



The RARE Foundation Alliance is a coalition of over 300 rare disease organizations that understand that together we are more powerful.

Global Genes Foundation Alliance partners exchange best practices and share lessons learned to drive better outcomes for the entire rare disease community. Global Genes aims to provide a culture of collaboration to support the activities of the RARE Foundation Alliance.

MEMBERSHIP REQUIREMENTS

TYPES OF GROUPS ELIGIBLE

- Support groups
- U.S. foundations with 501(c)(3) status
- International foundations

ELIGIBLE GROUPS MUST:

- Provide access to information through a website or active Facebook page*
- Offer rare disease information or support in one or more of the following areas:
 - Patient / Caregiver support
 - Healthcare provider education
 - Public awareness and advocacy
 - Research

* Websites and Facebook pages focusing on a specific patient or family's journey are not eligible

MEMBER BENEFITS

RARE Foundation Alliance membership provides access to effective strategies, tools, and resources to help build your foundation's capacity.

Exclusive access to RARE Foundation Alliance Networking and Sharing:

- Quarterly Foundation Alliance webinars to share rare industry updates, initiatives, resources, and expert speakers.
- Private Facebook for foundation leadership discussions.
- Technology support for one patient/family-focused educational content webinar.

Priority registration for Global Genes' Advocacy Events

- RARE Patient Advocacy Summit – September 14-15, 2017
- RARE Tribute to Champions of Hope Gala – September 16, 2017

RARE Patient Impact Grant Program

Exclusive annual opportunity for RARE Foundation Alliance partners and RARE support groups

Promotional opportunity for your Foundation

Events and breaking news shared with the RARE community in various Global Genes outlets including RARE Daily, social media, and RARECast podcast.

One-on-one Global Genes' support

Personal contact with the Global Genes advocacy team to answer your questions and connect you to Global Genes' and partner resources.

MEMBER COMMITMENT

- Actively engage in discussions about best practices, community challenges and lessons learned
- Willingness to partner with Global Genes on rare disease focused initiatives
- Share relevant educational resources (toolkits, webinars, initiatives) with your rare disease community
- Prominently display RARE Foundation Alliance badge on website and share in any additional venues as appropriate
- List Global Genes as a resource on organization's website
- Participate in half of the quarterly membership webinar calls
- Provide a primary contact person who is an active member of the organization's leadership

RESOURCES

Global Genes offers a number of educational resources and tools to the Foundation Alliance members at no charge.



RARE Toolkits

Print and online collaborative resources that educate rare disease advocates about issues critical to their journey including a resource section, FAQ section, video tutorials and patient advocate/ expert testimonials.



RARE Webinars

Online webcast sessions featuring multidisciplinary rare disease expert panels that educate, inform and offer access to the latest information on a broad range of rare disease topic.



RARE Daily

Leading online blog for rare disease stories, news and education by patients for patients, with industry news, patient tools and coverage of all things rare and genetic, updated daily.



Grant

Foundation Alliance members that care for patients affected by rare diseases are eligible to apply for this grant to secure funding for projects that will make a tangible difference to their members.



RAREcast

Revealing podcast interviews and hard hitting questions with some of the most influential leaders in the rare disease community.



RARE Patient Advocacy Summit

Two-day conference designed to educate and empower patients, caregivers, and advocates and equip them with actionable next steps whether they have been recently diagnosed or have been advocating in rare disease for decades.

OTHER PROGRAMS



Rare Meetups

Disease-specific in-person patient meetings to discuss the challenges of living with rare disease and gain valuable information and support from physicians, social workers, nutritionists, and other health care and support specialists.



Corporate Alliance

Collection of rare disease stakeholders committed to facilitating collaboration and an information exchange among patients, patient advocacy organizations, health-related organizations, industry, payers, policy makers and regulatory agencies.