



## What is #RAREis?

#RAREis began as a social media campaign launched by Amgen in 2017 to elevate the voices, faces and experiences of the rare disease community. It has since grown into a global, multifaceted program that connects people living with rare diseases and their families to resources that support, inform and educate them as they navigate their daily lives.

## The Power of Storytelling

#RAREis brings rare disease stories to life. By elevating personal stories of living with a rare disease, #RAREis empowers individuals to share the uncensored truth of their journey.

## RAREisCommunity.com

A website that connects people living with rare diseases and their families to unique resources developed by and for the rare disease community, personal stories and advocacy organizations. Visit [RAREisCommunity.com](https://www.rareiscommunity.com) to learn more.



**#RAREis Blog** features the personal stories of individuals, families, researchers, healthcare professionals and rare disease advocates to bring together firsthand experiences that are common in the lives of those impacted by rare diseases. Everyone has a story to share. Join the conversation [here](#).



**#RAREis Resources** helps individuals and families impacted by rare diseases understand the obstacles they might encounter during various life transitions or while dealing with difficult topics like genetic testing. #RAREis provides resources that strengthen health literacy and disease management among the rare disease community and connects them to organizations that offer supportive programs and services. Find support and rare resources [here](#).



**#RAREis Global Advocate Grant** is designed to support the rare disease community by providing financial assistance to global patient advocacy groups working to advance, educate and address the needs of the community. As of 2024, more than 150 grants have been awarded to advocacy organizations. Learn more about the Global Advocate Grant [here](#).



**#RAREis Whitepaper: Shared Insights and Opportunities to Drive Progress Across the Rare Disease Community** engaged Global Advocate Grant recipients representing 14 countries through a survey and live summit to discern the biggest challenges advocacy groups from around the world face and areas for opportunity. The findings uncovered valuable insights around barriers affecting access to care, funding obstacles, mental health challenges, the hurdles impeding diversity, equity and inclusion and opportunities for collaboration in the rare disease community. Learn more about the challenges and opportunities [here](#).



**#RAREis One** shares the diverse perspectives of storytellers from around the world who are navigating life with a rare disease, supporting a loved one and advocating for a change in the rare disease community – and the challenges they've encountered and overcome. Read the stories and share your #RAREis One journey in your own words by submitting your story [here](#).

**#RAREis is committed to providing support and resources to individuals living with rare diseases. With support built around the patient, we serve as a partner in their journey, providing each person with access to a range of programs, educational materials and opportunities to connect with the global rare disease community.**

## #RAREis Partnerships

#RAREis partners with several organizations to raise awareness of rare diseases and uniquely address the needs of individuals impacted by rare diseases.



**#RAREis Scholarship Fund** launched in 2020 in partnership with the EveryLife Foundation for Rare Diseases to address the significant gap in life enrichment support for adults living with rare diseases. As of 2024, more than 350 scholarships have been awarded. Learn more about the #RAREis Scholarship [here](#).



**#RAREis Adoption Fund** launched in 2019 in partnership with Gift of Adoption to help facilitate global adoptions of children with rare diseases. The #RAREis Adoption Fund has supported the adoption of more than 70 children living with rare diseases by providing financial assistance to complete the final steps of adoption.



**#RAREis Playlist** launched in 2018 in partnership with Sing Me a Story Foundation to elevate the stories of children living with rare diseases through music. Professional songwriters and musicians transform children's personal journeys into songs through the #RAREis Playlist, a collection of more than 50 songs.

Join the #RAREis conversation.  
Visit [RAREisCommunity.com](https://RAREisCommunity.com) to learn more.



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