Harmony Biosciences Hosts Summit Which Sheds Light on Impact of Sleep Disruption in Rare Diseases

March 19, 2021

Commonality of sleep disruption in people living with rare diseases not previously recognized

PLYMOUTH MEETING, Pa., March 19, 2021 /PRNewswire/ -- Harmony Biosciences Holdings, Inc. ("Harmony") (Nasdaq: HRMY), a pharmaceutical company dedicated to developing and commercializing innovative therapies for patients living with rare neurological disorders who have unmet medical needs, today announced publication of a white paper sharing outcomes from a Summit on Sleep Disruption the company hosted in December 2020. For the first time, this summit convened a diverse group of people living with rare diseases, caregivers and leaders of advocacy organizations, who represented diseases in which sleep disruption has been recognized, to discuss the role excessive daytime sleepiness (EDS) plays in their respective conditions.

In many therapeutic areas, treatment is a balance of – or decision between – managing symptoms, including those not as well known or manifested, and addressing the underlying cause of the disease. Often in rare diseases, one such "hidden" symptom is EDS. The goals of the summit were to describe the physical, emotional, social and cognitive challenges faced by patients with EDS; the challenges they face in having this symptom diagnosed; and its overall impact and burden on daily functioning.

"On the occasion of World Sleep Day 2021, we want to help raise awareness of how excessive sleepiness is prevalent across the spectrum of rare disease," said Cate McCanless, Senior Vice President, Corporate Affairs & Policy. "EDS is much more closely associated with rare sleep disorders, like narcolepsy, but it can pose significant physical, emotional, social and cognitive challenges for so many others with rare disorders who may not even realize it."

Participants in the summit discovered common issues related to sleep disruption across different disease states that had not previously been recognized. These issues include behavioral challenges, reduced social and cognitive abilities, increased comorbidities, increased anxiety and depression, and an overall reduced health-related quality of life. The summit also highlighted challenges in sleep measurement data collection in special needs populations and a difficulty with diagnosis and treatment in comparison with symptoms more commonly associated or accepted as a part of their respective rare disease.

The white paper can be accessed by clicking here. Harmony Biosciences will continue to work closely with advocacy and patient organizations to share these findings with the broader rare disease community.

Summit participants included:

- Terri Jo Bichell, PhD, MPH, Executive Director, COMBINEDBrain
- Casey Gorman, Executive Director, Parents and Researchers Interested in Smith-Magenis Syndrome
- Lindsay Jesteadt, PhD, Director of Development, Wake Up Narcolepsy
- Jeremy Kelly, Board Chair & Lifetime Trustee, Myotonic Dystrophy Foundation
- Erica Kelly, person with myotonic dystrophy
- Rebecca King, Board Member, Hypersomnia Foundation
- Steve Maier, President, KLS Foundation Board of Directors

- Sharon O'Shaughnessy, Vice President, Board of Directors, Narcolepsy Network
- Lara Pullen, PhD, President and Co-Founder, Chion Foundation
- Paige Rivard, Chief Executive Officer, Prader-Willi Syndrome Association USA
- Theresa Strong, PhD, Director of Research Programs, Foundation for Prader-Willi Research

About Harmony Biosciences
Harmony Biosciences is a pharmaceutical company headquartered in Plymouth Meeting, PA. The company was established by Paragon Biosciences, LLC, with a vision to provide novel treatment options for people living with rare, neurological disorders who have unmet medical needs. For more information on Harmony Biosciences, please visit the company's website: www.harmonybiosciences.com.

Harmony Biosciences Media Contact:
Nancy Leone
215-891-6046
nleone@harmonybiosciences.com

Harmony Biosciences Investor Contact:
Lisa Caperelli
484-539-9736
lcaperelli@harmonybiosciences.com

View original content to download multimedia:http://www.prnewswire.com/news-releases/harmony-biosciences-hosts-summit-which-sheds-light-on-impact-of-sleep-disruption-in-rare-diseases-301250664.html

SOURCE Harmony Biosciences