



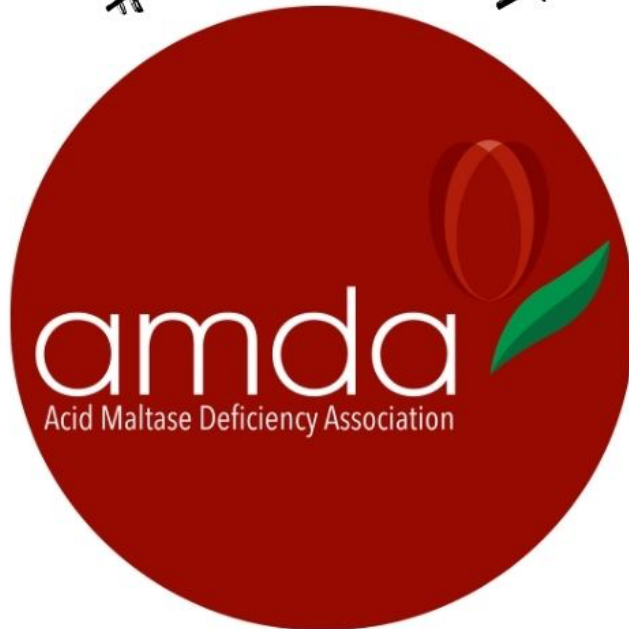
Videos

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AMDA Publications  
Talking With Your Pompe Peeps

*#PompePower*



**p**assionate  
**O**n  
**m**atters  
**p**ompe  
**e**veryday

<https://amda-pompe.org>

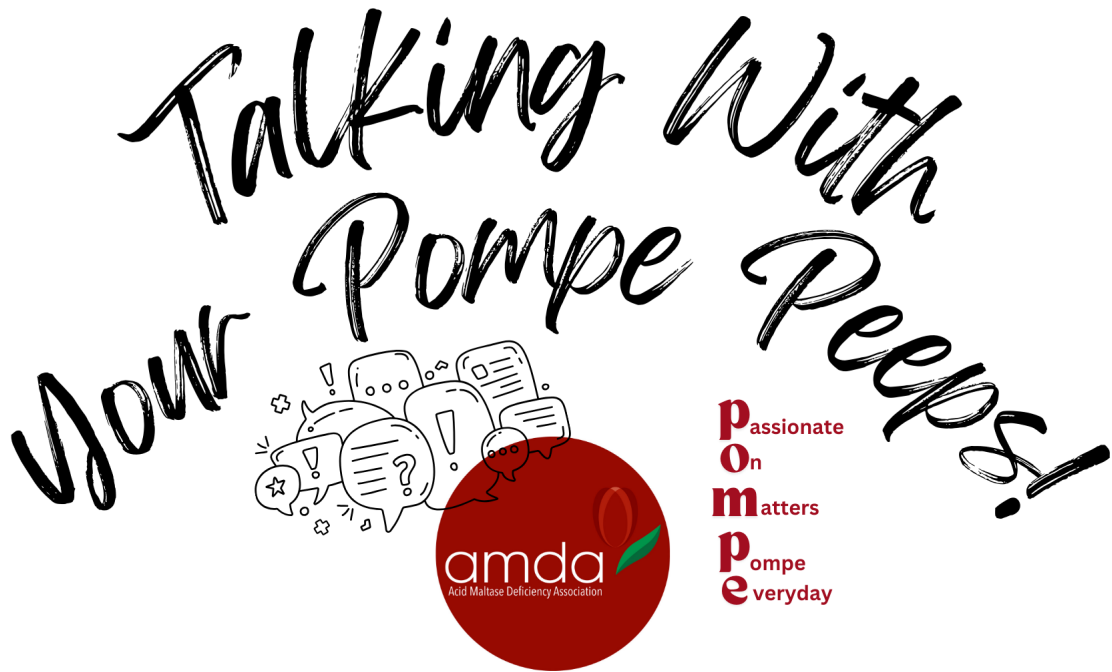


**AMDAVERSARY**

**February 2025**

# AMDA Newsletter

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We are only a month into 2025 and a good portion of people have already given up on their new year's resolutions. Are you struggling keeping yours? If so, join us **Wednesday, February 19, 2025 at 12 PM CT / 1 PM ET** for the fifth session of our *Talking With Your Pompe Peeps Series*. Moderated by **Matt Zimmerman**, Director of IT and Communications for the AMDA, this session is titled, **Kaizen: Adapting a Business Concept for Personal Growth**. In this session, we will explore the Japanese business concept of "Kaizen" and how it can be adapted to help you achieve your new year's resolutions. Bring your personal goals and an open mind and join the conversation!

***\* 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 Here!**

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## Meeting Details

**Title:** Kaizen: Adapting a Business Concept for Personal Growth

**Date:** Wednesday, February 19, 2025

**Time:** 12 PM CT / 1 PM ET

**Moderator:** Matt Zimmerman

### Summary:

"A new year, a new you." Studies show about 80 percent of new year's resolutions are abandoned by the month of February. How are you faring keeping up with yours? If you are struggling along with the rest of us, this session is for you. Pick up those abandoned resolutions and join us as we look at how adapting the Japanese business principle of "Kaizen" can help you with self-improvement, time management, and habit formation. Make 2025 the year you commit to keeping those resolutions!

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## Get To Know The Moderator



### Matt Zimmerman

Matt Zimmerman has been a performer since childhood. An avid theater kid and circus fan, he studied Theater at Texas A&M University in Corpus Christi, Texas and Ensemble-based Physical Theater at Dell'Arte International in Blue Lake, California. He moved to Los Angeles in 2011 where he has been working as a performer

at Universal Studios - Hollywood since. He joined the AMDA as the **Director of IT and Communications** in January of 2022 and loves the work the AMDA is doing!

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### Upcoming Webinar

## Evolving Our Understanding of Pompe Disease - Data Driven Insights

Join us **Wednesday, February 26, 2025 at 1 PM CT / 2 PM ET** for an overview of how NBS enabled significant updates to Pompe epidemiology, and how the strength of this data enables an improved foundation for evolving our understanding of Pompe around the world, and across the full spectrum of

disease. Presented by **Ryan Colburn**, who has a professional background in development, engineering and operations management; as applied to race cars, airplanes, rockets, satellites, and rare diseases. There will be a Q&A session after the presentation.

**Register Now!**

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## Webinar Details

**Title:** Evolving our understanding of Pompe Disease - data driven insights

**Date:** Wednesday, February 26, 2025

**Time:** 1 PM CT / 2 PM ET

**Speaker:** Ryan Colburn

### Webinar Overview:

An overview of how NBS enabled significant updates to Pompe epidemiology (Prevalence, etc), and how the strength of this data enables an improved foundation for evolving our understanding of Pompe around the world, and across the full spectrum of disease. We'll also cover how this foundation relates to other important topics, including some previously covered in this webinar series such as: ABC's of Pompe, Disease Management in the NBS era, Treatment Development, Emerging Research, etc.

## Ryan Colburn

Ryan Colburn has some genetic variants, just like everyone else. In 2015 he learned that some of his variants are associated with a rare metabolic disorder - and has unapologetically altered course ever since. His professional background is in development, engineering and operations management; as applied to race cars, airplanes,

rockets, satellites... and rare diseases. He's a driven student of process (its everywhere) and in this context, applying what he's learned along the way to contribute to the health of the rare disease ecosystem. He's passionate about empowerment and engagement - and shifting the view of patient as "subjects" to one of participants, collaborators, and partners who can help to find the most effective ways to accelerate progress on understanding and solving challenges in rare disease.

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14th Annual

2025



# PCMA of Texas' PULL FOR POMPE

Saturday, April 26th, 8 AM-2PM

National Shooting Complex

5931 Roft Rd San Antonio, TX 78253

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



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

**REGISTER NOW!**

Company \_\_\_\_\_

Contact Name/email \_\_\_\_\_

Company Address \_\_\_\_\_

Shooter Name \_\_\_\_\_

Shooter Name \_\_\_\_\_

Shooter Name \_\_\_\_\_

Shooter Name \_\_\_\_\_

Shooter Name \_\_\_\_\_



**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

**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**

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

The AMDA is excited to announce that the 14th Annual PCMA's Pull for Pompe will take place on Saturday, April 26, 2025 at the National Shooting Complex in San Antonio, Texas! The Pull for Pompe clay shooting event is designed for all ages and ability levels.

[To view the posting, click here.](#)

## February Observances



## Monthly Observances

**National Heart Health Month:** February is American Heart Month, a time to pay special attention to understanding, preventing and treating heart disease - the leading cause of death in the nation. This February, the 58th American Heart Association is urging people all over the country to "reclaim your rhythm." What does that mean? Quite simply, the AHA is encouraging people to reclaim control of their mental and physical well-being. Refer to the links below for more information:

- ['Reclaim your rhythm' during American Hart Month in February | American Heart Association](#)
- [American Heart Month | NHLBI, NIH](#)
- [About American Heart Month: Ways to Get Involved | NHLBI, NIH](#)

**National Self-Check Month:** Every year during February, National Self-Check Month serves as a reminder that we can take charge of our health. Self-check is a means to increase our odds of avoiding chronic disease and other often preventable conditions. We all have our reasons for avoiding a checkup or self-check. We're too busy. We don't want to know the truth. Or,



it just slipped our minds. It's time to do your important self-checks and/or visit your healthcare professional for a wellness check. **#NationalSelfCheckMonth**

**National Snack Food Month:** It's snack time! So this month, focus on snacking in the healthiest ways possible and still thoroughly enjoying treats between meals! Most days, we need a snack or two (or 7) to make it through the day... and if we choose nutritious choices, snacking more can make a positive impact on our overall health; believe it or not, it can even help with weight loss! Use **#NationalSnackFoodMonth** or **#SnackFoodMonth** to post your favorite healthy snack choices on social media.

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## Daily Observances

**National Wear Red Day, February 7th:** National Wear Red Day is supported by the American Heart Association and celebrated in conjunction with national heart health month. It focuses specifically on raising awareness of women's heart disease and stroke risks. Cardiovascular disease causes 1 in 3 deaths in women every year making it the number one health related killer in women. The good news is 87% of all heart issues are believe to be preventable making awareness, education, research, and resources vital to the cause this holiday supports. So put on your reddest red -- whether it be a lipstick, a pair of pants, or your favorite hat -- and paint the city red.

**National Don't Cry Over Spilled Milk Day, February 11th:** Promotes a positive attitude even when things might not be going your way. No matter who we are or what we do, things happen. Adjust, breathe, and move on-- do not worry or stress over little things; life is too short to let little things bother us. Share how you cope with life's twists and turns: **#Don'tCryOverSpilledMilkDay**

**National Set A Good Example Day, February 26th:** This day encourages us to set good examples that can positively inspire others to pay it forward. A simple act of kindness, helping hand, words of encouragement, mentorship, or simple respect can influence others in many ways: **#SetAGoodExampleDay**

**Rare Disease Day, February 28th:** Rare Disease Day is a global initiative to raise awareness and generate support for everyone who is on a rare medical journey. It takes place on the last day of February.



# NORD's Show Your Stripes for Rare Disease Day

## SHOW YOUR STRIPES

"The zebra is the official mascot for rare disease patients. Historically, medical professionals were told that when they "hear hoofbeats," they should not expect to see a zebra. In other words, look for the more common answer, a horse. Now, we know that one in ten Americans is actually a zebra! It might not be obvious when you look at us, which is why we show our stripes to raise awareness.

Wearing stripes can start a conversation that helps others learn about the prevalence and challenges of rare diseases. **Take a picture of your striped look and share it on social media with the hashtags #ShowYourStripes and #RareDiseaseDay** to join this celebration of the many faces of rare disease.

NORD recently hosted a webinar to kick off the excitement for Rare Disease Day 2025! Watch now to learn how you can #ShowYourStripes, raise awareness and take action.



## Important Dates



April 15th - International  
Pompe Day

April 26th - AMDA Pull for  
Pompe Fundraiser



If you are struggling or just interested in talking to someone, please contact us at [support@amda-pompe.org](mailto:support@amda-pompe.org). We have patients or family members ready and willing to talk to you. You don't have to feel alone.

## AMDA

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Texas 78270 United States

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us.



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