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**p**assionate  
**O**n  
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**e**veryday

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**December 2024**

## **AMDA Newsletter**

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### **Now Available: Educational Program on Late-Onset Pompe Disease**

Join experts Dr. Tahseen Mozaffar and Dr. Barbara Burton for insights on late-onset Pompe disease (LOPD). Explore new therapies,

(▶) Clinician Education Program

Newly Available Therapies to Improve Mobility and Respiratory Outcomes in Late-onset Pompe Disease: Early Diagnosis and Treatment Selection

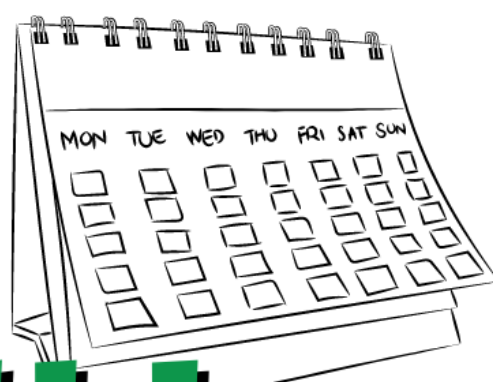

Available on-demand Thursday, November 21st

medlive  
neuro

NORD  
National Organization  
for Rare Disorders

amda

diagnostic challenges, and team-based care strategies, plus a patient's perspective on unmet needs in LOPD management. >> Watch on [Medlive Neuro](#)



# amda monthly observance

## December is the Month of Giving

It revolves around people making a difference by helping others and revolves around the concept of giving and spreading joy.

## Daily Observances



**Pretend to be a Time Traveler Day, December 8th:** When in time would you like to travel to and why?

**Hot Cocoa Day, December 13th:** Enjoy a cup of Hot Cocoa! Get a little creative by adding a peppermint stick, some red-hot candies, salted caramel sauce, or (for the adults in the room) even a bit of Bailey's Irish Cream Liqueur. Host a Cocoa Day gathering of friends and have everyone bring their favorite recipe and all their favorite varieties. White and Dark, Milk and Bittersweet, there are as many different Hot Cocoa recipes as there are individuals!

**Christmas is celebrated on December 25th** and is both a sacred religious holiday and a worldwide cultural and commercial phenomenon. For two millennia, people around the world have been observing it with traditions and practices that are both religious and secular in nature. Christians celebrate Christmas Day as the anniversary of the birth of Jesus of Nazareth, a spiritual leader whose teachings form the basis of their religion. Popular customs include exchanging gifts, decorating Christmas trees, attending church, sharing meals with family and friends, and, of course, waiting for Santa Claus

to arrive. December 25--Christmas Day--has been a federal holiday in the United States since 1870.

**Hanukkah (Chanukah)**, the Jewish Festival of Lights, commemorates the rededication of the Second Temple in Jerusalem after its desecration by the Greeks. It celebrates the Maccabean revolt's victory over oppression and the miracle of a single day's worth of consecrated oil lasting eight days in the temple's menorah. Observed over eight nights, Hanukkah begins on the 25th of Kislev in the Hebrew calendar, usually in December. Traditions include lighting the menorah, playing dreidel, singing songs, and eating fried foods like latkes and sufganiyot. It's a celebration of faith, resilience, and the triumph of light over darkness. **Chanukah 2024 runs from Dec. 25-Jan. 2.**

**Thank You Note Day, December 26th:** It's a day set aside to express gratitude through handwritten notes to friends, family, and anyone who has made a difference in your life over the past year. This tradition taps into the simple yet powerful act of saying "*thank you*" more personally and meaningfully. This day is a gentle reminder of the importance of gratitude, especially in our fast-paced, digital world.

**Call a Friend Day, December 28th:** Sure, friends might text each other or send an email, but there is nothing quite like a phone call and hearing each other's voice to help two people feel connected. Or go the next step and FaceTime, Zoom or Skype a friend!

**New Year's Eve, December 31st:** Civilizations around the world have been celebrating the start of each new year for at least four millennia. Today, most New Year's festivities begin on December 31 (New Year's Eve), the last day of the Gregorian calendar, and continue into the early hours of January 1 (New Year's Day). Common traditions include attending parties, eating special New Year's food, making resolutions for the new year and watching fireworks displays.

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## Helpful Organizations For The New Year

If you are looking for help with copays or prescription costs, these two sites can help.

- **[Accessia Health®](#)** is a national nonprofit 501(c)3 organization that provides programs and services to individuals of all ages who are living with a rare or chronic health conditions. With 80+ disease programs and over \$1 billion in assistance distributed, they offer case management, education, and financial support for health insurance premiums, medication copayments, travel, and other essential medical expenses.
  - Program space is limited and is offered on a first-come, first-served basis. Programs will only remain open as long as funding is available.  
If a program is full, you can still submit an application to add your name to the program waitlist. Once you are on the waitlist, you will be notified if assistance becomes available.
  - **To apply:**
    - Click [here](#).
    - Select 'open' under 'step two'.
    - Select the appropriate program and begin the application process.
- **[The PAN Foundation:](#)** Founded in 2004, the Patient Access Network Foundation™ is one of the nation's largest charitable organizations, providing financial assistance that helps people afford their prescription medications.

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## **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](mailto:info@amda-pompe.org).


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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.**

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Happy Holidays -  
from the AMDA  
family to yours!



## AMDA

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