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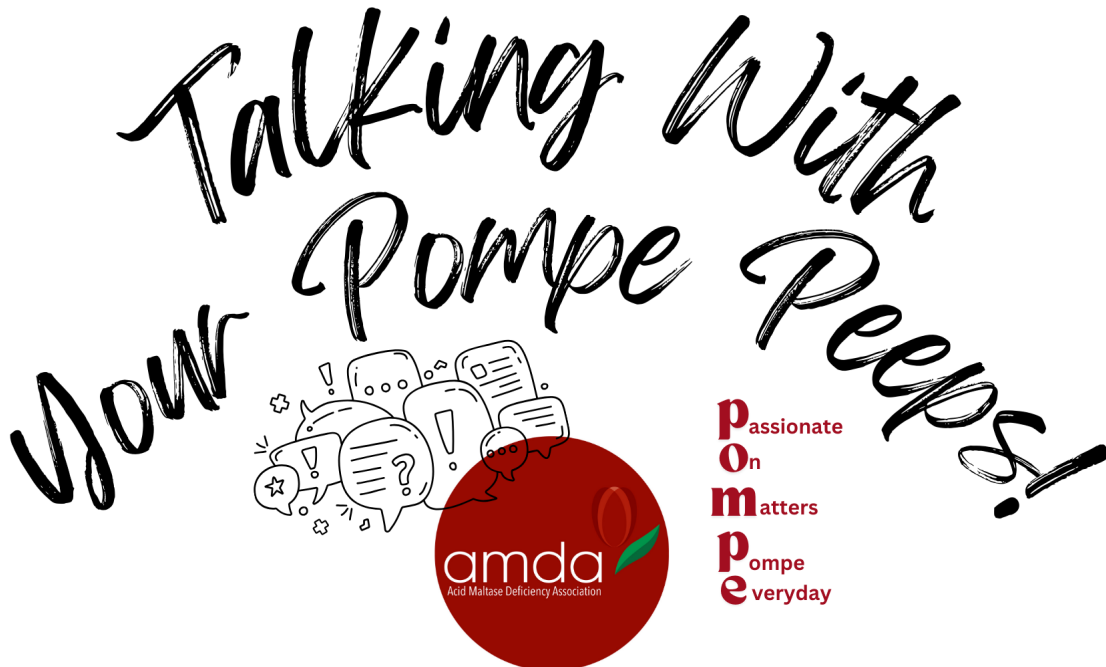


**p**assionate  
**O**n  
**m**atters  
**p**ompe  
**e**veryday

<https://amda-pompe.org>

October 2024

## AMDA Newsletter



Join us **Tuesday, October 22, 2024** at **12 PM CT** for the third session of our *Talking With Your Pompe Peeps Series*. This session will be a true open forum session with no presentation prior to the discussion. Moderated by **Tiffany House**, this session will focus on navigating Halloween with Pompe disease.

***\*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](#)

## Meeting Details

**Title:** Spooky Soirée - Enjoying Halloween with PD for You and Your Kiddos

**Date:** Tuesday, October 22, 2024

**Time:** 12 PM CT

**Moderator:** Tiffany House

**Summary:**

Calling all Pompe Parents! Are you stuck thinking up costume ideas? Have you made an awesome one that you would like to share? This is your chance to share and help each other. Halloween can be a challenging time for many parents when it comes to finding the right costumes. For our Pompe kiddos, there can be added challenges when mobility issues are involved. Do you need help? Do you have suggestions? Join us and share! Please share your past costume photos!

Also related to Halloween . . . have you found creative ways to deal with the massive candy haul? None of us want our kiddos to miss out on these experiences, but how can we modify when needed?



## The AMDA is now on Instagram!

We are upping our social media presence by expanding onto Instagram. Be on the lookout for opportunities to submit photos and videos to be promoted

on our account through patient stories, Halloween costume ideas, and October's daily observances, among others.

Stay up to date on AMDA/Pompe news by following us on Facebook and Instagram! Links below.



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## Coming Soon!

**Coach K's 5-minute workouts** -- if you have a few minutes, try her quick sessions to get you moving and feeling great! These will be posted on our social media accounts. #EveryMoveCounts #TogetherWeAreStrong



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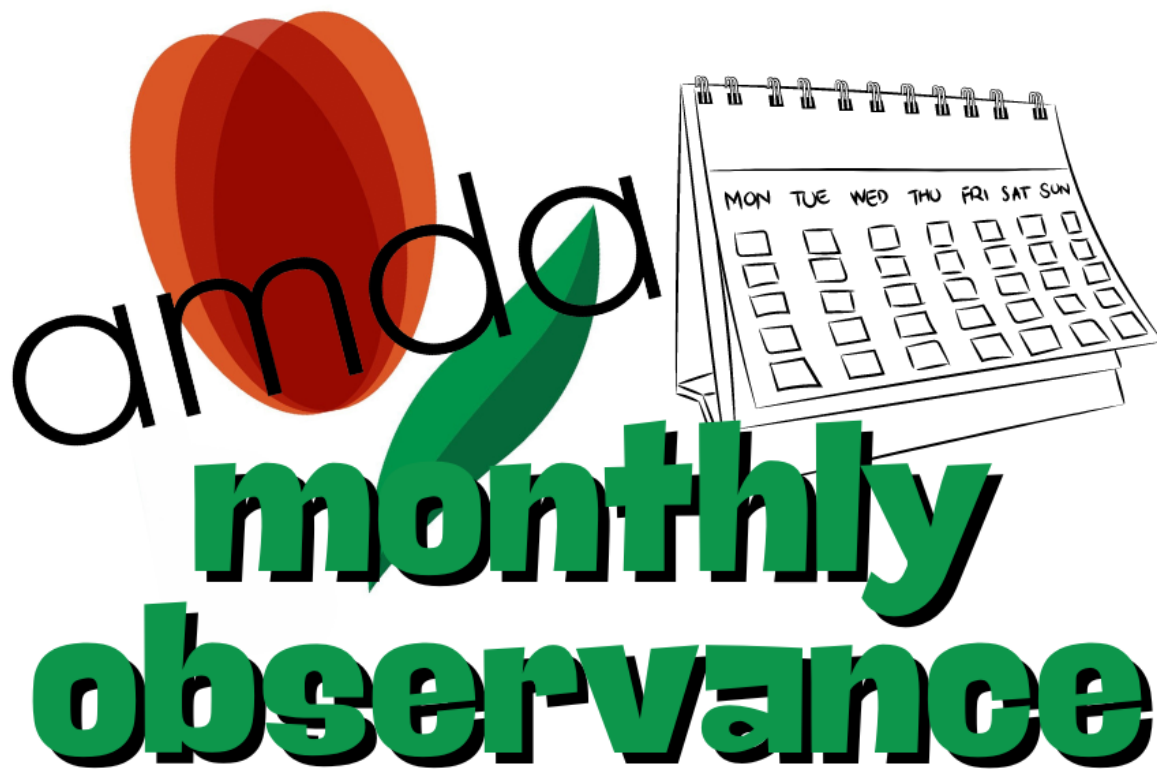
**Welcome the newest member to  
the AMDA team!**

**Social Media Manager**

**Andrea Faris**



As Social Media Manager, Andrea specializes in creating captivating content for all audiences. Her role involves engaging trends to develop content that will foster community engagement. Ultimately, her passion lies in connecting people in authentic and impactful ways in the Pompe community.



**amda**  
**monthly**  
**observance**

## **National Physical Therapy Month**

Nearly every part of the body can benefit from physical therapy. The observance promotes the importance of physical therapy and the role it plays

in improving physical activity and quality of life. During National Physical Therapy Month, give a physical therapist you know a shout-out! Visit these resources for more information:

**Aquatic Exercise: Applications for Pompe Disease w/ Dr. Kendra Lucas**

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## **AMDA Webinars**



**Aquatic Exercise:  
Applications for Pompe  
Disease**

**With:  
Dr. Kendra Lucas**

The unique properties of water provide surprising benefits for individuals struggling with gait difficulty, muscle weakness, cardiorespiratory impairments, balance problems and other symptoms associated with Pompe disease. Aquatic physical therapy offers a safe alternative to land-based programs. The water's buoyancy off-loads joint pressure, allowing you more freedom to move with less energy exertion. Join Dr. Lucas to learn much more about how aquatic exercise can help you stay active and healthy so you can live your best life.

[Watch Here!](#)

**Respiratory Muscle Strength Training in Pompe Disease w/Dr. Harrison Jones**

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## **AMDA Webinars**



**Respiratory Muscle  
Strength Training in  
Pompe Disease**

**With:  
Dr. Harrison Jones**

Title: Respiratory Muscle Strength Training in Pompe Disease Date:

Watch Here!

## Exercise Recommendations for LOPD w/Keyuna (Coach K) Milam

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### AMDA/IPA International Pompe Patient & Scientific Conference 2024



#### Exercise Recommendation for LOPD

With:  
Keyuna (Coach K) Milam

Since the introduction of enzyme replacement therapy (ERT) for the treatment of Pompe disease in 2006, patients and medical specialists have been searching for treatments additional to ERT which may further support patients' fitness and physical functioning. Therefore in 2011 we started our research on the safety and efficacy of an exercise training program in mildly affected adult patients with Pompe disease. Patients followed a standardized training program, consisting of aerobic training, muscle strength training and core stability training, 3 times a week for 12 weeks under supervision of physiotherapists near their home. After 12 weeks we could conclude that the exercise training could be performed safely and that it helped to improve endurance, core stability and muscle function. Furthermore patients were less fatigued and experienced less pain after the training period. More recently we investigated the long-term effects of this exercise training program and long-term physical activity to the WHO norm. We were able to show that patients who met the 2010 WHO healthy physical activity norm performed better on endurance, muscle strength and function compared to patients not meeting this norm. The majority of outcomes, including endurance and muscle strength, tended to be higher in the active patients of the 2011 training cohort who continued the program compared to the active control patients. So, now we know, that long-term healthy physical activity leads to physical benefits and a personalized exercise training program may have additional favorable effects in mildly affected adult Pompe patients, but how is this for the more severely affected patients and children with Pompe disease? So, now we know, that long-term healthy physical activity leads to physical benefits and a personalized exercise training program may have additional favorable effects in mildly affected adult Pompe patients, but

how is this for the more severely affected patients and children with Pompe disease? In this workshop results of more personalized lifestyle interventions consisting of exercise training and high-protein diet from different research groups will be discussed. Furthermore we will discuss how to implement a healthy physical active lifestyle in daily living and future research.

Watch Here!

## Daily Observances (please share a short comment of your observance on our social media)

**National Hero Day**

OCTOBER 8TH

*National Sweetest Day. October 19th*

National Kick-Butt Day  
October 14th



**NATIONAL HORROR MOVIE DAY**

**OCTOBER 23RD**

- **National Hero Day, October 8th:** Honors the real-life heroes who inspire us to be the best person we can possibly be. Today, let's spend a little extra time thanking those who go above and beyond to care for those who need help. If asked to define the word hero, many of us will name the qualities that demand a person rise above, the qualities that genuinely drive a person to be stronger, smarter, kinder and more than the average human being. They are the people who give when they have

nothing to give. Heroes act before anyone else realizes there's a problem. They volunteer to put someone else before them. Today tell and honor your (s)hero(s).

- **National Kick-Butt Day, October 14th:** The day aims to motivate toward goals or just get through the day, week, or whatever you're doing! We all have a purpose. Not all goals have to be weighty or long-term, even the day-to-day count (i.e., Tiffany's Spoon Theory from our last TWYPP series, Balancing Pompe; visit our website for recording). So go kick-butt!
- **National Sweetest Day, October 19th:** For over 100 years, National Sweetest Day encourages everyone to be generous even in the smallest ways. This day reminds us that even small tokens improve the lives of those around us. Give a gift to someone who needs a reminder of the sweetness in the world.
- **National Horror Movie Day, October 23rd:** Halloween is in the air bringing together fans of witches, ghouls, zombies, monsters, spiders, and pumpkins. It is also the time when horror movies are available for viewing in theatres, on TV, and on streaming apps. Family friendly ones are available on Disney+ and: [The "31 Nights of Halloween" Schedule | Freeform Updates](#) If you love a good fright, today is the perfect day to be scared by great horror movies!

**AMDA**

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