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Pompe Community Members Face a 2.5x Higher Risk of Mental Health Issues Compared to the General Population

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Pompe disease patients face 2.5x higher mental health risks, with 57% diagnosed. Only 19% get referrals, highlighting urgent need for access to mental health

KANSAS CITY, KS, UNITED STATES, September 26, 2024 /EINPresswire.com/ -- Mental Health for Rare, a non-profit initiative, is proud to announce the presentation of its latest research poster at the upcoming Week in Rare organized by Global Genes.

> Our research sheds light on the deeply intertwined physical and emotional burdens faced by our rare disease community,”
>
> *Heather Shorten, Executive Director Pompe Alliance*

The poster highlights critical mental health challenges faced by the Pompe disease community, offering key insights that underscore the urgent need for mental health integration into rare disease care.

For individuals living with Pompe disease—a rare genetic disorder affecting muscle and respiratory function—the mental health toll is high.

Mental Health for Rare's recent survey reveals that 57% of Pompe patients and caregivers have received a mental health diagnosis, a rate 2.5 times higher than the general population. Despite the need for support, only 19% of patients were recommended to see a mental health professional at the time of diagnosis, creating a gap in care.

“Our research sheds light on the deeply intertwined physical and emotional burdens faced by our rare disease community,” said Heather Shorten, Executive Director of the Pompe Alliance and a founding member of Mental Health For Rare. “The fact that nearly one-third of patients experience suicidal ideation demands that we rethink how mental health services are delivered”.

74% of those who had not seen a mental health professional expressed a desire to do so, citing barriers such as lack of local mental health resources, stigma, and the prioritization of physical over mental health.

By sharing these findings at Week in Rare, Mental Health for Rare aims to generate broader awareness and inspire changes that can lead to more access to mental health care for the rare disease community.

Attendees are encouraged to visit the poster to learn more about the findings and discuss potential pathways to improve mental health care for rare disease patients and their caregivers.

To learn more about the findings, visit
https://www.rareadvocacymovement.com/mentalhealthforrare/pompedisease

About Mental Health For Rare
Mental Health for Rare is a non-profit initiative dedicated to addressing the mental health needs of individuals living with rare diseases and their caregivers. Through research, advocacy, and education, the organization works to improve access to mental health resources and ensure holistic care for rare disease communities. For more information on Mental Health for Rare, visit https://www.rareadvocacymovement.com/mentalhealthforrare

About the Pompe Alliance
Founded in 2018, the Pompe Alliance (https://www.pompealliance.com) creates positive change for those affected by Pompe Disease by fostering awareness, education, and advocacy. Contact: Heather Shorten at pompealliance@gmail.com

About the Rare Advocacy Movement (RAM)
RAM actively empowers the rare disease community through education, collaboration, and robust advocacy efforts. Contact: Rare360 Admin team at admin@rare360.life

About MyRareData
MyRareData assists rare disease patient groups with the adoption of digital health solutions. Contact: JC Muyl at jc@myraredata.com

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