



## PTC Therapeutics' 2020 STRIVE Awards for Duchenne Muscular Dystrophy Recognize Four Patient Advocacy Organizations

September 8, 2020

- Advocacy organizations in Argentina, Hungary, Russia and the U.S awarded funding -

- Total of 32 projects have been awarded funding since Awards inception in 2015 -

SOUTH PLAINFIELD, N.J., Sept. 8, 2020 /PRNewswire/ -- PTC Therapeutics, Inc. (NASDAQ: PTCT) today announced the winners of its sixth annual STRIVE Awards grant program for Duchenne muscular dystrophy. This year's winning initiatives, spanning across four continents, include an online platform to improve peer-to-peer connections; a series of events designed to connect Duchenne families with healthcare professionals; a support program to help families navigate the emotional journey of living with a rare disease diagnosis; and an ambassadors program to raise awareness of Duchenne in schools.

"The role of patient advocacy organizations is now more vital than ever before, with the unprecedented events of this year disproportionately impacting many rare disease patients and communities," said Mary Frances Harmon, Senior Vice President, Corporate Relations, PTC Therapeutics. "I am so proud of the continued support we are able to provide to these organizations all around the world through the STRIVE Awards, so that they can keep Duchenne communities supported and connected through this turbulent time."

Programs awarded funding as part of the 2020 STRIVE Awards are:

- **Argentina:** *Asociacion Distrofia Muscular* will develop an online platform for the neuromuscular diseases community across Argentina, which aims to help improve the quality of life of those affected by Duchenne by increasing social connections and providing accurate information to support users of the platform.
- **Hungary:** *The Healing Goodwill Foundation* will support Duchenne patients and their families in Hungary by hosting a series of events throughout the year to connect Duchenne patients and carers with healthcare professionals, as well as provide boys with Duchenne the opportunity for peer-to-peer interaction through a range of fun activities.
- **Russia:** The *GAORDI* patient organization in Russia will provide emotional, practical and educational support to patients with Duchenne through the 'Not Alone' program, which aims to support families adjusting to life with Duchenne and improve the quality of home care that parents and caregivers are able to provide.
- **United States:** *Cure Rare Disease* will develop a Student Education & Life Science Immersion Program in the U.S. to provide students with correct guidance and tools to become Duchenne Ambassadors in their schools and the wider community.

"In an era where lockdowns and social distancing measures are keeping us physically apart, I have been inspired by the innovative solutions and resilience demonstrated by patient organizations supporting Duchenne communities to stay connected," said Anna Kole, MPH, Public Health Professional and one of the judges. "Applications were strong in all categories, but this focus on connections was a key theme we noticed in this year's STRIVE Awards winning programs."

### About the STRIVE Awards Program

PTC began the Strategies to Realize Innovation, Vision, and Empowerment (STRIVE) Awards program in 2015 to support initiatives that benefit the Duchenne community by increasing awareness, diagnosis and education, and fostering the development of future patient advocates. Each year, an independent panel of external experts with knowledge in rare diseases, patient advocacy and funding initiatives, judge the entries for innovation, vision and empowerment.

For further information about the program and each award recipient, please visit the STRIVE section of the PTC website: [www.ptcbio.com/en/about-ptc/ptc-strive-awards-program/](http://www.ptcbio.com/en/about-ptc/ptc-strive-awards-program/).

### About Duchenne Muscular Dystrophy

Primarily affecting males, Duchenne muscular dystrophy (Duchenne) is a rare and fatal genetic disorder that results in progressive muscle weakness from early childhood and leads to premature death in the mid-twenties due to heart and respiratory failure. It is a progressive muscle disorder caused by the lack of functional dystrophin protein. Dystrophin is critical to the structural stability of all muscles, including skeletal, diaphragm, and heart muscles. Patients with Duchenne can lose the ability to walk as early as age ten, followed by loss of the use of their arms. Duchenne patients subsequently experience life-threatening lung complications, requiring the need for ventilation support, and heart complications in their late teens and twenties.

More information regarding Duchenne is available through the Muscular Dystrophy Association and the Parent Project Muscular Dystrophy. Additionally, information and resources are available at [www.duchenneandyou.com](http://www.duchenneandyou.com)

### About PTC Therapeutics, Inc.

PTC is a science-driven, global biopharmaceutical company focused on the discovery, development and commercialization of clinically differentiated medicines that provide benefits to patients with rare disorders. PTC's ability to globally commercialize products is the foundation that drives investment

in a robust pipeline of transformative medicines and our mission to provide access to best-in-class treatments for patients who have an unmet medical need. To learn more about PTC, please visit us on [www.ptcbio.com](http://www.ptcbio.com) and follow us on [Facebook](#), on [Twitter at @PTCBio](#), and on [LinkedIn](#).

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