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June / 2026

## AMDA Newsletter

### Step Outside

Summer arrives with an invitation to step outside and into the season, community, and something bigger than any one of us. This month, we are celebrating a remarkable Pull for Pompe that raised thousands of dollars for Pompe disease research, and looking ahead to Rare Across America, where advocates across the country will step into the halls of Congress and make the rare disease community impossible to ignore. There is a lot of energy in this issue, and we hope some of it finds its way to you.

**AMDA Updates**



PCMA PULL FOR POMPE 2026

# Event Recap



All proceeds benefit the AMDA Research Grant



AMDA Team



Amanda Joost



Ryan Colburn

RAISED  
(SILENT AUCTION)  
**\$12,770**

SHOOTERS  
**441**

TEAMS  
**100**

TOTAL FUNDS  
RAISED  
**\$110,000**

Thank you to  
**Ryan Colburn**  
&  
**Amanda Joost**  
for joining us!

[amda-pompe.org](http://amda-pompe.org) • Proudly supporting Pompe disease research

## Pull for Pompe 2026 — Thank You, Texas!

Some days, this community takes your breath away. Pull for Pompe 2026 was one of these days.

With 411 shooters across 100 teams, this year’s event was truly one for the books. The energy on the field was electric from the first pull to the last, and the silent auction alone raised \$12,770, bringing the total funds raised to over \$110,000. Every dollar raised goes directly to the AMDA Research Grant. Formerly the Helen Walker Research Grant, it has been renamed in honor of our beloved late president, Tiffany House, whose dedication to this community will never be forgotten.

We were especially honored to welcome two extraordinary members of the Pompe community to Texas for the event: Amanda Joost and Ryan Colburn. Joost, founder of Marshall’s Mountains, is someone who knows firsthand what it means to build something in service of this community. Colburn, whose work with Rare X to build a patient-owned

Pompe research database is helping put the power of data back in the hands of our community. Having both of you alongside us made this day more meaningful. Thank you for making the trip; the impact of your presence at this event cannot be understated.

To every volunteer, sponsor, and participant who showed up: This community is something truly special. Mark your calendars now. Pull for Pompe 2027 is set for May 1st. We hope to see you there.

Together, we pull for a cure.

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## In Case You Missed It — May Webinar Now Available

A promotional graphic for an AMDA webinar. It features a white background at the top with the text "AMDA Webinars" in large, bold, red letters. Below this is a red rectangular area containing three circular headshots of speakers: Heather Shorten, Nadia Bodkin, and JC Muyl. To the right of the headshots, the text "Mental Health for Pompe Disease: The Importance of Being Understood" is written in white, with a white play button icon overlaid on the word "The". Below the title, the text "With: Heather Shorten, Nadia Bodkin, and JC Muyl" is also in white.

# AMDA Webinars

**Mental Health for Pompe Disease: The Importance of Being Understood**

**With:  
Heather Shorten, Nadia Bodkin, and  
JC Muyl**

Last month, the AMDA partnered with Pompe Alliance, the Rare Advocacy Movement, and Mental Health For Rare to bring our community a long overdue conversation: the emotional and psychological dimensions of living with Pompe disease, and why feeling understood matters so deeply.

Featuring Heather Shorten of Pompe Alliance, Nadia Bodkin of the Rare Advocacy Movement, and JC Muyl of Mental Health For Rare, the recording is now available on our website and YouTube channel for anyone who missed it or wants to revisit it.

Watch Now

## Talking With Your Pompe Peeps (TWYPP) — Session 15: Therapeutic Outlets

TWYPP • WEDNESDAY, JULY 1, 2026 • 1 p.m. CT / 2 p.m. ET

The graphic features a green and white color scheme. At the top left, it says '2026 TALKING WITH YOUR POMPE PEEPS'. The AMDA logo is in the top right. A central circular image shows Trevor Hedrich, a young man with blonde hair wearing a grey shirt and tie, sitting in a wheelchair. To the left of the image, the session title 'SESSION 15: THERAPEUTIC OUTLETS: HOW HOSPITALS CAN REDUCE STAYS AND IMPROVE PATIENTS' PROGNOSIS' is written in white on a green background. Below this, it says 'MODERATED BY: TREVOR HEDRICH'. At the bottom left, there is a calendar icon and the text 'WEDNESDAY JULY 1, 2026 1 p.m. CT / 2 p.m. ET'. At the bottom right, there are icons for 'OPEN DISCUSSION' (a microphone) and 'SHARE YOUR STORY' (two speech bubbles). The URL 'HTTPS://AMDA-POMPE.ORG' is at the bottom left, and a large green button with 'REGISTER NOW' is at the bottom right.

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

amda

**SESSION 15:**  
**THERAPEUTIC OUTLETS:**  
**HOW HOSPITALS CAN REDUCE**  
**STAYS AND IMPROVE**  
**PATIENTS' PROGNOSIS**

**MODERATED BY:**  
**TREVOR HEDRICH**

WEDNESDAY  
JULY 1, 2026  
1 p.m. CT /  
2 p.m. ET

OPEN  
DISCUSSION

SHARE YOUR  
STORY

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

**REGISTER NOW**

Our next TWYPP session is coming up on July 1, and it is one we think will resonate with many in our community.

Because of the deeply interconnected relationship between mental and physical health, this session turns its attention to therapeutic outlets and how hospitals can use them to reduce stays and improve patient outcomes. Moderator Trevor Hedrich, a person living with Pompe disease, will guide the conversation through the strengths and challenges of different therapeutic approaches and what we can do, individually and as a community, to support this idea in practice.

**Date:** Wednesday, July 1, 2026

**Time:** 1 p.m. CT / 2 p.m. ET

[Learn More](#)

[Register Today!](#)



ACID MALTASE DEFICIENCY ASSOCIATION



# Thank You

*with sincere gratitude to*

## The Krueger Family

for your generous support of our community

[amda-pompe.org](http://amda-pompe.org)

### A Heartfelt Thank You to the Krueger Family

Every now and then, an act of generosity reminds us why this work matters and why we are never doing it alone. We recently shared a message of deep gratitude to the Krueger family on our website, whose remarkable donation will help the AMDA keep its doors open and its mission moving forward for every individual and family we have the privilege of serving.

We invite you to read the full message.

[Read More](#)



Fresh Veggies Day is June 16, and we are marking the occasion the best way we know how: with food worth making.

In honor of the occasion, the AMDA is sharing three recipes to help you bring more vegetables into your everyday meals, whether you are cooking for yourself, your family, or anyone who could use a nourishing plate. We hope something here finds its way to your table.

*Click on a recipe card for a downloadable pdf.*



## O'S OVEN ROASTED VEGGIES

Servings: 4+ | Prep Time: 20 minutes | Cooking Time: 30-45 minutes

### Ingredients

- 2 ½ tsp avocado or vegetable oil
- 1 ½ tsp paprika (ajust to taste)
- 1 tsp garlic powder (ajust to taste)
- ½ tsp onion powder (ajust to taste)
- 1 tsp Italian seasoning (ajust to taste)
- ¾ tsp salt (ajust to taste)
- ½ tsp pepper (ajust to taste)
- Potatoes, cut into 1-inch cubes
- 1 small bag broccoli, cut to bite size
- 1 small can or fresh mushrooms
- 1 small bag Brussels sprouts, halved
- Other vegetables as desired (eg., carrots, squash, celery)

### Instructions

1. Preheat oven to 400°F. Prepare vegetables and place in a large baking dish or on a parchment-lined baking sheet.
2. In a small bowl, combine oil, paprika, garlic powder, onion powder, Italian seasoning, salt, and pepper. Pour over vegetables and toss until evenly coated.
3. Roast for 30 minutes. Check for desired tenderness and crispness; add up to 15 additional minutes as needed.
4. Remove from oven. Garnish with Parmesan or preferred cheese if desired. Serve alongside protein and a starch of your choice.

*Tip: Adjust seasonings to individual tolerance — salt, garlic, and onion powder are all optional. Protein (chicken, steak, burger) can be added directly to the baking dish and roasted alongside the vegetables.*



## AUNT TIFFY'S BROCCOLI

Servings: 2-4 | Prep Time: 2 minutes | Cooking Time: 10 minutes

### Ingredients

- 1 bag (12-16 oz) frozen broccoli
- 4 tbsp water
- 3-4 tbsp soy sauce
- Garlic salt to taste
- 1 tsp chicken bouillon (powder or half a cube)

### Instructions

1. Add frozen broccoli to a pan with 4 tbsp of water over medium heat.
2. Sprinkle garlic salt and chicken bouillon evenly over the broccoli.
3. Drizzle soy sauce over the top.
4. Cover with a lid and cook, stirring occasionally, until broccoli is heated through and tender, about 8-10 minutes. Add a splash more water if the pan gets dry before broccoli is done.
5. Taste and adjust seasoning before serving.

*Tip: For a little heat, add a pinch of red pepper flakes.*



## ROTISSERIE CHICKEN POWER BOWL

Servings: 1 | Prep Time: 10 minutes | No cooking required

### Ingredients

- Rotisserie chicken, pulled or sliced
- Pre-washed salad greens
- ½ avocado, sliced
- Handful of cherry tomatoes, halved
- Drizzle of olive oil + fresh lemon juice or dressing of choice
- Optional: small scoop of quinoa or brown rice

### Instructions

1. Add a generous handful of salad greens to a bowl.
2. Top with pulled rotisserie chicken
3. Arrange avocado slices and cherry tomatoes alongside.
4. Add a small scoop of quinoa or brown rice if desired.
5. Drizzle with olive oil and a squeeze of lemon, or your dressing of choice.
6. Serve immediately



PATIENT

# Spotlight

Real stories from the Pompe disease community



## Patient Spotlight — Rachel's Story



*Rachel Foster and her daughter  
Courtney Foster*

*As told by her daughter, Courtney.*

Every story in our community carries the weight of diagnosis, perseverance, and love that shows up in unexpected ways. This month, we invite you to meet Rachel, whose journey with Pompe disease is shared through the eyes of one of the people who know her best.

Her daughter Courtney's telling of Rachel's story is a reminder of why community, advocacy, and connection matter so much.

[Read Rachel's Story](#)

## Community & Events

### 2026 Duke Pediatric Pompe Conference — Registration Now Open

Registration is now open for the 2026 Hybrid Pediatric Pompe Conference, hosted by the Duke team on Saturday, July 11, 2026. Whether you join in person or virtually, this is one of the most important gatherings in the pediatric Pompe calendar, and the Duke team has put tremendous care into making it accessible and meaningful for families and healthcare providers alike.

Upon registering for the conference, a confirmation email with important event details will be sent. Be sure to check your spam folder if it does not arrive in your inbox. Families are also invited to submit photos for the patient slides by July 3 to [dukepomme@duke.edu](mailto:dukepomme@duke.edu). The full conference agenda will be available on the event website soon.

[Register Today](#)

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## BEACONS-NBS Webinar for Health Care Professionals

The Association of Public Health Laboratories (APHL) is hosting a webinar on BEACONS-NBS, an NIH-funded study exploring the feasibility of integrating genomic newborn screening into public health programs. The session will cover study goals, the types of results providers may encounter, referral workflows, and available clinical resources, with a Q&A to follow.

**Date:** Wednesday, June 3, 2026

**Time:** 5:00-5:30 p.m. PT / 8:00-8:30 p.m. ET

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

[Register Here](#)

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## Rare Across American 2026 — Registration Now Open

If you have ever wanted to bring your Pompe story directly to the people who make policy decisions, this is your opportunity. Rare Across America 2026 gives rare disease advocates the chance to meet with members of Congress, both virtually and at their in-district offices, and share firsthand what is at stake for the rare disease community.

The event runs August 10–21, 2026, and registration closes Friday, July 17, 2026.

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

[Register Today](#)

## **Oklahoma Rare Disease Fair — September 30, 2026**

The Oklahoma Rare Disease Fair will bring together patients, families, and advocates for action-oriented discussions around the diagnostic odyssey, genetic testing, and gene therapy. If you or someone you love is navigating the rare disease landscape in Oklahoma, this is a community worth connecting with.

*Note: This is a third-party initiative. Inclusion doesn't constitute an endorsement by the AMDA.*

[Learn More and Register](#)

## **2nd Annual Colorado Rare Disease Fair — October 12-13, 2026**

The Colorado Rare Disease Fair returns for its second year with a two-day program focused on the diagnostic odyssey, genetic testing, and gene therapy. It is an opportunity to connect, learn, and advocate alongside the broader rare disease community.

*Note: This is a third-party initiative. Inclusion doesn't constitute an endorsement by the AMDA.*

[Learn More and Register](#)

## **Advocacy & Science**

### **RDLA Legislative & Community Update**

*The following updates were shared by the Rare Disease Legislative Advocates (RDLA). We are passing them along because staying informed is one of the most powerful things our community can do.*

## Legislation on the Hill

### Home and Community-Based Services (HCBS) Access Act & Long-Term Care Workforce Support Act

Two recently introduced bills aim to expand access to home and community-based care for people with disabilities while strengthening and better compensating the direct care workforce. For our community, where reliable home care can be essential to daily life, both represent meaningful progress.

[Learn More](#)

### FY27 Ag-FDA Appropriations: Rare Disease Innovation Hub

The House Appropriations Committee released

### Fast-tracking Approval for Innovative Rare Disease Therapies (FAIR) Act — H.R. 7953

This bill would allow the FDA to approve drugs within 30 days if they have already been cleared by trusted international regulators. For rare disease patients who have waited years for treatment options, faster access to proven therapies could be life-changing.

[Learn More](#)

### FDA FY27 Congressional Justification

The FDA's FY27 proposals include permanently reauthorizing the

### Improving Care in Rural America Reauthorization Act — H.R. 2493

This bipartisan bill passed the House last month and is now before the Senate. It reauthorizes rural health grant programs through 2030, targeting the provider gaps that many rare disease patients in underserved communities know all too well.

[Learn More](#)

report language encouraging the Senate to include \$5 million in funding for the Rare Disease Innovation Hub, which supports the development of new rare disease therapies.

[Learn More](#)

pediatric review program creating a faster pathway for investigational new drugs to begin early-phase trials, both with direct implications for rare disease drug development.

[Learn More](#)

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## State Level Action

### IL SB 3049 — Illinois Newborn Screening Improvement

This bill seeks to align Illinois' newborn screening program with the Recommended Uniform Screening Panel (RUSP) and recently passed the Senate. Earlier newborn screening means earlier diagnosis, and for conditions like Pompe disease, that timing can change everything.

[Learn More](#)

### CA AB 1887 — Prior Authorization & Step Therapy Reform

This California bill would remove prior authorization and step therapy barriers for drugs treating rare diseases, making it easier for patients to access the treatments their doctors prescribe. For Pompe patients navigating insurance hurdles, this kind of reform matters.

[Learn More](#)

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## Community Action Alerts

*Your voice matters. Here are four ways to take action right now, ordered by urgency.*

### **Act Now — FDA Comments Due June 30**

The FDA is seeking public input on how Patient-Focused Drug Development (PFDD) meetings have shaped drug development and community advocacy. Comments are due June 30, 2026. If PFDD has touched your rare disease journey, your perspective deserves to be heard. Contact [patientfocused@fda.hhs.gov](mailto:patientfocused@fda.hhs.gov) with questions.

**Submit Your Comment**

### **Cosponsor the Medical Foods & Formulas Access Act — S.3304 / H.R. 5684**

Ask your legislators to cosponsor this bill, which would require Medicaid, CHIP, Medicare, and the Federal Employees Health Benefit Program to cover the medical foods and formulas that many in the rare disease community depend on.

**Take Action**

### **Support the Rare Disease Innovation Hub — FY 2027 Funding**

Contact your members of Congress and ask them to support \$5 million in FY 2027 funding for the Rare Disease Innovation Hub, which is working to transform how rare disease therapies are developed.

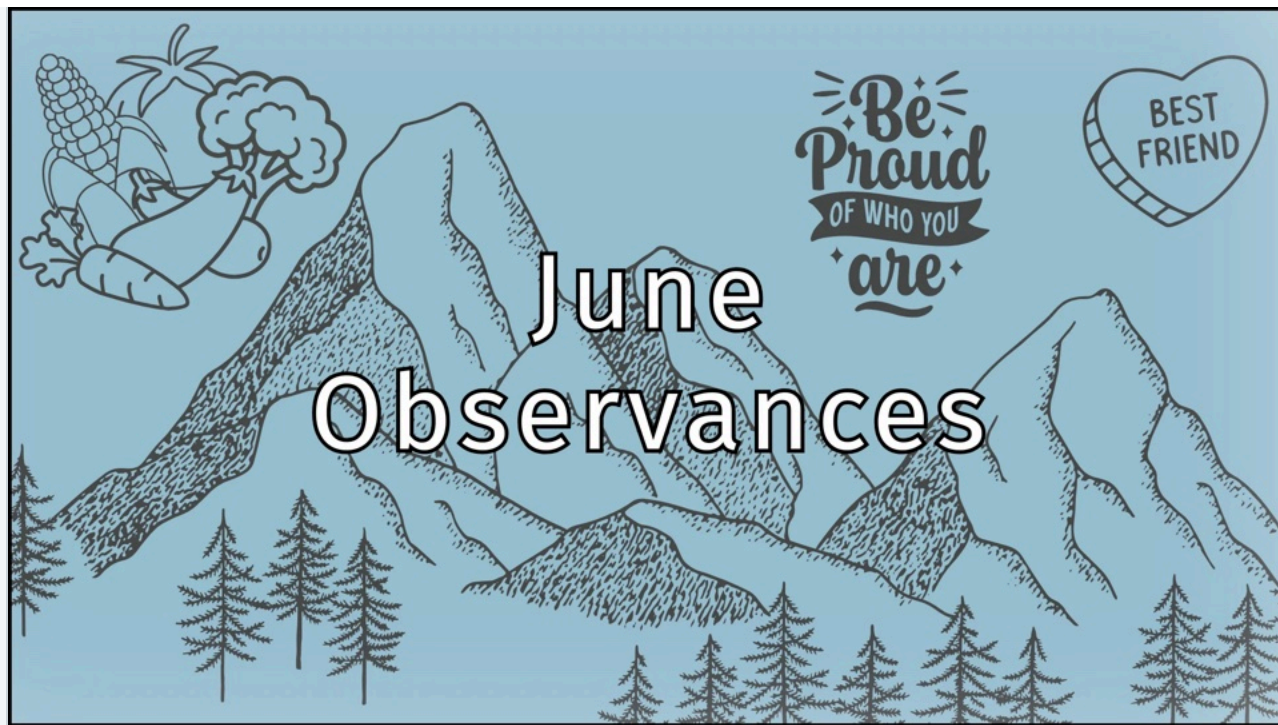
**Take Action**

### **Cosponsor the Genomic Answers for Children's Health Act — H.R. 7118**

Urge your member of Congress to cosponsor H.R. 7118, which would clarify Medicaid coverage of genomic sequencing for children, helping families get needed care before irreversible harm occurs during the search for a diagnosis.

**Take Action**

**Observances**



## Monthly Observances

[Great Outdoors Month](#): June has a way of reminding us that the world outside our doors is still there, patient and waiting. For those living with Pompe disease, getting outside can look like many different things: a slow walk in the early morning quiet, sitting in a patch of sunlight, breathing in air that does not come from a hospital or a waiting room. None of it has to be grand to be good for you. This month, we gently encourage our community to find their version of the outdoors and let it do what it does best: restore something in you that nothing else quite can.

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## Daily Observances

[National Best Friends Day](#) | [June 8](#): There is a particular kind of friendship that only forms in the presence of real difficulty, the kind that does not look away, does not tire of hard conversations, and somehow always knows when to show up. For many in our community, a best friend is also the person who first Googled a diagnosis at midnight, who sat through appointments without being asked, who learned how to help without making you feel like you needed it. Today is for them.

[Fresh Veggies Day](#) | [June 16](#): Eating well with Pompe disease is its own kind of navigation, one that looks different for every person in our

community. Today is a small reminder that nourishment is worth attention, and that what we put on our plates is one of the quieter ways we can take care of ourselves. Whether you are trying something new from the Pompe Kitchen this month or simply adding a little more green to what you already love, it counts.

[International Being You Day](#) | June 22: Living with a rare disease has a way of asking you, again and again, to explain yourself: your condition, your limitations, your needs, your choices. International Being You Day offers a gentle counterweight to all of that. A reminder that you were never meant to be a diagnosis, a case study, or a cautionary tale. You are a whole person, and the world is better for the particular way you occupy it. Today, just be you.



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

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**AMDA**

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