



Horizon Therapeutics plc Makes Founding Gift to Support the University of Notre Dame's Patient Advocacy Initiative

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-- Novel Program Supports Student Education and Future Careers in Patient Advocacy --

DUBLIN--(BUSINESS WIRE)--Sep. 16, 2022-- Horizon Therapeutics plc (Nasdaq: HZNP) today announced it has made a founding, five-year gift to establish the University of Notre Dame's Patient Advocacy Initiative in the College of Science. The gift will help advance Notre Dame's Interdisciplinary Minor in Science and Patient Advocacy (MSPA) to further support training students interested in careers in advocacy for patients with rare and neglected diseases.

Notre Dame's Patient Advocacy Initiative is a novel approach to enable advanced training, outreach and research to better serve the rare disease community. Horizon's gift will support curriculum development, experiential learning opportunities and student engagement with the rare disease community through an annual patient advocacy summit at Notre Dame. It will also offer students a unique opportunity to work directly with a rare disease non-profit to navigate challenges unique to the rare disease community, drawing from connections to hundreds of patient advocacy groups that Horizon has engaged with through its day-to-day work, as well as the company's [#RAREis program](#).

Notre Dame will host their second annual [Patient Advocacy Summit and Rare Disease Weekend](#) on Friday, Sept. 16, with students, leaders from Horizon and advocates from the patient community to convene around a variety of [patient advocacy topics](#). The summit aims to elevate discussion and identify innovative solutions for continued pharmaceutical development, challenges with clinical trials and drug development, and most importantly, understand the perspectives of people affected by rare diseases.

"In our work, we are constantly learning from incredible rare disease advocates who are mobilizing people living with rare diseases to create communities and advance science toward potential new treatments," said Tim Walbert, chairman, president and chief executive officer, Horizon. "It is crucial that we support Notre Dame's innovative Patient Advocacy Initiative to help train the next generation of patient advocates and serve a broader segment of the rare disease community."

There are more than 7,000 known rare diseases impacting over 400 million people worldwide. Advances in rare disease awareness, education, research and treatment require dedicated champions who advocate for the disease and create a path toward uniting impacted individuals toward a common goal. Both Notre Dame and Horizon share a commitment toward empowering future leaders in the patient advocate community who are equipped with skills to make a difference.

"We are grateful for this generous support from Horizon Therapeutics, which demonstrates their commitment to patient advocacy and acknowledges Notre Dame's expertise in rare disease research and the institution's commitment to patients and their families," said Santiago Schnell, William K. Warren Foundation dean of the College of Science. "This gift will help the next generation of physicians, researchers and industry leaders to become forces for good for patients with rare diseases."

"The need for skilled patient advocates is clear," said Barbara Calhoun, director of patient advocacy education and outreach at Notre Dame. "Lack of understanding of rare diseases, the length of time to diagnosis, a lack of specialists and ineffective treatments are a few of the challenges rare disease patients face."

"We want to equip our students to become understanding patient advocates in their future careers as physicians and researchers. Our goal is to build collaborations among patients, families, students, researchers, clinicians and industry. This gift helps put the Notre Dame Patient Advocacy Initiative on a path to forming successful patient advocates."

To learn more about the program, visit the Notre Dame College of Science and Patient Advocacy [website](#).

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](#) and [Facebook](#) page and visit the website at [www.RAREisCommunity.com](#).

About Horizon

Horizon is a global biotechnology company focused on the discovery, development and commercialization of medicines that address critical needs for people impacted by rare, autoimmune and severe inflammatory 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, visit [www.horizontherapeutics.com](#) and follow us on [Twitter](#), [LinkedIn](#), [Instagram](#) and [Facebook](#).

About University of Notre Dame

The University of Notre Dame has been dedicated to finding cures for rare diseases since the early 2000s. At that time, there was a single faculty member working on one disease. In 2014, the College of Science established the [Boler-Parseghian Center for Rare and Neglected Diseases](#) with aspirations of becoming a national center of excellence for rare disease research and expanding the breadth of diseases studied at Notre Dame. Today, the Boler-Parseghian Center is one of only three academic rare disease centers in the country focused on basic research and faculty are

seeking cures for 12 different diseases. In the fall of 2021, the College of Science launched the first minor program in the country focusing on rare disease patient advocacy. For more information visit www.crnd.nd.edu.

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