Resources for the Rare Disorders Patient Community

At Novartis Gene Therapies, we are as passionate about our patients as we are about research. We are dedicated to supporting the communities and families affected by rare genetic diseases, and committed to our continued pursuit of reimagining solutions for the significant and unique challenges that life with a rare genetic disease can bring. That's why we strive to be an ally and resource to the communities affected by the conditions we study.

Our efforts to help patients and caregivers

Novartis Gene Therapies has worked with leading rare disease advocacy organizations on matters of policy and patient support. We proudly share our resources and voice to activities that benefit families impacted by rare disease.

Ongoing support of communities

Whether it is an educational presentation, a workgroup to better understand the patient journey, or participation in an event, we are honored to be an active ally in the communities we serve.

The following organizations offer resources and information for patients and loved ones impacted by rare disorders:

- Cure SMA provides support to patients and families affected by SMA and funds and directs research for a cure for the disease.
- Global Genes helps build awareness, educate the global community, and provide critical connections and resources that equip advocates to become activists for their rare disease.
- Muscular Dystrophy Association sponsors research seeking causes and effective treatments for neuromuscular diseases.
- National Organization for Rare Disorders (NORD) provides support for individuals with rare diseases by advocating and funding research, education, and networking among service providers.
- NEVER GIVE UP is dedicated to raising global SMA awareness, advocating for research, and providing family support.
- RareConnect is a platform with disease-specific online communities that enables people living with rare diseases to meet, share stories and learn from each other.
- SMA Foundation funds research to accelerate the development of treatments for SMA.
- SMA News Today provides SMA news, education, and occasional insights about clinical trials in the SMA research community.
- The EveryLife Foundation for Rare Diseases is dedicated to accelerating biotech innovation for rare disease treatment through science-driven public policy.
- Treat-NMD provides a platform to ensure the most promising new therapies in the neuromuscular field reach patients as quickly as possible.

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