



[Conference Registration Form](#)

[Clinical Trial Survey](#)



**Happy Holidays from our families
to yours!**

2024 AMDA/IPA Conferece

Conference Registration Is Now Open

We are excited to announce that the 2024 AMDA/IPA Conference registration form is now open.

[Please click here for the 2024 Conference Registration Form.](#) Each person (patient, family, speaker, patient organization representative, industry representative, and physician) should complete the Online Registration Form.

For a tentative agenda of the conference, and a FAQ, [click here](#) to view the official post on the AMDA website.

Acid Maltase
Deficiency
Association
(AMDA)/International
Pompe Association
(IPA) Conference

**MAY 3-5
2024**

San Antonio,
Texas

*Stay tuned for
more details!*



AMDA-POMPE.ORG

**SAVE
THE
DATE**

McMaster University Clinical Trial Survey

Next year, McMaster University will be running a randomized clinical trial on nutrition (supplements) and home-based exercise (elastic bands [seated or standing], indoor cycling/under desk mini cycle, and Pompe Disease specific breathing exercises).

Both Canadian and US Pompe Disease patients will be invited to participate and visit McMaster University for testing 2-3 times over the experimental period (including blood draws, muscle biopsies, body composition, and functional testing by Dr. Mark Tarnopolsky).

This is an ideal opportunity to support Pompe Disease research and also for patients to get started on high-quality supplements targeted to improve oxidative damage, autophagic impairment, and muscle wasting with Pompe Disease. While the supplements alone may indeed be sufficient to mitigate

pathogenesis, the addition of exercise is always ideal and will improve pathology.

To take the survey, [click here!](#)

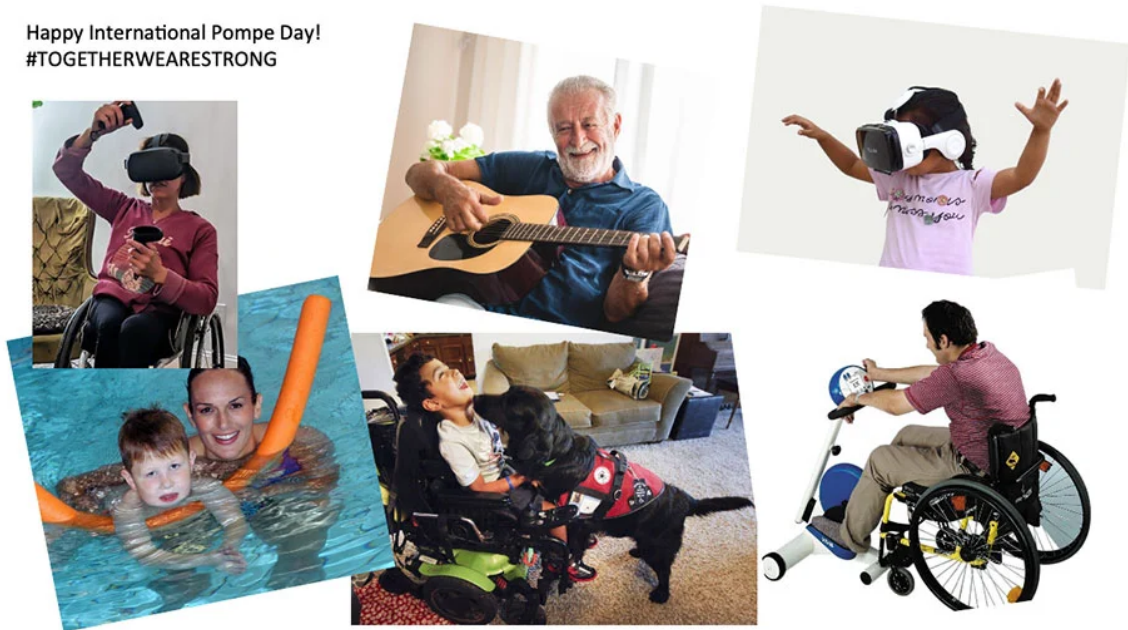
*****This survey is intended to gauge patient interest, not as an application for the upcoming trial. Your contact info will be shared with the team overseeing this trial so that they can reach out regarding the application process.*****



IPA CALL TO ACTION

CALL to participate in IPA Project Every Move Counts

Happy International Pompe Day!
#TOGETHERWEARESTRONG



At International Pompe Day the International Pompe Association kicked off the Every Move Counts project. This project focuses on raising awareness of the importance of movement. We all have different abilities and levels of disability, but the important thing to remember and focus on is that “Every Move Counts.” We should celebrate what we can do, not focus on what we can’t.

We want to show all the ways that individuals in the Community show that Every Move Counts. Several of you already submitted valuable contributions that will be used in this project. More participants are still needed to reach our goal. · Do you have modified physical therapy that you can share? · Do you keep moving by playing with your dog? · Do you focus on music or other hobbies to keep yourself moving? The ways that we can show that Every Move Counts will be as diverse as our community! By sharing how

YOU believe Every Move Counts, you can help others in our community! If you are interested in being part of this project, please reach out to us at info@worldpompe.org.

IPA is collecting these stories, videos, pictures, etc. and will then work with experts in the field to compile a set of resources that will be available on the IPA website. We will need representatives from all around the world, and across the disease spectrum so please consider joining our Project!

AMDA Webinars

We want to hear from YOU!

We are working very hard to schedule interesting and valuable webinars for next year. Do you have a topic you would like the AMDA to do a webinar about? Submit your suggestions to info@amda-pompe.org!

AMDA

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