

Raregivers™ Coalition Expands Global Reach to Support Rare Disease Families & Professionals

Fondation Ipsen Joins as a Key Partner, Enabling Free Digital & Print Distribution of the Raregivers™ Emotional Journey Map Across Six (6) Continents

ORANGE COUNTY, CA, UNITED STATES, February 18, 2025 /EINPresswire.com/ -- [Raregivers Global](https://www.raregivers.global), a pioneering nonprofit dedicated to providing emotional relief for the rare disease community, has partnered with [Fondation Ipsen](https://www.fondationipsen.com) to distribute free digital and print versions of the Raregivers™ Emotional Journey Map Guidebook across six (6) continents.

This first of its-kind resource will now be accessible - at no cost - to caregivers, patients and professionals navigating the complex emotional challenges of rare disease.

As International Rare Disease Day approaches on February 28th, Raregivers Global and

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When life gets medical, people get emotional. Caring for someone and living with a rare disease is a deeply emotional journey.”

Cristol Barrett O’Loughlin

Fondation Ipsen are working to prioritize emotional support alongside medical treatment. This collaboration shines a light on the mental health crisis affecting the rare disease community, where 350 million people worldwide live with over 10,000 uncured rare, chronic, and complex conditions, supported by more than 2.8 billion caregivers and medical professionals.

“When life gets medical, people get emotional,” said Cristol

Barrett O’Loughlin, Founder & CEO of Raregivers Global. “Caring for someone and living with a rare disease is a deeply emotional journey. This publishing partnership with Fondation Ipsen, the newest member of the Raregivers Coalition, ensures our methodology reaches the people who need it most—those holding both hope and grief in the same human heart.”



Raregivers Emotional Journey Map

A Research-Driven Resource for Emotional Well-Being

The Raregivers™ Emotional Journey Map Guidebook is an evidence-based resource, developed from 287 peer-reviewed studies, expert stakeholder reviews and insights from global leaders in mental health and rare disease care. It shifts the focus from disease-specific diagnoses to the universal emotional experiences shared across the rare disease journey.

Co-developed by a coalition of world-class experts, the guidebook offers:

- Practical strategies for caregivers, patients and professionals to sustain well-being and resilience
- Deepening exercises by Dr. Laura Riordan, helping families process emotional challenges
- Coping tools to manage the overwhelming nature of caregiving and 24/7 medical management
- A holistic, person-centered framework that fosters connection and emotional balance

By offering free, multilingual access, Raregivers Global ensures that this critical resource serves an often difficult to reach global community. Thanks to Microsoft employee volunteers, the guidebook is now available in twelve (12) languages with 400+ dialects in various stages of AI-generated translation using Sharepoint.

Fondation Ipsen as a Strategic Partner

Fondation Ipsen supports the multilingual publication and distribution of the guidebook to expand access to emotional health resources worldwide. Fondation Ipsen will email and ship printed copies of the guidebook to Rare Disease Centres of Excellence (COEs) around the world, including Europe, the Middle East, Africa, Asia, Australia, Latin America and the 40+ NORD-certified COEs across North America.

"At Fondation Ipsen, we believe in using our technology and resources to make a meaningful impact," said James A. Levine, MD, Ph.D, Professor, President of Fondation Ipsen. "Partnering with Raregivers Global allows us to support an underserved community and ensure that caregivers and patients worldwide have access to the emotional relief they need."

A Call to Action for International Rare Disease Day (February 28)

Rare Disease Day is more than just a date—it's a global movement to advocate for the emotional and mental well-being of those affected by rare diseases. Through the Empowering Raregivers™ Global Mental Health Initiative, the nonprofit is calling for corporate and philanthropic partners to invest in:

- Volunteer service & employee engagement
- Sponsorships & grants
- Social impact investments
- Research-backed emotional support programs, like Raregivers

By supporting this initiative, corporations, companies and organizations can help scale

emotional support resources worldwide, ensuring that caregivers, patients and professionals are never left to navigate this journey alone.

About the [Raregivers™ Coalition](#)

The Raregivers Coalition underscores the importance of stakeholder collaboration in global social impact initiatives. They actively seek partners to further their mission to emotionally support 3.5 million Raregivers by 2026. Foundational contributors to the Raregivers™ Emotional Journey Map Guidebook include: IndoUSrare, Acadia Pharmaceuticals, Amgen, Amicus, Alexion Charitable Foundation, BioMarin, EMD Serono, Harmony Biosciences, IONIS, PTC Therapeutics, Regenxbio, Sanofi, Ultragenyx, National Organization for Rare Disorders (NORD), Ford/Tuttle-Click Automotive, Davis/Dauray Family Fund, The Ehlers-Danlos Society, Prader-Willi Syndrome Association, The Assistance Fund, Remember the Girls, Global Genes, Children's Hospital of Orange County (CHOC)/UCI Health, The Epilepsy Foundation, SCN2A-Australia, Purrble, Tides Foundation, University of New South Wales (UNSW)/Sydney Children's Hospitals Network (SCHN-Australia), Wildflower Apothecary, We Are Brave Together, Microsoft employee volunteers and Raregivers Inc (formerly ANGEL AID). Learn more at www.raregivers.global

About Raregivers Inc.

Raregivers Global is a nonprofit dedicated to supporting the mental and emotional health of caregivers, patients, and professionals within rare, chronic and complex disease communities. Through peer-to-peer support, research-backed tools, and global advocacy, Raregivers™ is building a sustainable ecosystem of emotional care for the 350 million people living with rare diseases and the 2.8 billion caregivers and professionals supporting them. Learn more at www.raregivers.global

About Fondation Ipsen

Fondation Ipsen, a charity under the aegis of Fondation de France, supports initiatives in healthcare, research, and education. Fondation Ipsen focuses on advancing the needs of people living with rare diseases, improving patient care, and promoting social and educational projects to enhance well-being in the rare disease community and foster innovation. A key part of this mission includes publishing educational books and resources, free of charge, to raise global awareness and foster better understanding of rare diseases. Learn more at www.fondation-ipsen.org

Rachel Svoboda

Sunday Brunch Agency

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