PRESS RELEASE

FOR IMMEDIATE RELEASE

Jesse's Journey and Parent Project Muscular Dystrophy Award $172,000 (CAD) Clinical Fellowship in Duchenne Endocrinology and Bone Fragility

Award Will Sponsor a Two-Year Fellowship Under Dr. Leanne Ward, University of Ottawa with Focus on Endocrine and Bone Complications of Duchenne

HACKENSACK, NJ – June 16, 2021 – Parent Project Muscular Dystrophy (PPMD), a US nonprofit organization leading the fight to end Duchenne muscular dystrophy (Duchenne), and Jesse's Journey, Canada's leading charity fighting to defeat Duchenne, today announced a collaborative research award of $172,000 (CAD) in support of a two-year Clinical Fellowship in Duchenne Endocrinology and Bone Fragility. The award will sponsor the fellowship of Dr. Kim Phung under the guidance of Dr. Leanne Ward, Professor of Pediatrics and Research Chair in Pediatric Bone Health at the University of Ottawa.

Duchenne is the most common fatal genetic disorder diagnosed in childhood, affecting approximately one in 5,000 live male births. Because people with Duchenne do not have dystrophin (a protein found in muscle), their skeletal muscles gradually become weak. A class of medications called corticosteroids ("steroids") are used in Duchenne to slow down muscle damage and weakness.

Endocrine issues can be common in Duchenne, especially if a person is on steroids. When steroids are taken every day over a long period, they change the way the body's natural hormones are made and work, leading to issues such as adrenal suppression, delayed puberty, and impaired growth. In addition, people with Duchenne, especially those taking steroids, have weak bones (osteoporosis), putting them at risk for fractures.

Under the guidance of Dr. Ward, the award will support Dr. Phung, currently finishing her Pediatric Endocrinology fellowship at St. Justine Hospital in Montreal, in completing a two-year fellowship in pediatric endocrine and bone diseases at the University of Ottawa, with specific focus on endocrine and bone complications of Duchenne. The Fellowship will expand research on Duchenne and its treatment-related complications, education of families and healthcare providers about the management of endocrine and bone complications, and encourage ongoing partnership to foster advocacy in these areas of care.

Rachel Schrader, MS, APRN, CPNP-PC, PPMD's Vice President of Clinical Care and Education and Nicola Worsfold HBSc, MSc, Director of Research and Advocacy at Jesse's Journey explained in a joint statement: "The endocrinology and bone fragility effects of Duchenne and its treatment represent important clinical care issues, and are a key concern for families living with Duchenne. Jesse's Journey and PPMD are pleased to partner with each other to provide support for this important area of research as we work to educate physicians and families on

common endocrine and bone issues in Duchenne, including growth, puberty, adrenal suppression, obesity and related complications, and bone fragility due to osteoporosis."

"Dr. Phung and I are extremely excited and most grateful for the support of Jesse's Journey and PPMD. I have always admired the work of these organizations to support families. For Dr. Phung to be the beneficiary of a Fellowship position is yet another example of their empowering initiatives. I very much look forward to our ongoing work together in the areas of endocrine and bone complications of Duchenne," said Dr. Ward.

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 **$14.8M** in projects around the world.

Join our fight to defeat Duchenne at jessesjourney.com. Follow us on Facebook, Twitter, Instagram, and YouTube.

ABOUT PARENT PROJECT MUSCULAR DYSTROPHY:

Duchenne is a fatal genetic disorder that slowly robs people of their muscle strength. Parent Project Muscular Dystrophy (PPMD) fights every single battle necessary to end Duchenne.

We demand optimal care standards and ensure every family has access to expert healthcare providers, cutting edge treatments, and a community of support. We invest deeply in treatments for this generation of Duchenne patients and in research that will benefit future generations. Our advocacy efforts have secured hundreds of millions of dollars in funding and won five FDA approvals.

Everything we do—and everything we have done since our founding in 1994—helps those with Duchenne live longer, stronger lives. We will not rest until we end Duchenne for every single person affected by the disease. Join our fight against Duchenne at EndDuchenne.org. Follow PPMD on Facebook, Twitter, Instagram, and YouTube.

Media Contacts:

Stephanie Ivanov
stephanie@parentprojectmd.org

Rochelle ten Haaf
rochelle@jessesjourney.com