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Talking With
Your (Pompe) Peeps



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**Join us for our first "Talking With
Your Pompe Peeps" session!**

We are excited to announce that the topic of our first "Talking With Your Pompe Peeps" session is **The Elementary School Experience: Building Success for IOPD/LOPD Children Through Collaboration and Partnership!**

Join us August 16, 2024 at 1 PM CT for an open forum group meeting moderated by **Colleen Sackos**. She will present on how to create partnerships and collaboration between key stakeholders (family, general education team, special education team, healthcare team, etc.) for IOPD/LOPD children in elementary school. Topics include 504 plans, IEPs, how to prepare for transitioning to elementary school, and time for questions and answers.

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

Title: The Elementary School Experience: Building Success for IOPD/LOPD Children Through Collaboration and Partnership!

Date: August 16, 2024

Time: 1 PM CT

Moderator: Colleen Sackos

Summary:

This presentation will entail how to create partnerships and collaboration between key stakeholders (family, general education team, special education team, healthcare team, etc.) for IOPD/LOPD children in elementary school. While every child's journey is unique, ALL children have a right to experience growth and success as a student! Topics include 504 plans, IEPs, how to prepare for transitioning to elementary school, and time for questions and answers. We can all learn from each other!

Get To Know The Moderator

Colleen Sackos

Colleen Sackos is a proud mother of three and educator with over 15 years of experience as a teacher and administrator in the elementary school setting in both Oregon and Arizona. Her youngest son, Axel, has Infantile Onset Pompe Disease and just finished kindergarten. She lives in Happy Valley, OR, and is grateful to be a part of the Pompe community: together we are strong!



2023 Helen Walker Grant Recipient

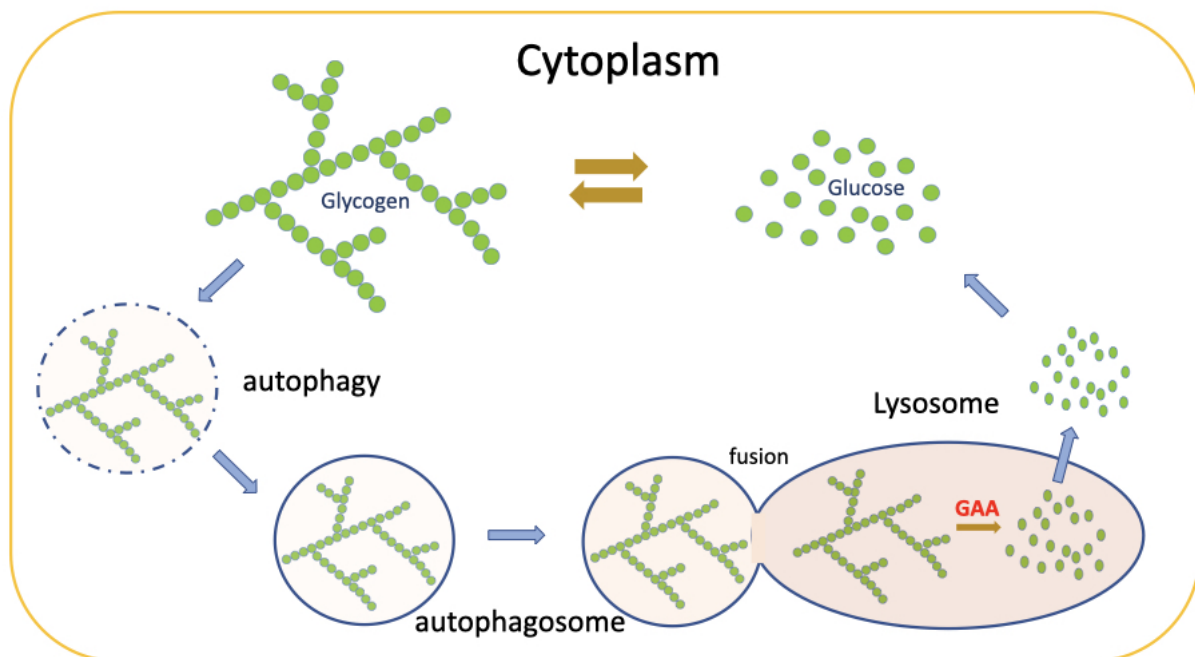
Project title: **Autophagy control of glycogen in skeletal muscle**

This year, the AMDA was fortunate to receive 13 grant applications focusing on both clinical research and basic science. It has been a challenge to select one.

Dr. Wyant was chosen because he has embarked on a discovery project aimed at solving a missing piece of the puzzle: how does glycogen enter the lysosomes? A presumptive pathway for glycogen traffic to the lysosome is autophagy - a familiar term in Pompe disease research. In fact, one of the canonical images describing the disease illustrates glycogen transport to the lysosome in a vesicle (autophagosome) that is formed during autophagy. Although the concept of glycogen autophagy, called glycopyagy, recently gained a lot of interest, the mechanism of muscle glycogen entrapment into the autophagosome has eluded the researchers for a long time.

The team developed a novel sophisticated approach to directly follow glycogen trafficking to the lysosome in skeletal muscle. The proposed study holds promise to identify a protein(s) that bind to glycogen and anchors it to the autophagosomal membrane. The implications of this discovery could be manipulated, so that less glycogen is delivered to the lysosomes, thus limiting damage to the muscle cells.

The application scored highest for novelty and scientific depth. We welcome Dr. Wyant and his team to the Pompe community.



Invitation to Enroll Into the IPA/Erasmus MC Pompe Survey

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.

AMDA

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