

#RAREis...



What is #RAREis?

#RAREis began as a social media campaign launched by Horizon Therapeutics in 2017 to elevate the voices, faces and experiences of the rare disease community. It has since grown into a multi-faceted 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. It has given a platform and a voice to those living with diseases so rare that no dedicated organization exists for their condition.

#RAREis is anchored by a community website as well as an Instagram and Facebook page. Individuals are encouraged to create their own #RAREis photo and share their story via social media. The #RAREis hashtag (#) is a way to follow the conversation and remains in the name and logo to represent the broader movement and community.

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 links to advocacy partners to stay connected.



#RAREis Blog features the personal stories of individuals, families, researchers, physicians and rare disease advocates to bring together firsthand experiences that are common in the lives of those impacted by rare diseases.



#RAREis Resources program helps individuals and families impacted by rare disease 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. By bringing together the rare disease community, #RAREis generates awareness, support and education for hundreds of rare disease states.



#RAREis Voices is a video series featuring leading physicians, researchers, advocates, individuals and parents who share common experiences faced by many people in the rare disease community.

Everyone has a story to tell

Share yours at RAREisCommunity.com



#RAREis Initiatives

#RAREis has launched several initiatives with organizations to raise awareness of rare diseases and address the unmet needs of individuals impacted by rare disease in a unique way.



#RAREis Scholarship Fund: Launched July 2020 in partnership with EveryLife Foundation for Rare Diseases to address the significant gap in life enrichment support for adults living with rare diseases. Over five years, the #RAREis Scholarship will provide financial support to enable adults living with rare diseases complete lifelong educational goals and life enrichment activities.



#RAREis Adoption Fund: Launched April 2019 in partnership with Gift of Adoption to help facilitate global adoptions of children with rare diseases. Over three years, the #RAREis Adoption Fund will support the adoption of more than 30 children living with rare diseases by providing financial assistance to complete the final steps of adoption.



#RAREis Playlist: Launched February 2018 in partnership with Sing Me a Story Foundation and Global Genes to elevate the stories of children living with rare diseases through song. Professional songwriters and musicians transform children's personal journeys into songs through the #RAREis Playlist, a collection of almost 50 songs about stories of children living with rare diseases.



Join the #RAREis conversation. Visit RAREisCommunity.com to learn more.



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