



## Horizon Therapeutics plc Partners with EveryLife Foundation to Establish \$1 Million #RAREis Scholarship for Adults with Rare Diseases

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DUBLIN--(BUSINESS WIRE)-- Horizon Therapeutics plc (Nasdaq: HZNP) today announced a \$1 million commitment over five years to establish the #RAREis scholarship, a program that will be made available by the EveryLife Foundation for Rare Diseases. The #RAREis scholarship will support the pursuit of life enrichment activities for adults living with rare diseases for a variety of educational pursuits, including educational courses, travel stipends for rare disease conferences and obtaining two-and four-year degrees.

The novel scholarship is an extension of Horizon's #RAREis program, which is dedicated to providing individuals living with rare disease and families access to resources that connect, inform and educate as they navigate their daily lives.

"Every person who lives with a rare disease is more than just a patient. We want our community to have an opportunity to pursue their dreams to be teachers, doctors, lawyers, executives, artists, or anything they aspire to be," said Julia Jenkins, executive director at EveryLife Foundation. "For the past 11 years we have been working to remove roadblocks for the development of lifesaving treatments and diagnostic opportunities for rare disease patients. Now, thanks to the #RAREis scholarship fund, we can help patients not just to live with their disease but to thrive."

In the past decade, more than 770 new medicines have been developed in the United States to treat rare diseases, opening the door for people living with rare diseases to have a longer lifespan and more opportunities. However, adults living with rare disease can face unique challenges and their pursuit of milestones has traditionally been under supported. There is a large disparity in the health-related quality of life adults living with rare diseases experience when compared to other adults with or without chronic diseases.<sup>1</sup> Social and environmental barriers like stigma limit the ability for adults living with rare disease to participate in social roles and activities.

"Our work within the rare disease community has uncovered many unique perspectives and experiences among adults living with rare disease, and we've learned that traditional education opportunities and career paths are sometimes missed or delayed due to challenges associated with their diagnosis," said Timothy Walbert, chairman, president and chief executive officer, Horizon.

"By partnering with EveryLife Foundation on the #RAREis scholarship our hope is that more adults living with rare disease have the opportunity to pursue continuing education and become leaders in their community, whether that be a four-year college, vocational training, or even classes that empower them to advance rare disease awareness and make a significant impact."

The #RAREis scholarship details will be announced later this Spring by EveryLife Foundation and the application window will open in Fall 2020. EveryLife will manage the scholarship application process, selection process and distribution of funds independent of Horizon input. All scholarship recipients will be selected by an EveryLife Foundation-appointed, independent board of reviewers. Those interested can sign-up to receive updates at [EveryLifeFoundation.org](https://EveryLifeFoundation.org).

### About EveryLife

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy. We do not speak for patients. We provide the training, education, resources and opportunities to make their voices heard. By activating the patient advocate, we can change public policy and save lives. To learn more, visit the EveryLife website at [EveryLifeFoundation.org](https://EveryLifeFoundation.org).

### About #RAREis

In February of 2017, Horizon launched the #RAREis program aimed at elevating the voices, faces and experiences of people living with rare diseases, as well as highlight programs and resources for the rare disease community. The program is anchored by an [Instagram](#) page and website that showcases photos and stories of people touched by rare disease and captures elements of their patient, caregiver or advocate experience. To learn more, visit the #RAREis [Instagram](#) page and visit the website at [www.RAREisCommunity.com](http://www.RAREisCommunity.com).

### About Horizon

Horizon is focused on researching, developing and commercializing medicines that address critical needs for people impacted by rare and rheumatic diseases. Our pipeline is purposeful: we apply scientific expertise and courage to bring clinically meaningful therapies to patients. We believe science and compassion must work together to transform lives. For more information on how we go to incredible lengths to impact lives, please visit [www.horizontherapeutics.com](http://www.horizontherapeutics.com), follow us [@HorizonNews](#) on Twitter, like us on [Facebook](#) or explore career opportunities on [LinkedIn](#).

<sup>1</sup> Bogart, K.R., Irvin, V.L. Health-related quality of life among adults with diverse rare disorders. *Orphanet J Rare Dis* 12, 177 (2017). <https://doi.org/10.1186/s13023-017-0730-1>

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