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May / 2026

## AMDA Newsletter

### Mind, Body, & Community

May arrives with longer days, warmer air, and a reminder that caring for ourselves — mind, body, and spirit — is not a luxury. It is a practice. This month, in recognition of Mental Health Awareness Month, we are shining a light on the emotional and psychological dimensions of living with Pompe disease. These areas of life tie in to the concept of whole-person care, an approach to health that addresses all the physical, behavioral, social, and spiritual needs of an individual, not just treating their disease or symptoms. Inside this issue, you will find our May webinar on mental health and Pompe disease, a celebration of everything our community accomplished at International Pompe Day, and some exciting new community resources to explore. We are grateful, as always, to be traveling this road alongside you.

### AMDA Updates

## May's AMDA Webinar: Mental Health for Pompe Disease — The Importance of Being Understood

WEBINAR • THURSDAY, MAY 14, 2026 • 12 p.m. CT / 1 p.m. ET

**2026  
AMDA  
WEBINAR**

**MENTAL HEALTH FOR POMPE  
DISEASE: THE IMPORTANCE  
OF BEING UNDERSTOOD**

**WITH  
HEATHER SHORTEN,  
NADIA BODKIN, AND JC  
MUYL**

**THURSDAY  
MAY 14, 2026  
12 p.m. CT / 1  
p.m. ET**

**WWW.AMDA-POMPE.ORG**

**REGISTER NOW**

In recognition of Mental Health Awareness Month, the AMDA is proud to partner with Pompe Alliance, the Rare Advocacy Movement, and Mental Health For Rare to bring our community an important conversation about whole-person care.

Living with Pompe disease means navigating far more than its physical realities. The emotional toll, including the uncertainty, isolation, and challenge of finding care that truly sees you, is a dimension of this journey that deserves the same attention we give to everything else. This webinar brings together three advocates at the forefront of mental health and rare disease to explore the unique emotional challenges tied to life with Pompe, why feeling understood matters so deeply, and what meaningful support can look like for our community.

Whether you are someone living with Pompe disease, a caregiver, healthcare provider, or advocate, this is your invitation to be part of a much-needed conversation.

#### **Speakers:**

Heather Shorten, [Pompe Alliance](#)

Nadia Bodkin, [Rare Advocacy Movement](#)

JC Muhl, [Mental Health For Rare](#)

**Date:** Thursday, May 14, 2026 | **Time:** 12 p.m. CT / 1 p.m. ET

[Learn More](#)

[Register Today!](#)

**Disclaimer:** The content provided in this webinar is for informational purposes only and does not constitute an endorsement by the AMDA.

## Talking With Your Pompe Peeps (TWYPP) — Session 14: Let's Talk Diet

TWYPP • THURSDAY, MAY 28, 2026 • 12 p.m. CT / 1 p.m. ET

The banner features a green and red color scheme. At the top left, it says '2026 TALKING WITH YOUR POMPE PEEPS' in green. The AMDA logo is in the top right. A large red circle in the center contains the AMDA logo and the text 'Acid Maltase Deficiency Association'. To the left of the circle, it says 'SESSION 14: LET'S TALK DIET — THE REAL TALK' and 'MODERATED BY: THE AMDA STAFF'. At the bottom left, there is a calendar icon and the text 'THURSDAY MAY 28, 2026 12 p.m CT / 1 p.m ET'. At the bottom right, there are icons for 'OPEN DISCUSSION' and 'SHARE YOUR STORY'. A green button at the bottom right says 'REGISTER NOW'. At the bottom left, there is a globe icon and the URL 'HTTPS://AMDA-POMPE.ORG'.

**2026**  
TALKING WITH YOUR  
**POMPE PEEPS**

amda

**SESSION 14:  
LET'S TALK DIET — THE  
REAL TALK**

**MODERATED BY:  
THE AMDA STAFF**

amda  
Acid Maltase Deficiency Association

THURSDAY  
MAY 28, 2026  
12 p.m CT /  
1 p.m ET

OPEN  
DISCUSSION

SHARE YOUR  
STORY

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

**REGISTER NOW**

Let's be honest: eating well is one thing, but actually sticking to it is another. Life gets busy, cravings are real, and the foods we are told to eat do not always make us excited to be in the kitchen. Add Pompe disease to the mix, and the conversation gets even more layered.

That is exactly why we are dedicating our May TWYPP session to diet, the real talk version. We will kick things off with a few recipes to get ideas flowing, but more than anything, we want to hear from you. What is on your plate? What works? What does not? This is your space to share, swap, and connect with people who genuinely get it.

**Date:** Thursday, May 28, 2026 | **Time:** 12 p.m. CT / 1 p.m. ET

[Learn More](#)

[Register Today!](#)

## Remembering Tiffany House

There are people who shape an organization not just through what they build, but through who they are. Tiffany House was one of those people.

As the President of the AMDA, Tiffany brought her whole heart to this community. Her dedication to the Pompe disease community, her warmth, and the legacy she leaves behind are felt in everything we do.

We are honored to announce that a memorial page in Tiffany's name is now live on the AMDA website. We invite you to visit, learn more about who she was, and share a memory or photo on her Memory Wall. This space belongs to all of us who were fortunate enough to know her, be guided by her, or simply be touched by her story.

[Remember Tiffany](#)

## Advocacy & Science



# Rare Disease Legislative Advocates Youth & Teen Advocacy Day

Do you know a young person between the ages of 10 and 18 who has a rare disease story to tell? The Rare Disease Legislative Advocates Virtual Youth & Teen Advocacy Day is an opportunity for young advocates to connect directly with U.S. Representatives and Senators, learn how to share with policymakers, and find their voice in the broader rare disease movement.

Participants will receive training on effective communication with lawmakers, key policies affecting the rare disease community, and what it really means to advocate for change. **Registration closes Friday, May 22.**

## Training & Event Schedule:

- **May 31, 2026** | 3 p.m. - 4 p.m. ET — Virtual Meet & Greet
- **June 3, 2026** | 5 p.m. - 6 p.m. ET — General Training Webinar
- **June 10, 2026** | 5 p.m. - 6 p.m. ET — Share Your Story with Policymakers
- **June 18, 2026** | 9 a.m. - 5 p.m. ET — Meetings with Members of Congress

*Recordings will be made available to advocates who are unable to attend sessions live.*

**Note:** *This is a third-party initiative. Inclusion does not constitute an endorsement by the AMDA.*

[Register and Learn More](#)

## Community & Events

### You Showed Up — Thank You



This year's International Pompe Day: Run, Walk, or Roll event was something special, and that is because of you.

Together, our community logged **6,406 miles (10,309.9 kilometers)**, rallied **160 participants**, and generated **100 donations** in a single celebration of movement, resilience, and connection. Every step, every mile, and every contribution was a reminder of what this community is capable of when we come together.

Thank you for showing up, for moving, and for representing the Pompe community with so much heart. We are proud to run, walk, and roll alongside every one of you.



# Living Strong with Pompe — A 4-Week Nutrition & Wellness Series

Our friends at the Canadian Association of Pompe are hosting a four-part nutrition and wellness series led by Dr. Seema Kanwal, and we wanted to make sure our community knew about it.

Over four consecutive Saturdays from May 2 to May 23, 2026, Dr. Kanwal is walking participants through the foundations of eating well with Pompe: what to eat, how your body responds, what may be blocking absorption, and how to build habits that actually last. Each session runs one hour, and all sessions are being recorded so you can catch up on anything you miss.

**Dates:** May 2, 9, 16, and 23, 2026, 12 p.m. ET

**Format:** Four consecutive Saturdays, one hour each | All sessions recorded

**Note:** *This is a third-party initiative. Inclusion does not constitute an endorsement by the AMDA.*

[Learn More and Register](#)

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## The Pompe Kitchen — Introducing a New AMDA Community Feature

We are excited to introduce something new: The Pompe Kitchen.

Each month, we will be sharing recipes chosen with the Pompe community in mind, starting with a few favorites from Coach K at [Wanna Go Fit](#). This month's selections are as nourishing as they are delicious!

### Cauliflower Casserole

## CAULIFLOWER CASSEROLE

### Ingredients:

- 2 16 oz bags of frozen cauliflower
- 1 cup of nonfat Greek yogurt
- 1 ½ cups of sharp cheddar cheese
- Sea salt and fresh ground pepper
- Garlic & onion powder
- Chopped green onion

### Directions:

- Preheat oven to 375°F
- In large mixing bowl mix cauliflower, Greek yogurt & 1 cup of the shredded cheese. Season with garlic & onion powder, sea salt and fresh ground black pepper to taste.
- Top with remainder of the shredded cheese.
- Bake covered 40-45 minutes. Remove cover and bake 10 more minutes.
- Top with green onion if desired.

*Enjoy!*



[www.WannaGoFit.com](http://www.WannaGoFit.com)  
[Info@WannaGoFit.com](mailto:Info@WannaGoFit.com)  
210-910-7229

## Veggie Breakfast Casserole

# VEGGIE

## Breakfast Casserole

### Ingredients:

- 32 oz carton of egg whites
- ½ cup sweet onion
- 2 tbsp of minced garlic
- 12 oz carton of choice of mushrooms
- ½ of each red, yellow & orange bell peppers
- 3 handful of fresh spinach
- 1 ½ sharp cheese
- Sea salt and fresh ground pepper
- Garlic & onion powder

### Directions:

- Preheat oven to 400°F (200°C).
- In a skillet, sauté minced garlic, mushrooms, peppers, & onions in 2 tbsp of avocado oil. Season with salt and pepper.
- Remove the skillet from heat and let cool a few minutes.
- In a large mixing bowl mix skillet mix, spinach, egg whites and cheese. Season with garlic powder, onion powder and sea salt and pepper.
- Bake for 30-40 mins covered and 5-10 mins uncovered.
- Use a toothpick or forks to check if done.

*Enjoy!*



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210-910-7229

## Turkey Sausage & Spinach Breakfast Casserole

### TURKEY SAUSAGE & SPINACH

#### Breakfast Casserole

#### Ingredients:

- 32 oz carton of egg whites
- 1 roll of turkey sausage
- ½ cup sweet onion
- 2 tbsp of minced garlic
- 3 handful of fresh spinach
- 1 ½ sharp cheese
- Sea salt and fresh ground pepper
- Garlic & onion powder

#### Directions:

- Preheat oven to 400°F (200°C).
- In a skillet, cook minced garlic, turkey sausage & onions.
- Remove the skillet from heat and let cool a few minutes.
- In a large mixing bowl mix skillet mix, spinach, egg whites and cheese. Season with garlic powder, onion powder and sea salt and pepper.
- Bake for 30-40 mins covered and 5-10 mins uncovered.
- Use a toothpick or forks to check if done.



*Enjoy!*



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[Info@WannaGoFit.com](mailto:Info@WannaGoFit.com)  
210-910-7229

## Turkey Spaghetti with Spaghetti Squash

## TURKEY SPAGHETTI W/ SPAGHETTI SQUASH

### Ingredients:

- 1 lb of 93% lean ground turkey
- 1 roll of turkey sausage
- ½ cup onion
- 2 tbsp of minced garlic
- 1 spaghetti squash
- Spaghetti Sauce of choice
- Sea salt and fresh ground pepper
- Garlic & onion powder
- Cumin
- Italian Seasoning
- Avocado Oil

### Directions:

- Preheat oven to 400°F (200°C).
- Cut spaghetti squash in half. Coat inside of squash lightly with avocado oil and season with sea salt and fresh ground pepper. Bake 40-50 minutes. Let cool.
- In a skillet, cook minced garlic, turkey, turkey sausage & onions. Season with Italian seasoning, cumin, garlic & onion powder, sea salt and fresh ground black pepper.
- Stir in sauce and season to taste.
- Use a fork to shred the inside of the squash into noodle form.
- Season noodles with Italian seasoning and top with sauce.
- Top with parmesan if desired.



*Enjoy!*



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[Info@WannaGoFit.com](mailto:Info@WannaGoFit.com)  
210-910-7229

Good food should feel accessible, not overwhelming. We hope these recipes bring something good to your table.

**Note:** *These recipes are sourced from a third-party provider. Inclusion does not constitute an endorsement by the AMDA.*

# Pompe Family Meet Up



# 2026

## Grant's Giants 4th Annual Pompe Family Meet Up

Mark your calendars. The team at Grant's Giants is bringing the community together for their 4th Annual Pompe Family Meet Up, and it promises to be a weekend worth traveling for.

The event is designed for children and young people living with Pompe disease, both infantile- and late-onset classifications, and their families, though adults living with Pompe are warmly welcome. Set at Bradford Woods, a universally accessible camp in Martinsville, Indiana, approximately 30 minutes from Indianapolis International Airport, the weekend will be filled with community, fun, and education.

Travel stipends are available because Grant's Giants wants every interested family to be able to experience this weekend together.

**When:** October 2-4, 2026

**Where:** Bradford Woods, Martinsville, IN

Register Today

***Note:** This is a third-party event hosted by a fellow Pompe disease nonprofit. Inclusion does not constitute an endorsement by the AMDA.*

## Celebrating Creativity

### A Gallery for the Rare Disease Community — and an Invitation to Be Part of It

The rare disease experience is one that is difficult to put into words, which is exactly why one organization has chosen to express it through art.

[SketchNF](#) is a nonprofit founded by Shilp Shah, a medical student at Johns Hopkins, and his family after his brother Sahil was diagnosed with neurofibromatosis type 1 as an infant. What began as one family's way of processing a rare disease journey has grown into a community of artists, advocates, and families finding connection through creativity.

This July, SketchNF is opening a rare disease art show at the Positive Exposure gallery in New York City, opening July 7, 2026. The show is open to anyone living with a rare disease, any condition, any age, as well as advocates, physicians, nurses, genetic counselors, and anyone touched by the rare disease community. Every piece in the exhibit will be accompanied by its creator's personal story.

We are sharing this with our Pompe community because this space was built for people like us. If you or someone you love has a story to tell through art, we encourage you to submit.

Learn More



★ EMPOWER ★ FUNDRAISE ★ COMMUNITY ★

## **WANT TO BE PART OF AN NYC ART SHOW?**

SketchNF/Rare Square has partnered with Rick Guidotti and Positive Exposure to share the voices of everyone involved in the rare disease journey, from patients and their families to students and providers.

If you would like to participate, please follow the three steps below. If your piece is accepted, it will be displayed in Positive Exposure's New York City art gallery in July!

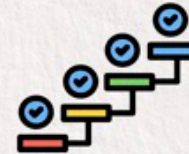
**STEP 1: Fill out the interest form linked to the QR code to learn more about the exhibit and how to participate!**



**STEP 2: Grab your art supplies and get creative! We ask that pieces have a sturdy backing/frame for display!**



**STEP 3: Email [shilp@sketchnf.org](mailto:shilp@sketchnf.org) when your artwork is completed to receive instructions on what comes next!**



**Deadline to complete steps is June 1st.**

Questions? Contact  
Shilp Shah [shilp@sketchnf.org](mailto:shilp@sketchnf.org)

[sketchnf.org](http://sketchnf.org) / [raresquare.org](http://raresquare.org)  
[positiveexposure.org](http://positiveexposure.org)

*Note: This is a third-party initiative. Inclusion does not constitute an endorsement by the AMDA.*

## **Observances**



## Monthly Observances

[Mental Health Awareness Month](#): There is a particular kind of exhaustion that does not show up on any scan or test result. It lives in the spaces between appointments, in the questions asked in the middle of the night that have no easy answers, and in the quiet work of learning to ask for help. For those living with Pompe disease, mental health is not a separate conversation from physical health. This month, we hold space for all of it, and we remind our community that you do not have to carry any of it alone.

We are also sharing two resources from last year that are worth revisiting: our Mental Health Check-in with Daily Wellness Log, and our Self-Care Workbook. Both are available on our Facebook page.



**Acid Maltase Deficiency Association - AMDA** ✓

2025-03-22



Saturday check in! 🌿 How are you feeling today—mentally and/or physically?  
Taking a moment to check in with ourselves is so important. 🧘✨






I've created a wellness log to help track your mood, energy, and overall well-being. It's a great tool if you're looking to be more mindful and intentional about your health.

Feel free to use it, and let me know how you're doing in the comments! ❤️

[#MentalHealthMatters](#) [#WellnessJourney](#) [#SelfCare](#) [#pompe](#)

# MENTAL HEALTH

## Check-in

-  I'M FEELING GREAT
-  I'M DOING OKAY
-  I'M STARTING TO STRUGGLE
-  I'M HAVING A HARD TIME
-  I NEED TO REACH OUT FOR SUPPORT



 Like  Comment  Share



**Acid Maltase Deficiency Association - AMDA** 

2025-02-06



I'm so thrilled to share my Self-Care Workbook with you all!  Whether you're looking to deepen your mindfulness practice, set healthy boundaries, or simply take time for yourself, this workbook is designed to guide you through the process with intention and love. 

If you want downloadable copies of this book email me @ [Faris.amda@yahoo.com](mailto:Faris.amda@yahoo.com)

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# SELF CARE WORKBOOK

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👍 Like    💬 Comment    ➦ Share

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## Daily Observances

[National Clean Your Room Day](#) | May 10: There is something quietly powerful about reclaiming your space. For those managing the daily

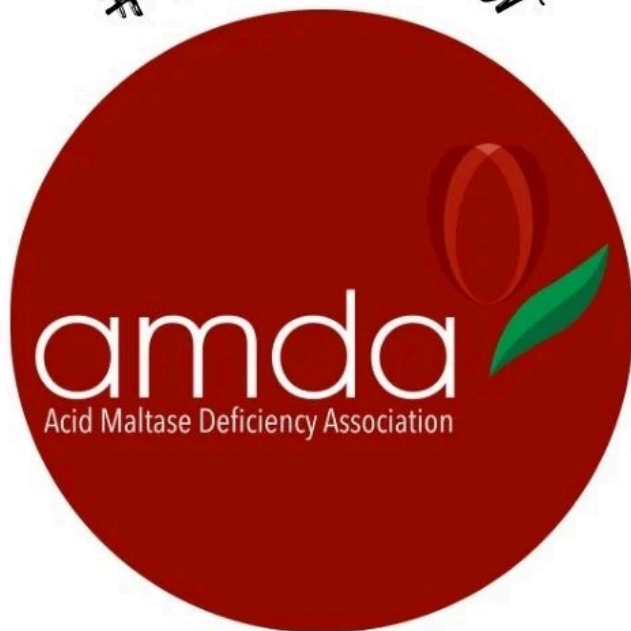
demands of a chronic condition, clutter can accumulate not just in rooms but in routines, in to-do lists, and in the mental load that never fully powers down. Today is a gentle invitation to clear one corner, one drawer, one surface, and notice how a little order on the outside can bring a little ease on the inside.

[National Mental Health Provider Appreciation Day](#) | May 12: Behind every person navigating a rare disease diagnosis is often a quiet constellation of support: a therapist who learned what Pompe disease was in order to show up better, a counselor who sat with uncertainty without rushing off to fix it, a social worker who helped a family find language for something they had never had to name before. Today is for them. The providers who tend to the inner life of this community deserve to know the difference they make.

[Eat More Fruits and Vegetables Day](#) | May 21: Food is one of the most personal and complicated parts of managing life with Pompe disease. What we eat, how our bodies absorb it, and what actually feels good are things that take time and patience to understand. Today is a gentle nudge toward color, variety, and nourishment. Don't view it as a lecture, but as an invitation to explore what eating well can look and taste like for you.

[National Smile Day](#) | May 31: Joy is not the absence of difficulty. It is something that coexists with it, often in the smallest moments: a good meal shared, a laugh that catches you off guard, a message from someone who was thinking of you. On the last day of Mental Health Awareness Month, we want to remind you that you are allowed to feel good, you are allowed to smile, and we are glad you are here. 🌸

#PompePower



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

<https://amda-pompe.org>

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**AMDA**

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