



## Horizon Pharma plc and the National Organization for Rare Disorders (NORD) Illustrate 35 years of Progress in Rare Disease at the Biotechnology Innovation Organization (BIO) International Convention

June 4, 2018

-- People can join the campaign by texting the word "RARE" to 56512, which generates a donation to NORD --

DUBLIN, Ireland, June 04, 2018 (GLOBE NEWSWIRE) -- Horizon Pharma plc (NASDAQ:HZNP) and the National Organization for Rare Disorders (NORD) today launched a new campaign recognizing rare disease innovation since the passing of the Orphan Drug Act in 1983. Beginning today in the main lobby of the 2018 Biotechnology Innovation Organization (BIO) International Convention in Boston, innovators from throughout the world can view the creation of a work of art that illustrates rare disease progress and the major ongoing need to discover and develop new rare disease medicines.

People at BIO and across the world can join in the celebration of progress and call for continued innovation by texting the word "RARE" to 56512. For each text message, Horizon will donate \$1 (up to \$10,000) to NORD, a non-profit organization committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research and patient services. A reply message to each text provides a link to a mobile site where people can add their voice by uploading an image and a statement representing what gives them hope for themselves or others living with rare disease. Select photo submissions will be shared on Horizon's **RAREis**<sup>TM</sup> [Instagram](#) page as well as other social media channels throughout the year.

"The Orphan Drug Act has resulted in tremendous progress, with more than 600 orphan therapies having been FDA approved since its passing in 1983 – compared with only 34 before that time," said Peter L. Saltonstall, president and chief executive officer of NORD. "With thousands of known rare diseases affecting 30 million Americans there is a great deal of work still to be done, and BIO is the perfect place to illustrate this unmet need as it pulls together innovators who thrive on finding solutions to challenges – rare diseases continue to be among the most daunting."

There are approximately 7,000 different types of rare diseases and only five percent have approved treatments available. In the United States, a condition is considered "rare" if it affects less than 200,000 people while other countries have different definitions based on population.<sup>1</sup> This year marks the 35th anniversaries of both the formation of NORD and the passage of the Orphan Drug Act, which provides incentives for the development of medicines for people living with rare diseases.

"In addition to the six medicines we currently make available for rare diseases, we are rapidly growing our research and development team to accelerate the development of new medicines," said Shao-Lee Lin, M.D., Ph.D., executive vice president, head of research and development and chief scientific officer, Horizon Pharma plc. "As we collectively strive to accelerate the progress made over the last 35 years, there is tremendous opportunity in our interactions at BIO with many of the brightest minds in rare disease and innovation."

### **About NORD**

The National Organization for Rare Disorders, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 280 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. Learn more at [www.rarediseases.org](http://www.rarediseases.org).

### **About Horizon Pharma plc**

Horizon Pharma plc is focused on researching, developing and commercializing innovative medicines that address unmet treatment needs for rare and rheumatic diseases. By fostering a growing pipeline of medicines in development and exploring all potential uses for currently marketed medicines, we strive to make a powerful difference for patients, their caregivers and physicians. For us, it's personal: by living up to our own potential, we are helping others live up to theirs. For more information, please visit [www.horizonpharma.com](http://www.horizonpharma.com). Follow [@HZNPplc](#) on Twitter, like us on [Facebook](#) or explore career opportunities on [LinkedIn](#).

### **U.S. Media Contact:**

Matt Flesch  
Executive Director, Product Communications  
[media@horizonpharma.com](mailto:media@horizonpharma.com)

### **Ireland Media Contact:**

Ray Gordon  
Gordon MRM  
[ray@gordonmrm.ie](mailto:ray@gordonmrm.ie)

### **References:**

1. National Organization for Rare Disorders. Rare Disease Facts. Available at: [http://cdn.rarediseases.org/wordpresscontent/wp-content/uploads/2014/11/NRD-1008-FactSheet\\_5.pdf](http://cdn.rarediseases.org/wordpresscontent/wp-content/uploads/2014/11/NRD-1008-FactSheet_5.pdf). Accessed May 30, 2018.

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