

Mental Health for Rare Presents Latest Research on Pompe Disease and Mental Health at WORLDSymposium 2025

Mental Health for Rare to present research at WORLDSymposium 2025 showing Pompe patients face 2.5x higher mental health risks, urging better access to support.

SAN DIEGO, CA, UNITED STATES, January 29, 2025 /EINPresswire.com/ -- Mental Health for Rare, a



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Heather Shorten, Co-Founder and Program Director

leading nonprofit organization dedicated to improving mental health support for individuals living with rare diseases, is proud to announce the presentation of its latest research findings on the mental health impacts of Pompe disease at the prestigious WORLDSymposium 2025. The event will be held from February 3-7, 2025, in San Diego, California.

The organization’s research poster, titled “[Pompe](#)

[Community Members Face 2.5x Higher Risk of Mental Health Issues](#) Compared to the General Population,” sheds light on the critical mental health challenges faced by individuals with Pompe disease and their caregivers. Conducted in collaboration with the Pompe Alliance, Rare Advocacy Movement (RAM) and MyRareData, this study highlights the urgent need for comprehensive mental health support within the Pompe community.

Key Findings:

- 57% of respondents reported receiving a mental health diagnosis, a rate 2.5 times higher than the general U.S. population.
- 25% of respondents, including 31% of Pompe patients, disclosed experiencing suicidal thoughts—nearly double the general prevalence.
- 52% of respondents had never consulted a mental health professional, despite 74% expressing a desire to do so.
- Barriers to care include difficulty finding specialists, lack of family support and therapists unfamiliar with rare diseases.

“This research underscores the urgent need to integrate mental health support into Pompe disease care,” said Heather Shorten, Co-Founder and Program Director at Mental Health for Rare. “By sharing these findings at WORLDSymposium 2025, we hope to drive awareness,

influence clinical practices, and advocate for better access to specialized mental health resources for Pompe patients and caregivers.”

The Mental Health for Rare’s poster presentation will be featured during the symposium’s scientific poster sessions. Attendees are encouraged to visit the presentation to explore the findings and engage in discussions about collaborative efforts to address these challenges for rare disease communities.

About Mental Health for Rare

Mental Health for Rare is a nonprofit organization committed to advancing mental health support for individuals living with rare diseases and their families. Through sound research, targeted advocacy, and educational initiatives, the organization bridges the gap between mental health care and rare disease management.

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