Improving Access to Mental Health For Rare Patients And Their Families

90% of the 400 million rare disease patients in the world struggle with mental health issues. Improving Access to Mental Health Support is a Must.

Mutually Beneficial Digital Health Collaborations To Improve the Lives of Rare Disease Patients and Families

NEW YORK, NY, UNITED STATES, February 28, 2023 /EINPresswire.com/ -- RAM, the Rare Advocacy Movement & MyRareData along with founding Member Pompe Alliance today announced a collaboration to improve access to mental health treatment for rare disease patients, caregivers, care partners and siblings.

90% of the approximately 400 million rare disease patients in the world (30 million of which reside in the US) struggle with mental health issues (1)

Mental Health for Rare envisions a world where rare disease patients, caregivers, care partners and siblings have access to mental health resources and services that are adapted to their unique needs.

To help achieve this vision, Mental Health For Rare will incubate and launch projects designed to:
- Adapt existing Mental Health solutions to the needs of the rare disease community
- Improve access to Mental Health resources for rare disease patients, caregivers, care partners and siblings
- Promote the use of Mental Health resources across the rare disease ecosystem
- Support research & publications on Mental Health solutions dedicated to addressing the unique needs of the rare disease community.

Call to action: the Mental Health for Rare collaboration is currently seeking sponsorships to build

the first Rare Therapist CME Curriculum.

- A free CME course to help therapists be more effective when working with rare patients
- Developed by Therapists with Rare experience & certified by NASW
- Therapist receive free CE credits and are promoted on the resources pages of participating rare patient groups
- Go to https://www.rareadvocacymovement.com/mentalhealthforrare for more details

For information, contact JC Muyl, Founder, MyRareData at (917) 579-5692 or jc@Myraredata.com

(1) Mental health care for rare disease in the UK - recommendations from a quantitative survey and multi-stakeholder workshop. Rosa Spencer-Tansley, Nick Meade, Farhana Ali, Amy Simpson, Amy Hunter. . 2022 May 14;22. doi: 10.1186/s12913-022-08060-9)

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