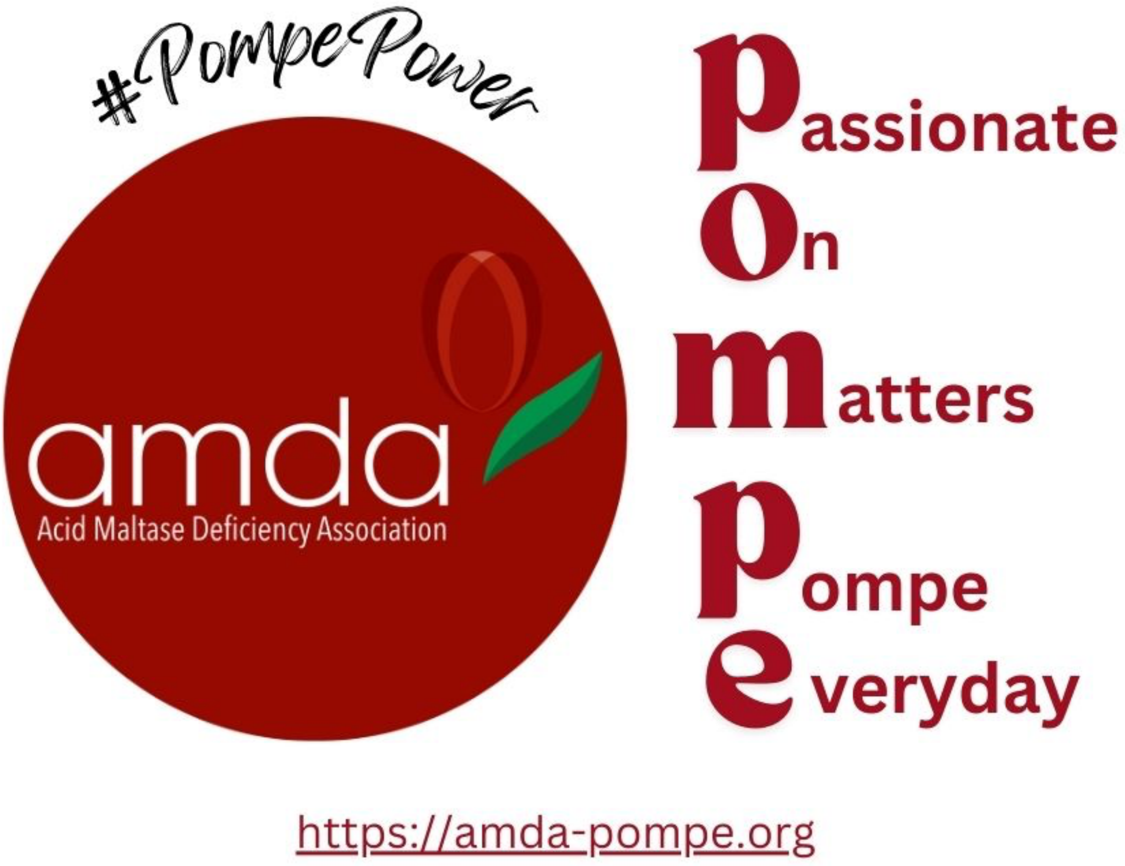
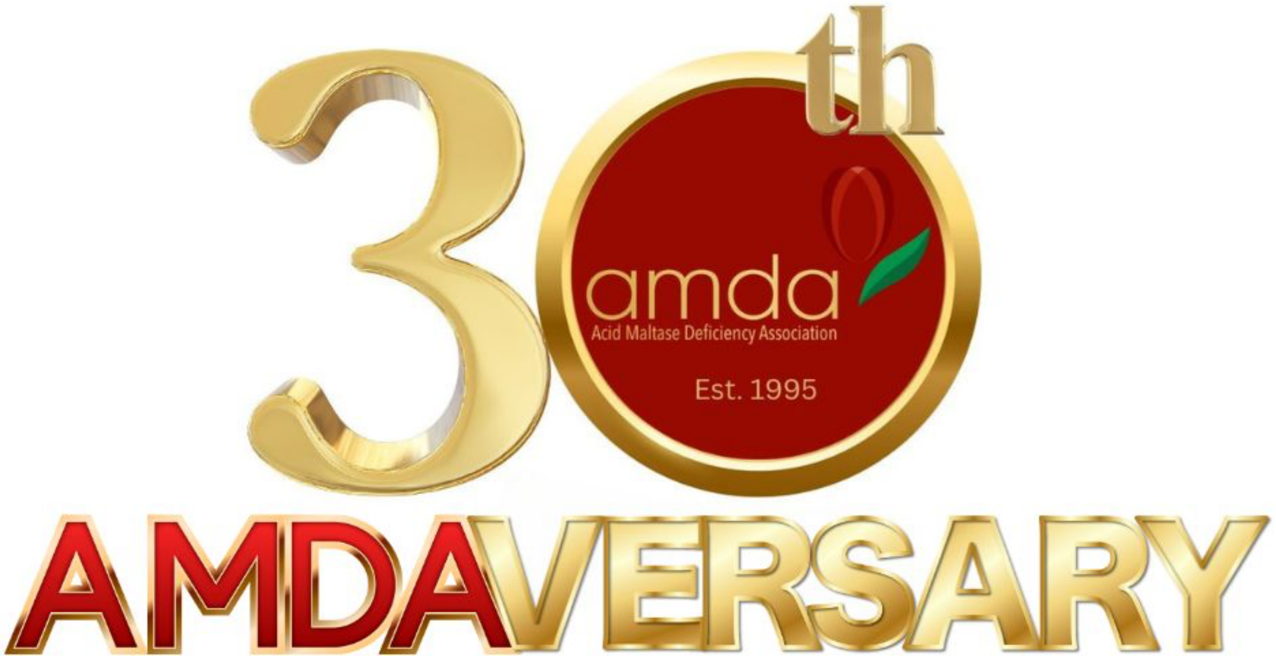
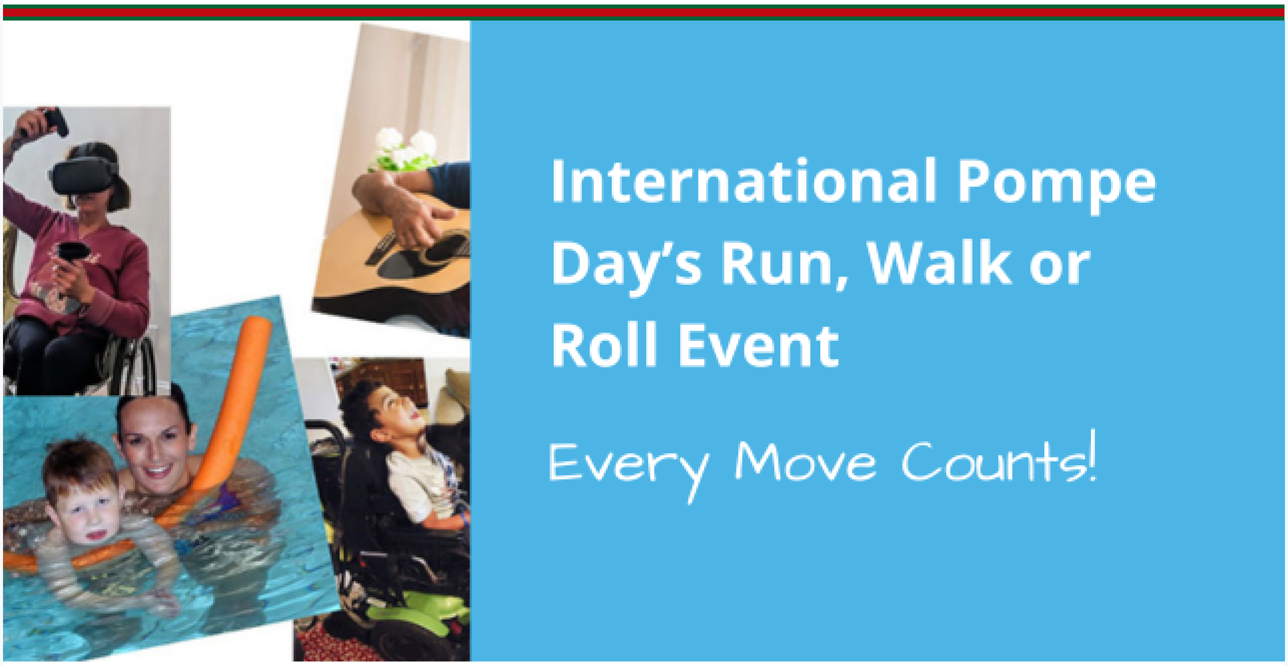

#PompePower
amda
Acid Maltase Deficiency Association
Passionate
On
Matters
Pompe
Everyday
https://amda-pompe.org


30th
amda
Acid Maltase Deficiency Association
Est. 1995
AMDAVERSARY

April 2025

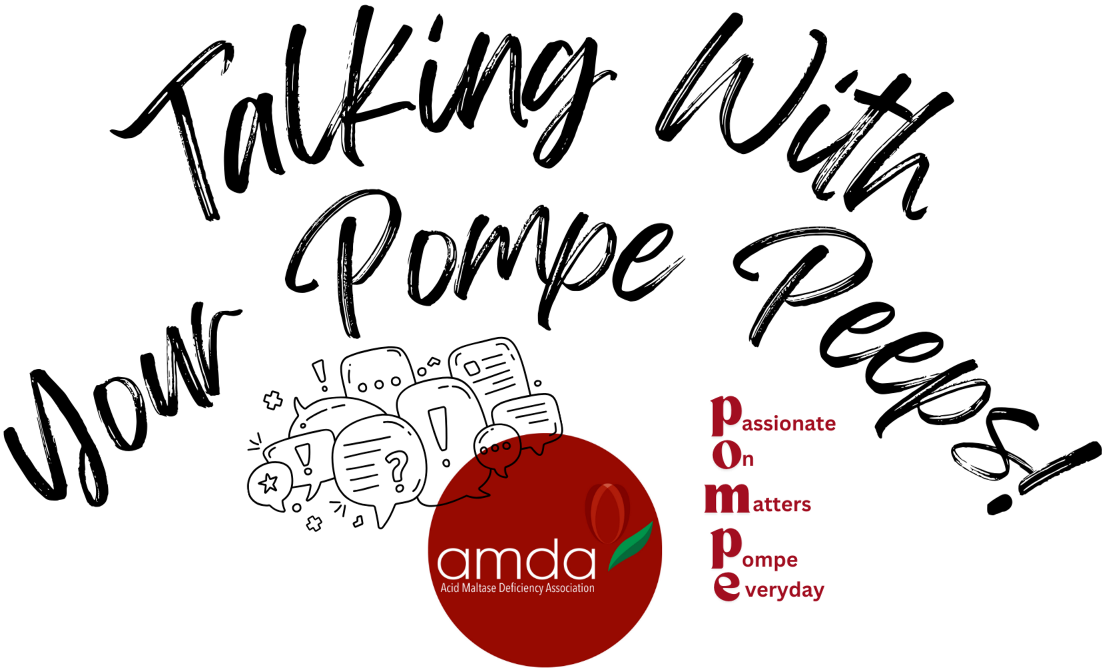
AMDA Newsletter



Join the International Pompe Association for their virtual Run, Walk or Roll event in celebration of International Pompe Day! Taking place from **April 1st to April 15th,** this event is all about raising global awareness for Pompe disease. **Registration is open through April 14th,** so don't wait—get involved, share your journey using the hashtags *#EveryMoveCounts #PompeAwareness #InternationalPompeDay2025*, and let's come together in resilience and unity!

For more information on the IPD Run, Walk or Roll event, visit the International Pompe Day website.

Register here



Has this ever happened to you? You are talking with your friends or family about the struggles of living with Pompe disease, and they offer up the most unhelpful, uninsightful piece of unsolicited advice you have ever heard. How did you react? Join us **Tuesday, April 15, 2025** at **12 PM CT / 1 PM ET** for our next *Talking With Your Pompe Peeps Session*. Moderated by **Tiffany House**, President of the AMDA, this session is titled, **The Good, The Bad and The Ugly: How to Approach Unsolicited Advice and Unexpected Actions That Made Your Day**. This session is all about the characteristics, behaviors, and kindnesses that mean the most to you from people who are not living with Pompe disease and the most annoying or unsolicited advice you've received.

**** 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.***

Register now

Meeting Details

Title: The Good, The Bad and The Ugly: How to Approach Unsolicited Advice and Unexpected Actions That Made Your Day

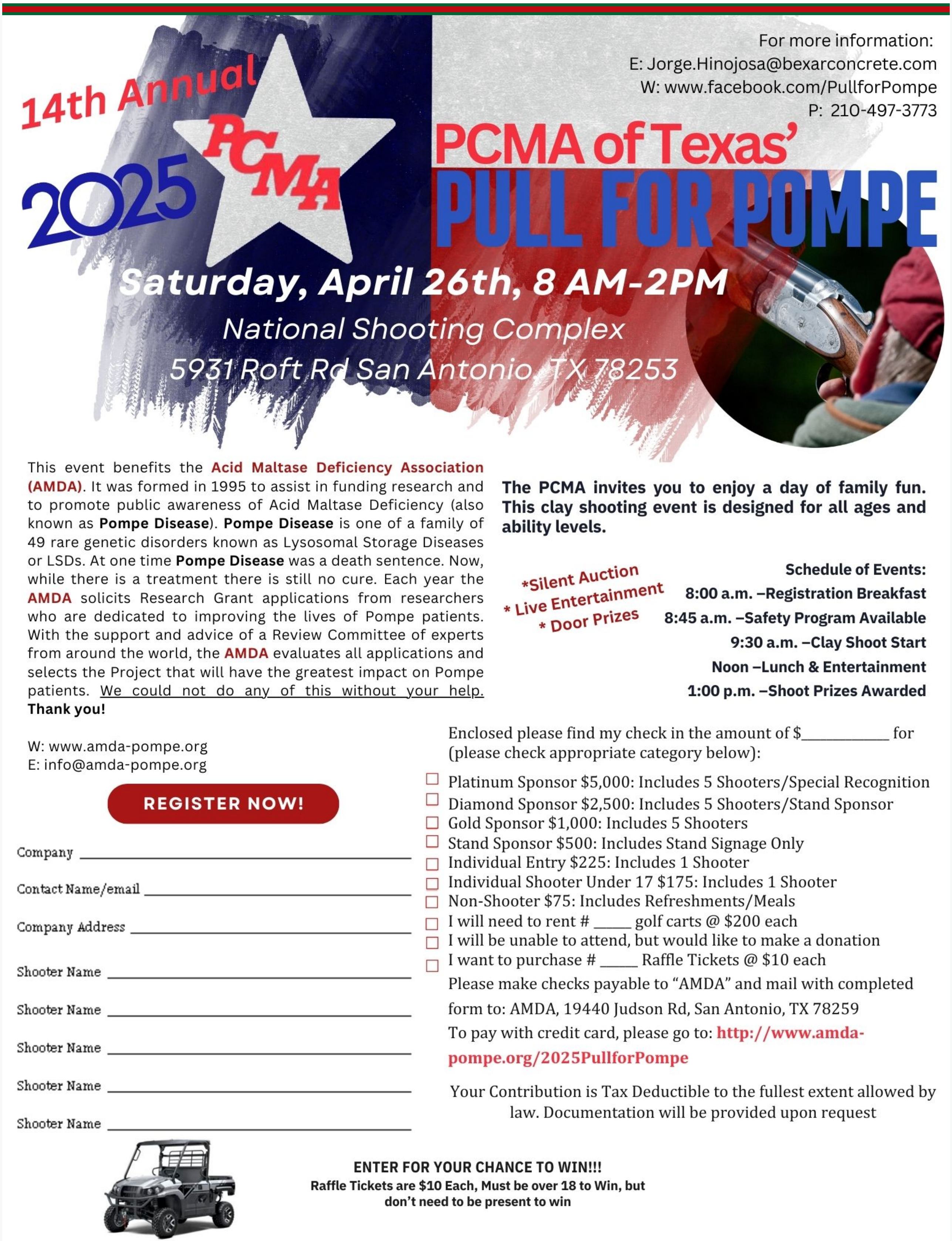
Date: April 15, 2025

Time: 12 PM CT / 1 PM ET

Moderator: Tiffany House

Summary:
Many patients have shared the common experience of receiving unsolicited advice from well-intentioned friends or family members—suggestions such as lifestyle changes, home remedies, or long-held beliefs passed down through generations. While often meant to help, this advice can feel misinformed or dismissive, especially coming from individuals who do not live with the challenges of Pompe firsthand. We will explore personal reflections on these experiences, discussing not only the kinds of unsolicited advice that have felt unhelpful or frustrating, but also the moments when support from others has felt truly meaningful. We will consider what qualities, behaviors, or simple acts of kindness from those outside the Pompe community have provided real comfort, validation, or encouragement. This will be a space for open, respectful conversation where all voices are welcome—whether you wish

to share your story or simply listen and connect with others who understand your journey.



For more information:
E: Jorge.Hinojosa@bexarconcrete.com
W: www.facebook.com/PullforPompe
P: 210-497-3773

14th Annual 2025 PCMA

PCMA of Texas' PULL FOR POMPE

Saturday, April 26th, 8 AM-2PM
National Shooting Complex
5931 Roft Rd San Antonio, TX 78253

This event benefits the **Acid Maltase Deficiency Association (AMDA)**. It was formed in 1995 to assist in funding research and to promote public awareness of Acid Maltase Deficiency (also known as **Pompe Disease**). **Pompe Disease** is one of a family of 49 rare genetic disorders known as Lysosomal Storage Diseases or LSDs. At one time **Pompe Disease** was a death sentence. Now, while there is a treatment there is still no cure. Each year the **AMDA** solicits Research Grant applications from researchers who are dedicated to improving the lives of Pompe patients. With the support and advice of a Review Committee of experts from around the world, the **AMDA** evaluates all applications and selects the Project that will have the greatest impact on Pompe patients. We could not do any of this without your help. **Thank you!**

W: www.amda-pompe.org
E: info@amda-pompe.org

The PCMA invites you to enjoy a day of family fun. This clay shooting event is designed for all ages and ability levels.

*Silent Auction
* Live Entertainment
* Door Prizes

Schedule of Events:
8:00 a.m. –Registration Breakfast
8:45 a.m. –Safety Program Available
9:30 a.m. –Clay Shoot Start
Noon –Lunch & Entertainment
1:00 p.m. –Shoot Prizes Awarded

REGISTER NOW!

Company ______________________________
Contact Name/email ______________________________
Company Address ______________________________
Shooter Name ______________________________
Shooter Name ______________________________
Shooter Name ______________________________
Shooter Name ______________________________
Shooter Name ______________________________

Enclosed please find my check in the amount of $___________ for (please check appropriate category below):

☐ Platinum Sponsor $5,000: Includes 5 Shooters/Special Recognition
☐ Diamond Sponsor $2,500: Includes 5 Shooters/Stand Sponsor
☐ Gold Sponsor $1,000: Includes 5 Shooters
☐ Stand Sponsor $500: Includes Stand Signage Only
☐ Individual Entry $225: Includes 1 Shooter
☐ Individual Shooter Under 17 $175: Includes 1 Shooter
☐ Non-Shooter $75: Includes Refreshments/Meals
☐ I will need to rent # _____ golf carts @ $200 each
☐ I will be unable to attend, but would like to make a donation
☐ I want to purchase # _____ Raffle Tickets @ $10 each

Please make checks payable to "AMDA" and mail with completed form to: AMDA, 19440 Judson Rd, San Antonio, TX 78259

To pay with credit card, please go to: **http://www.amda-pompe.org/2025PullforPompe**

Your Contribution is Tax Deductible to the fullest extent allowed by law. Documentation will be provided upon request

ENTER FOR YOUR CHANCE TO WIN!!!
Raffle Tickets are $10 Each, Must be over 18 to Win, but don't need to be present to win

Contribute to Pompe Research—MAKE YOUR VOICE HEARD!

Would you like to make your voice heard and help shape future Pompe research? We are excited to invite you to participate in the **IPA/Erasmus MC Pompe Survey**.

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.

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

Participate here

Looking For Patient Volunteers to Participate in Surveys/Panels With

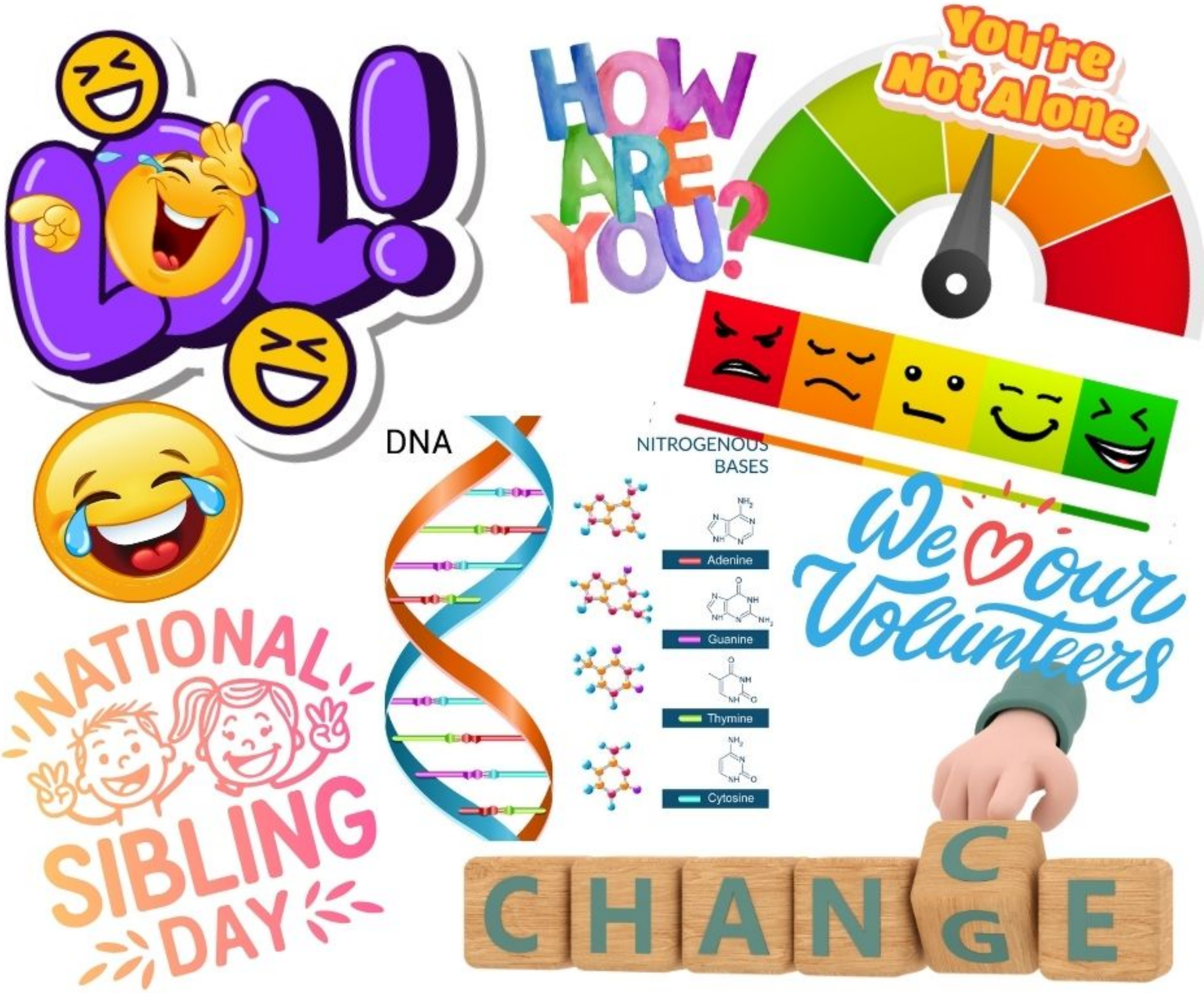
Industry!

The AMDA is often contacted by Biotech companies and other organizations needing volunteers for special projects, surveys or other Pompe disease related initiatives.

If you would like to be considered when we get asked for these types of volunteers, please fill out the following form. The AMDA will use the information on this form to see if you are qualified. If you are, the AMDA will email you with the details and if you are interested in volunteering, the AMDA will send your name and email address to the requesting company's representative/project manager, and they will contact you directly. If you have any questions or need more information, please contact our Patient Advocate, Marsha Zimmerman, at marzim50@gmail.com.

Take me to the form!

April Observances



Monthly Observances

National Humor Month: Humor is a vital contributor to our well-being. Smiling, laughing, and embracing playfulness are deeply connected to how we showcase our personalities, making them some of our most admirable traits. When we learn to laugh at ourselves, we become better equipped to navigate the world. Laughter and lighthearted fun elevate our heart rate and boost circulation, delivering oxygen to the brain and vital organs. With a twinkle in our eyes, stress and pain fade as feel-good hormones course through our bodies, leaving us healthier and happier. Add more humor to your life! Share some of your humor on our social media! *#NationalHumorMonth*

National Stress Awareness Month: Stress is a common experience for everyone. While a small amount of stress can actually be beneficial, excessive stress can harm both our emotional and physical well-being. Striking a healthy balance is key to leading a fulfilling and productive life. Challenge yourself this month to distinguish between positive and negative stress and carve out time and a space for serenity amidst the busyness. Exercise, caffeine reduction, and doing something fun can also help! Check out some of our *Talking With Your Pompe Peeps* (TWYPP) *Series* related to stress and balance:

- Balancing Pompe (School, Work & Life): How Do You Balance Yours?
- Kaizen Your New Year's Resolutions: Small Steps, Big Success!
- The Holidays - How to deal with stressors and fun family traditions

Daily Observances

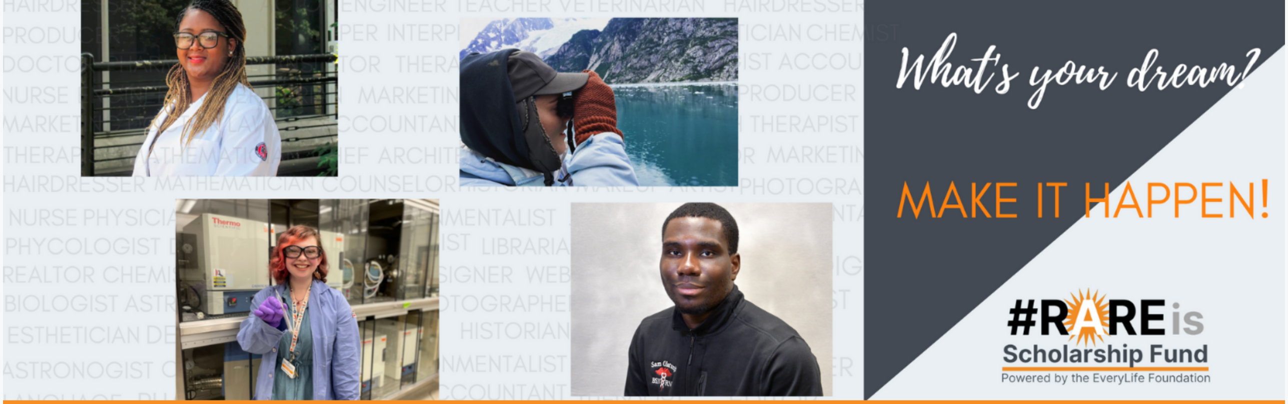
National Siblings Day, April 10th: Siblings—our greatest allies or fiercest rivals. They can be our toughest competitors, our strongest sources of encouragement, and the keepers of our most mortifying memories. How many siblings do you have? Do you find yourselves at odds, or are you each other's biggest cheerleaders? Share a quick memory on our social media. *#NationalSiblingsMonth*

National Volunteer Recognition Day, April 20th: We celebrate the incredible impact of those who dedicate themselves to assisting others. Their kindness benefits both people and animals, inspiring all of us to work toward a brighter future. Remember to show gratitude to those who step outside their routine to make a difference. *#VolunteerRecognitionDay*

National Take a Chance Day, April 23rd: Unfulfilled goals and dreams are a common part of life. But what if today marked the beginning of turning them into reality? A single step forward is progress worth celebrating—Take a Chance Day; Just Do It! See our TWYPP Series: Kaizen Your New Year's Resolutions: Small Steps, Big Success!

National DNA Day, April 25th: Honoring the discovery of DNA's double helix in 1953 and the completion of the Human Genome Project in 2003, this is a day to recognize breakthroughs in genetics and their impact on science, medicine, and society. Events and activities inspire curiosity about DNA's role in our health, identity, and evolution.

#RAREis Scholarship Fund



The #RAREis Scholarship Fund enriches the lives of adults living with rare diseases by providing support for their educational pursuits.

Applications open March 17 - April 28, 2025 at RareScholarship.org

What is the scholarship amount?

- One-time awards of $5,000 each will be granted to up to 104 recipients for the Fall 2025 semester.

Who can apply?

- Anyone diagnosed by a physician as having any form of rare disease regardless of treatment status. A disease is defined as rare when it affects fewer than 200,000 people in the United States. Undiagnosed diseases qualify.
- Anyone age 17 or older and who are residents of the United States.
- Applicants must plan to be enrolled in an accredited educational program for the Fall 2025 semester. Educational programs include full-time or part-time undergraduate or graduate studies, vocational-technical or trade school, or accredited classes. No minimum number of classes or credits are required.
- Students are eligible to apply and receive the scholarship no more than four times.

How do I apply?

- Visit rarescholarship.org and click 'apply now' at the top
- You will be taken to Scholarship America's application portal. Enter your information
- Answer the 1-page essay question about your rare disease journey
- Upload documents: your most recent transcript and Diagnosis Verification Form
- Review & submit your application by April 28, 2025 at 2:00 PM ET

EVERYLIFE FOUNDATION FOR RARE DISEASES

#RAREis Scholarship Fund
Powered by the EveryLife Foundation

AMGEN

Applications close April 28, 2025 at 2 PM ET

The #RAREis Scholarship Fund was established in 2020 to help adults with rare diseases to pursue their dreams through education. Since then, 387 scholarships have been awarded. Thanks to the support of the #RAREis program by Amgen, The EveryLife Foundation is pleased to announce its sixth year of the #RAREis Scholarship Fund, **awarding up to 104 $5,000 scholarships for the Fall 2025 semester.**

The scholarship application is open March 17 through

April 28, 2025 at 2 PM Eastern at RareScholarship.org.

The #RAREis Scholarship is available to applicants who are:

- Ages 17 or older
- Residents of the United States
- Diagnosed by a physician as having any form of rare disease regardless of treatment status. Undiagnosed patients are also encouraged to apply.
- Must by planning to enroll full-time or part-time in undergraduate or graduate study at an accredited two- or four-year college, university, or vocational-technical/trade school for the Fall 2025 semester. There is no minimum amount of credit hours to be part-time.
- Scholarship awards are not renewable, but students may reapply to the program each year they meet the eligibility requirements. The lifetime limit to receive the scholarship is 4 times.