



Serving the rare disease community since 2008

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. Our focus is helping individuals and families build and find communities, locate the tools and resources needed to accelerate advocacy efforts, and also support opportunities to drive research and therapy development to continue next-generation advocacy.



CONNECT

Engage with members of the rare disease community and find ways to get involved through our events and webinars. Join our online rare community portal to connect with other likeminded individuals worldwide. Seek connection from our patient service guides who are here to guide you through your rare disease journey.



ENGAGE

Access a multitude of free education & resources. Find organizations specific to your rare disease through our Global Advocacy Alliance, search our rare list for disease-specific resources, get the latest updates from our RARE Podcast and blog, learn what clinical trials are available to you, and understand the importance of knowing your family history.



INSPIRE

Share your rare disease story through our website. Find out ways non-profit organizations can qualify for our annual financial grants. Discover the power of data and check out the RARE-X platform. Participate in the Rare Compassion program to encourage others and influence the medical community.

Our Patient Services Guides are here to provide resources, direct you to rare disease specific organizations, and make connections. We understand what it is like to navigate the complicated and complex world of rare diseases and are here to help. This service is free and available to everyone.



CONTACT US



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