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Talking With Your Pompe Peeps

AMDA Publications

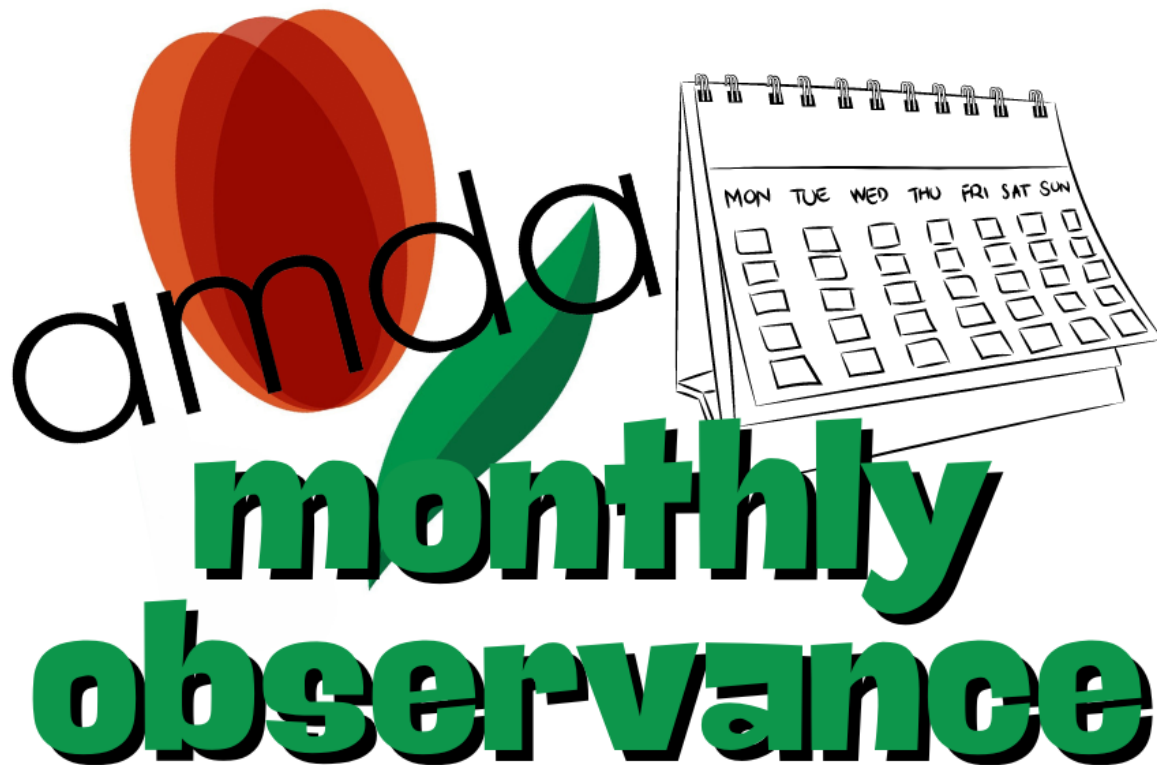


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On
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pompe
everyday

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November 2024

AMDA Newsletter



November is National Family

Caregivers Month!

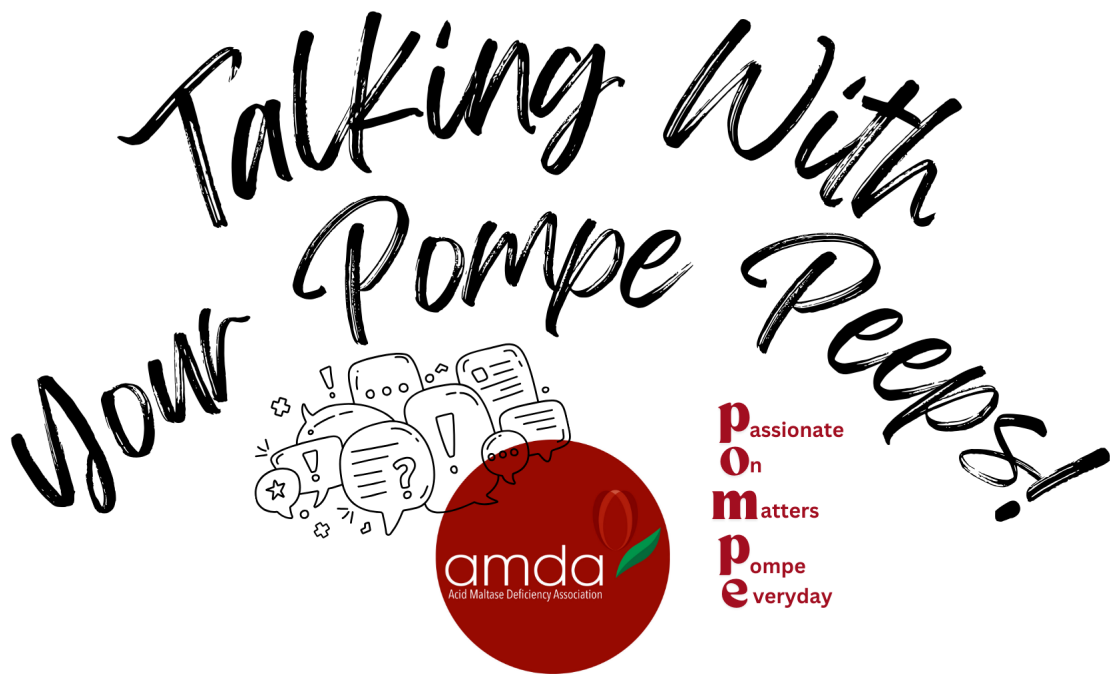
NATIONAL
Family
Caregivers
MONTH!



National Family Caregivers Month recognizes the dedication of family members who provide round the clock care to loved ones. When medical conditions demand attention, family step into roles they are often unprepared to accept. The month sheds light into their demanding days, but it also identifies their needs. From morning to night, a caregiver balances the needs of the patient and their family. They also see to financial matters and the household necessities. Caregivers rarely have time for themselves. There's always another thing to be done. However, a caregiver requires rest, too. **Consider providing a respite for someone you know who provides care for a loved one. Offer to spend time with them or to learn to help out. Ask what you can do to make a difference.** Use #FamilyCaregiversMonth to post on social media.

The National Organization for Rare Diseases (NORD)'s Rare Caregiver Respite Program provides financial assistance to eligible caregivers covering up to \$500 annually so that a respite caregiver may be secured to care for a loved one: [Rare Caregiver Respite Program](#)

For other guidance and assistance, please contact the AMDA's Patient Advocate, Marsha Zimmerman, at marsha.zimmerman@amda-pompe.org



Join us **Thursday, November 21, 2024** at **12 PM CT** for our next *Talking With Your Pompe Peeps* session. Moderated by Tiffany House, this session is all about **The Holidays**. What are your family traditions? Share yours!

This session WILL be recorded and posted on the AMDA YouTube channel at a future date. By attending this session you are agreeing to be recorded.

To register for the session, click the button below.

[Register Here!](#)

Meeting Details

Topic: The Holidays - How to deal with stressors and fun family traditions

Date: Thursday, November 21, 2024

Time: 12 PM CT

Moderator: Tiffany House



**Boston
Children's
Hospital**

Participate in a Pompe Disease Brain Research Study!

• ELIGIBILITY

- diagnosis of Pompe Disease (IOPD/LOPD)
- **3-65** years of age
- on at least a **3-month stable dose of ERT**

• PAYMENT

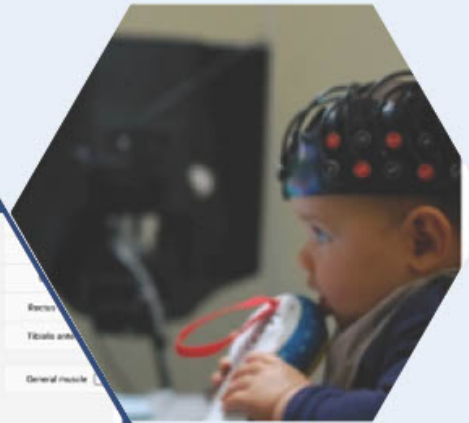
- \$200 study stipend
- Travel costs can be reimbursed!

• STUDY TASKS

- questionnaires
- cognitive and motor tasks
- assessing muscle health
- all **safe** and **pain-free**

• DURATION

- **3 - 6 hours**
- tasks can be performed over two days to fit your schedule



Interested in participating?

Raquel.VanGool@childrens.harvard.edu | (617) 301-0920
Jaymin.Upadhyay@childrens.harvard.edu | (917)-736-1541

Jaymin Upadhyay and his team at The Boston Children's Hospital are looking for more IOPD patients to enroll in their Pompe Disease Brain Imaging Research Study. If you have a family member or know of someone diagnosed with IOPD please consider enrolling/informing them about enrolling in this study. See flyer above for more information.

"All research procedures (non-contrast musculoskeletal and brain MRI) will be paid for by the study. They or their clinician will have access to their MRIs. There is a up to \$1500 (travel) +

\$200 study stipend. If participants do not or cannot undergo MRI, they can still enroll in the study and undergo other non-invasive study procedures.

Our age range is 3-65 years of age for the entire study, but we are especially looking for IOPD patients to enroll."

-Jaymin Upadhyay, PhD

Assistant Professor, Harvard Medical School

Department of Anesthesiology, Critical Care and Pain Medicine

If you are interested in participating, email or call Jaymin Upadhyay or Raquel Van Gool.

Raquel.VanGool@childrens.harvard.edu | **(617) 301-0920**

Jaymin.Upadhyay@childrens.harvard.edu | **(917) 736-1541**

Invitation to Enroll Into the IPA/Erasmus MC Pompe Survey

The United States got **24 new participants** in the IPA/Erasmus MC Pompe Survey, but we think we can do better!

If you have been diagnosed with Pompe disease and are at least 16 years old or older and live in the US, the AMDA would like to invite you to participate in the IPA/Erasmus MC Pompe Survey (the Pompe Survey).

The Pompe Survey is a collaboration between the Pompe Center of the Erasmus MC and the International Pompe Association (IPA) that started in 2002. Over the past two decades many patients from all over the world have participated in this annual survey. The data collected by this survey is very useful for both clinicians and researchers, so we encourage participation.

If you would like to participate in the Pompe Survey, please email Marsha Zimmerman (marsha.zimmerman@amda-pompe.org) with your full name and home address.

The AMDA will provide this information to the Erasmus/IPA Pompe Survey team, and they will send you the Pompe Survey consent form to sign.

If you have any questions, please email Marsha. She will be able to help you.

Daily Observances



NAT'L FAMILY PJ DAY!



NAT'L TAKE A HIKE DAY



NAT'L DAY OF LISTENING



FROM THE AMDA FAMILY TO YOURS!

Veterans Day, November 11th, honors military veterans who served in the United States Armed Forces.

Family PJ Day, November 14th: You know you have a favorite pair of pajamas! How many have matching sets for everyone in the family?! Set up the camera and take a family picture, especially for those holiday greeting cards. PJs, the family, and a cozy day together. Snuggle in for extra sleep or binge watch your favorite series or movies, the day will be filled with family highlights. Board games in your warm flannels or pillow fights while wearing your best footie PJs will create lasting memories.

National Take A Hike Day, November 17th, encourages us to get out there and hit the trails. Take a hike doesn't have to mean hard; it can be a simply stroll with friends and family in your neighborhood. Besides experiencing the great outdoors, we also exercise our bodies. Hiking not only gets our hearts

pumping and our muscles moving, but being outdoors is good for our minds. Many of us spend too much time indoors behind a desk. Hiking can burn between 400-500 calories per hour. What better way to get a head start on all those 'other' holiday temptations and observe Take a Hike Day?

"On International Pompe Day (April 15th), the AMDA and the IPA (International Pompe Association) stand united in the belief that every move counts. It's a day to honor the strength and resilience of those affected by Pompe disease, reminding us that our collective efforts, big or small, contribute to progress and hope and can lead to monumental change. Together, every move we make counts toward a future filled with hope, support, and groundbreaking advancements."

For more information, visit [International Pompe Day: 15 April 2024 - Every Move Counts - International Pompe Association](#)
#NationalTakeAHikeDay

Thanksgiving, November 28th, is observed each year in the United States on the fourth Thursday in November. The observance is a time when families and friends gather and give thanks for many reasons, each often as different as each person who gathers around the table. Share your Thanksgiving traditions by using #ThanksgivingDay to post on our social media.

National Day of Listening (the day after Thanksgiving), November 29th, encourages you to gather your family and friends and record family history and stories for preservation. Our stories connect us, and hearing others' stories opens our eyes to the broader world; especially our Pompe community. If you've shared your story before, now is a great time to update it or if you haven't yet, we'd love to hear from you! Interview each other and share with the AMDA. See [link](#) to help write a patient story, as well as: <https://www.nationaldaycalendar.com/national-day/national-day-of-listening-day-after-thanksgiving>

We Want To Hear From YOU!!!

Tell us what you would like to discuss, hear about, a guest speaker you would like to hear from, a specific topic you want to know more about-- Anything!-- in a future Webinar or Talking With Your Pompe Peeps session. We value your feedback and interests! **You are not alone; we are here to help!**

Send your feedback to info@amda-pompe.org.

AMDA

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