FOR IMMEDIATE RELEASE: Jesse's Journey grants $1.7 million to Duchenne muscular dystrophy research.

Jesse's Journey has been Canada's largest funder of Duchenne research for more than 25 years.

Thousands of families are in a race against time to find a cure for Duchenne muscular dystrophy – the most common fatal genetic disease diagnosed in childhood.

LONDON, ONTARIO - May 4, 2021 - Jesse's Journey, Canada's leader in Duchenne muscular dystrophy funded research, is proud to announce that it will grant **$1.7M** toward four promising research projects this year - the largest annual amount in its 26-year history.

Duchenne muscular dystrophy is a life-threatening, progressive, neuromuscular disorder with no cure. Affecting approximately 1 in every 5,000 boys in Canada, Duchenne is caused by mutations within the dystrophin gene, one of the largest genes in the body responsible for strengthening muscles and protecting them from injury.

One of the funded projects is led by Dr. Ronald Cohn, President and CEO of The Hospital for Sick Children (SickKids) in Toronto, Ontario. His team has successfully implemented a genome-editing technique in mice that imitates the genetic mutation of a patient with Duchenne. Using CRISPR-Cas9 technology, they have demonstrated restoration of full functionality to the disease-causing gene for the first time in a living animal (*in vivo*).

"Precision medicine solutions, such as genome editing, have emerged as a beacon of hope for patients with rare genetic disorders such as Duchenne. While this research is charging ahead in some areas, it has been hampered for patients with duplication mutations," says Dr. Cohn. "Our research seeks to open up treatment avenues that we previously weren't able to explore for these patients."

The researchers hope to test their strategy in older mice to see if they can not only prevent the development of Duchenne symptoms but reverse symptoms that have already started. They will also continue refining this treatment in the hopes of translating it into clinical trials for patients.

“The truly outstanding fundraising efforts produced by the Jesse’s Journey team is a testament to their collective desire to drive change in Duchenne muscular dystrophy research,” says Ted Garrard, CEO, SickKids Foundation. “Their generous gift to the project led by Dr. Cohn will further ground breaking precision medicine research, which in turn will lead to better outcomes for those affected by Duchenne.”

This project, along with the three others funded by Jesse's Journey in 2020/21, is part of a large pipeline of potential treatments that bring hope to families living with Duchenne.

"Jesse's Journey is a partnership of scientists and families who help fund the research that fundamentally reshapes how boys and men live with Duchenne," shares Perry Esler, Executive Director of Jesse's Journey. "This focus and fundraising effort have brought us to granting more than **$14.7 million** across 50 research projects around the world. We know research is the only way to defeat Duchenne, and we will continue to invest in the most promising science toward prevention, improved treatments, and ultimately a cure.”

Learn more about this year's research grant recipients and their transformational work here: www.jessesjourney.com/research-is-the-road-to-hope.

About Jesse's Journey

Jesse's Journey is Canada's leading charity fighting to defeat Duchenne muscular dystrophy – the most common fatal genetic disease diagnosed in childhood. For more than 25 years, Jesse's Journey has empowered patients, families, and caregivers living with Duchenne through education and resources, provided a collective voice to advocate for access to treatments in Canada, and has become the country's largest funder of Duchenne research investing more than **$14.7M** in projects around the world.

www.jessesjourney.com

Facebook: @defeatduchenne
Twitter: @jesses_journey
Instagram: @jesses_journey

Rochelle ten Haaf
Manager, Marketing and Stakeholder Engagement
226-234-7497
rochelle@jessesjourney.com