



## Horizon Pharma plc Announces Release of the First RAREis™ Song in Partnership with Sing Me a Story Foundation and Global Genes

February 22, 2018

*-- Yearlong partnership will create 20 songs from the stories of children living with rare diseases --*

*-- Downloads of each RAREis song in 2018 will benefit the patient organization supporting the child's disease and Sing Me a Story Foundation --*

DUBLIN, Ireland, Feb. 22, 2018 (GLOBE NEWSWIRE) -- Horizon Pharma plc (NASDAQ:HZNP) today announced the release of the first song for the RAREis™ Playlist, a yearlong program in partnership with the Sing Me a Story Foundation (SMAS) and Global Genes, to elevate the stories of children living with rare diseases by transforming them into songs. The first song was written and performed by Cris Jacobs, one of Rolling Stone's top 10 country artists to watch, and is based on a story from Lilly, a 15 year-old living with a rare, inherited disease called a urea cycle disorder.

Downloads of "Whatever She Believes, She Can Be" benefit SMAS and Global Genes' Alliance Partner Connecting Families UCD Foundation, and Horizon will match the first \$5,000 in donations. Watch, listen and donate [here](#).

"Since launching RAREis, we've received an outpouring of stories of resilience and courage from those caring for and living with rare diseases," said Robert Metz, senior vice president, patient advocacy, Horizon Pharma plc. "As we approach the celebration of Rare Disease Day, we're proud to release 'Whatever She Believes, She Can Be', the first of many songs to be created for the RAREis Playlist that will give voice to the experiences of children living with rare diseases."

Throughout the year, Horizon, Global Genes and SMAS will work together to help rare disease non-profit organizations combine the imagination of children with the talents of songwriters and musicians. As part of the process, SMAS works with children to write their stories, and then delivers completed stories to songwriters. Each story is transformed into song for the [RAREis Playlist](#), available for download on the SMAS website. Donations for each download will benefit SMAS and the non-profit organization supporting the child's rare disease.

"Approximately 50 percent of the people affected by rare diseases are children and their experiences are often told through parents, or upon reflection when these children grow into adults – the RAREis Playlist helps give these children a voice now," said Nicole Boice, founder and chief executive officer of Global Genes. "Global Genes is proud to be a part of this unique opportunity to connect Sing Me a Story to some of the many rare disease non-profits we assist – helping them raise awareness, support and funds in a truly unique way."

New songs will continue to be released and added to the [RAREis Playlist](#) throughout 2018, spotlighting the stories and experiences of children living with some of the more than 7,000 rare diseases.

"By empowering children who live with a rare disease, like Lilly, to tell their stories we provide the opportunity for them to show how special they are and the importance of their own, unique and creative voice," said Austin Atteberry, executive director and co-founder of Sing Me a Story. "Our hope is that each song on the RAREis Playlist will not only raise a child's voice, but also inspire and further support organizations making a difference in the rare disease community."

### **About RAREis**

RAREis is an initiative by Horizon Pharma that aims to elevate the voices, faces and experiences of people living with rare diseases, as well as highlight programs and resources for the rare disease community. Launched in February of 2017, the initiative is anchored by an [Instagram page](#), which showcases photos, videos and stories of people touched by rare disease and captures elements of their patient, caregiver or advocate experience.

### **About Urea Cycle Disorders**

A urea cycle disorder (UCD) is a rare genetic disorder that affects approximately 1 in 35,000 live births in the United States. It is caused by an enzyme deficiency in the urea cycle, a process that is responsible for dealing with ammonia from the bloodstream and ultimately removing it from the body. Because of this, people with a UCD experience hyperammonemia, or elevated ammonia levels in their blood, that can then reach the brain and cause irreversible brain damage, coma or death. UCD symptoms may first occur at any age depending on the severity of the disorder, with more severe defects presenting earlier in life.

### **About Sing Me a Story Foundation**

The Sing Me a Story Foundation is a program that combines the imaginations of children with the talents of songwriters to create stories and songs that bring joy to all those involved. The organization works with organizations serving children in need – including those with rare diseases – to turn children's stories into songs created by songwriters. To learn more – and hear songs created as part of this process – visit [www.SingMeAStory.org](http://www.SingMeAStory.org). Follow @SMASFoundation on social media.

### **About Global Genes**

Global Genes is a leading rare disease patient advocacy organization whose mission is to connect, empower, and inspire the rare disease community. With international scope, Global Genes develops educational resources, programs, and events that unite patients, advocates, and industry experts. It is committed to fostering these meaningful connections to catalyze therapeutics and cures for the estimated 7,000 rare diseases that impact approximately 1 in 10 Americans, and 350 million people worldwide. For more information, please visit [www.globalgenes.org](http://www.globalgenes.org) and follow @GlobalGenes on social media to join the RARE conversation!

**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](https://twitter.com/HZNPplc) on Twitter, like us on [Facebook](https://www.facebook.com/horizonpharma) or explore career opportunities on [LinkedIn](https://www.linkedin.com/company/horizonpharma).

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