International Pompe Day

Mental Health Matters.

Pompe Alliance led a study on mental health in adult patients and caregivers that found 57% of respondents said they had been diagnosed with a mental health condition – this is 2.5 times more than the general population.

Only 19% of patients in this study were advised to see a mental health professional when diagnosed.

*Source:
Shorten et al (2025, February 3-7). Pompe Community Members Face 2.5x Higher Risk of Mental Health Issues Compared to the General Population. WORLDSymposium, San Diego, CA

https://doi.org/10.1016/j.ymgme.2024.108948

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Activity Matters.

Regular physical activity has been shown to provide benefits beyond ERT alone for people with Pompe.

Exercise can take on many forms. Adding fun elements to your routine can increase your motivation to be consistent and prevent boredom.

*Source:
Tarnopolsky, M. A., & Nilsson, M. I. (2019). Nutrition and exercise in Pompe disease. Annals of Translational Medicine, 7(13), 282–282.
https://doi.org/10.21037/atm.2019.05.52

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Newborn Screening (NBS) Matters.

Currently NBS for Pompe is available for 89% of births in the US, but less than 3% of births worldwide.

NBS is the ONLY proven process to diagnose Pompe in a timely manner - while the best health outcomes are still possible.

*Source:
https://www.newsteps.org/data-center/reports/screened-conditions-report

Colburn, R., & Lapidus, D. (2024). An analysis of Pompe newborn screening data: A new prevalence at birth, insight and discussion. Frontiers in Pediatrics, 11, 1221140. https://doi.org/10.3389/fped.2023.1221140

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Timely Diagnosis Matters.

Pompe disease affects over 350,000 people world-wide, yet less than 3% of those have been diagnosed.

Previous studies describe differences in prevalence by geographies, but more recent studies have suggested that isn't the case.

The adoption of NBS for Pompe is crucial to provide timely diagnosis that saves lives and enables the best health outcomes for all.

*Source:
Colburn, R., & Lapidus, D. (2024). An analysis of Pompe newborn screening data: A new prevalence at birth, insight and discussion. Frontiers in Pediatrics, 11, 1221140. https://doi.org/10.3389/fped.2023.1221140

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Treatment Matters.

95% of rare diseases lack a treatment. Current treatment for Pompe is life-saving, but it is not a cure.

Enzyme Replacement Therapy for Pompe relies on weekly or bi-weekly infusions, along with nutrition and activity to maximize potential.

There are 30+ companies working on next generation treatments for Pompe disease.

*Source:
Pompe Consortium

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Nutrition Matters.

Pompe is a genetic disorder that affects a metabolic process in the cells.

What we eat “feeds” the metabolic processes in our bodies. In addition to Enzyme Replacement Therapy (ERT), nutrition is considered an important opportunity to maximize health outcomes for people with Pompe.

*Source:
Pompe Warrior Foundation

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Community Matters.

Advancements in Pompe, from basicunderstanding of disease to developments oftreatments, that benefit people around the worldhave been catalyzed by a strong patient community.

The spirit of collaboration, amongst patients, families, researchers, clinicians, industry is critical to accelerate progress.

*Source:
https://pompestory.blogspot.com/

House, T., O'Donnell, K., Saich, R., Di Pietro, F., Broekgaarden, R., Muir, A., & Schaller, T. (2019). The role of patient advocacy organizations in shaping medical research: The Pompe model. Annals of Translational Medicine, 7(13), 293–293. https://doi.org/10.21037/atm.2019.04.28

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