



## Horizon Pharma plc Announces the Launch of “Cystinosis United” to Educate, Inspire and Connect the Cystinosis Community

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DUBLIN, Ireland, Jan. 30, 2018 (GLOBE NEWSWIRE) -- Horizon Pharma plc (NASDAQ:HZNP) today announced the launch of [Cystinosis United](#), an initiative created for people living with nephropathic cystinosis, a rare genetic metabolic disease that causes the amino acid “cystine” to accumulate in all organs of the body. Created in partnership with people living with cystinosis and their families, *Cystinosis United* includes a [website](#) and [Facebook page](#) providing videos, graphics, stories from families and experts, and links to resources from advocacy organizations.

“I’ve gotten to know quite a few people living with cystinosis over the years, and one thing I’ve learned is that this journey is complex and everybody experiences it differently,” said Rebekah P., an adult writer living with cystinosis who contributed her story and ideas to the launch of *Cystinosis United*. “What excites me about *Cystinosis United* is that it pulls from common themes that seem to have impacted us all, and aims to help others navigate living with the disease – from diagnosis, to addressing mental health, to living a fulfilling adult life. I hope this page makes the cystinosis journey a little bit brighter for those who may not be aware of all the support and resources available to them.”

*Cystinosis United* provides educational videos showing how cystinosis affects the body, the role of medicine in managing the disease, animations and infographics, and testimonials from people living with cystinosis who offer tips and advice from their unique cystinosis journey. *Cystinosis United* will also link to leading advocacy organizations, including The Cystinosis Research Foundation, the Cystinosis Research Network, the National Kidney Foundation, the National Organization for Rare Disorders, and Global Genes.

“Many of us at Horizon have been humbled to participate in cystinosis community events across the country, and I’m particularly taken by the strength and resilience among people living with cystinosis and their families,” said Robert Metz, senior vice president, patient advocacy, Horizon Pharma plc. “We have learned a great deal through these interactions, and our aim is for *Cystinosis United* to provide a steady stream of education and inspiration while connecting people to resources that can make a major difference in their lives.”

### **About Cystinosis**

Nephropathic cystinosis is a rare, life-threatening metabolic lysosomal storage disorder that causes toxic accumulation of cystine in all cells, tissues, and organs in the body. If untreated, elevated cystine accumulation leads to progressive, irreversible tissue damage and multi-organ failure, including kidney failure, blindness, muscle wasting and premature death. It is estimated that only about 2,000 people worldwide are currently diagnosed with nephropathic cystinosis. Nephropathic or “classic infantile” cystinosis – the most common and most severe form of the disease – is typically diagnosed in infancy and requires lifelong cystine depleting therapy.<sup>1</sup>

### **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](#).

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