

# Pompe Alliance Survey Reveals Gap in Mental Health Care

*Only 10% Are Recommended Mental Health Support at Time of Diagnosis, Yet 75% Want Assistance*

NEW YORK, NY, UNITED STATE, January 30, 2024 /EINPresswire.com/ -- The [Pompe Alliance](#), in collaboration with [RAM](#) & [MyRareData](#), recently conducted a survey revealing a significant unmet need in mental health care in the Pompe Community.



Unmet need: mental health of rare patients and caregivers

Across both individuals diagnosed with Pompe and their caregivers, only 10% were recommended a mental health professional at time of diagnosis, although 75% expressed a desire for such support.

The survey also found that 50% of the Pompe disease community has been diagnosed with a mental health condition, and a third have had suicidal thoughts. Caregivers are similarly affected, with 60% having a mental health diagnosis.

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*Heather Shorten, Executive Director, Pompe Alliance*

“These findings underscore an urgent need to prioritize mental health care for the Pompe community”, says Heather Shorten, Executive Director, Pompe Alliance.

But the Mental Health support provided must understand the living experience of the Pompe community. Indeed only 1/3 of the individuals diagnosed with Pompe disease

who received mental health support indicated that it was beneficial.

The Pompe Alliance will use these results as it continues to work collaboratively with its community and stakeholders to build appropriate mental health resources for its members.

To access the details of the survey, visit

[https://www.rareadvocacymovement.com/files/ugd/850d88\\_a757cd8f2faa4e7b92a7c2b565e45479.pdf](https://www.rareadvocacymovement.com/files/ugd/850d88_a757cd8f2faa4e7b92a7c2b565e45479.pdf)

#### About the Pompe Alliance

Founded in 2018, the Pompe Alliance creates positive change for those affected by Pompe Disease by fostering awareness, education, and advocacy.

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#### About RAM

Rare Advocacy Movement actively empowers the rare condition community through education, collaboration, and robust advocacy efforts.

Contact: Nadia Bodkin, [nbodkin@rareloveventures.com](mailto:nbodkin@rareloveventures.com)

#### About MyRareData

MyRareData assists rare disease patient groups by fostering mutually beneficial digital health collaborations with industry.

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