DEFEAT DUCHENNE CANADA

THE JESSE DAVIDSON FOUNDATION
PO BOX 51, STATION B LONDON, ON N6A 4V3
TEL: 519.645.8855
INFO@DEFEATDUCHENNE.CA
CHARITABLE NUMBER: 89509-7756-RR0001

Position: National Director, Research

Full-time: 40 hours per week, Monday to Friday (occasional evenings and weekends for events)
Location: Remote (within Canada) / Head office in London, ON
Reports to: Executive Director

About Defeat Duchenne Canada

Defeat Duchenne Canada is the country's only national charity solely dedicated to ending Duchenne muscular dystrophy.

Throughout our 30-year history, we have provided leadership in research, advocacy, education and support. Our organization, originally known as Jesse's Journey, was founded in 1995 when John Davidson embarked on an epic journey, pushing his son Jesse in his wheelchair across Ontario to raise awareness and funds for Duchenne research. We are now the largest funder of Duchenne research in Canada, with more than $20 million invested in research projects worldwide

We fight alongside Canadian families impacted by Duchenne, for improved treatments and equitable access to care, so every Canadian with Duchenne can live a long, active life.

About Duchenne muscular dystrophy

Duchenne muscular dystrophy is the most common form of muscular dystrophy diagnosed in childhood. The Canadian Neuromuscular Disease Registry estimates that between 800 and 1,000 individuals in Canada are living with Duchenne.

It is a progressive, rare genetic disorder caused by the absence of dystrophin, a protein essential for muscle function and repair. While it primarily affects boys and young men, Duchenne has a profound impact on families, communities and healthcare systems. The treatment landscape has expanded significantly over the past decade, yet there remains an urgent need for both a cure and comprehensive, lifelong support. Access to equitable treatments in Canada continues to be a challenge, and coordinated adult care is limited for many in our communities.

Role Overview

The National Director, Research provides strategic leadership and oversight of Defeat Duchenne Canada's research and scientific initiatives. Reporting to the Executive Director, this position plays a key role in advancing the organization's mission to fund innovative research and accelerate access to effective therapies, and serves as the organization's lead scientific voice.

The National Director, Research is responsible for developing, implementing, and evaluating Defeat Duchenne Canada's research strategy and investments, ensuring alignment with organizational priorities and community needs. This role works closely with the Community

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Engagement and Education team, providing scientific expertise so that health and research information shared with families and healthcare providers is accurate and current. The Director also builds collaboration among researchers, healthcare providers, and industry partners in Canada and around the world.

Key Responsibilities

1. *Research Leadership*

- Lead the development and execution of Defeat Duchenne Canada's research strategy and funding priorities
- Oversee research grant programs, including application review processes, peer review coordination, and outcome evaluation
- Monitor national and international Duchenne research trends to identify emerging opportunities and gaps
- Build and maintain relationships with academic, clinical, and industry partners to foster collaboration and knowledge exchange
- Track and evaluate ongoing research projects and provide regular updates to leadership, board, and stakeholders
- Manage the annual research budget and grant portfolio, including grant agreements, payment schedules, and progress reporting, in line with Canada Revenue Agency requirements for charities
- Coordinate and lead the Research Funding Advisory Committee (RFAC), including member recruitment, terms of reference, conflict of interest management, and meetings
- Develop co-funding partnerships with Canadian and international research funders to extend the reach of each research investment

2. *Scientific Expertise*

- Provide scientific expertise, input, and review to the Community Engagement and Education team so that educational resources, webinars, family forums, and health-related materials are accurate, clear, credible, and current, and reflect the Duchenne community's perspective
- Translate complex scientific information into accessible content for a range of audiences
- Represent Defeat Duchenne Canada at scientific meetings and conferences
- Work with the Community Engagement and Education team, clinicians, patient registries, and trial networks to help families find reliable information about clinical trials and research participation in Canada

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3. *Strategic and Operational Support*

- Advise the Executive Director, Board, and staff on research impact, grant budget impact, priorities, and emerging issues
- Contribute to fundraising and partnership initiatives by providing scientific context and impact metrics
- Support communications and advocacy efforts through data-driven insights and subject matter expertise
- Ensure ethical standards and transparency in research funding and partnerships
- Provide scientific evidence to support the Advocacy team's work with Health Canada, Canada's Drug Agency, and provincial drug plans on timely, equitable, and affordable access to treatments
- Serve as a member of the senior leadership team and contribute to organizational strategic planning, budgeting, and risk management

4. *Knowledge Translation*

- Provide research content for impact reports, success stories, and presentations led by the Marketing and Communications team for fundraising and awareness initiatives
- Work closely with the Marketing and Communications team to highlight research news, Canadian research leadership, and global contributions
- Provide research updates to the Philanthropy team for donor stewardship, including progress reports for donors and funders who support specific research projects
- Report on research outcomes and impact using clear measures, such as projects funded, trials launched, and publications, to show progress to the community and supporters

Qualifications

- Graduate degree (MSc or PhD) in a relevant scientific or health discipline (e.g., biomedical sciences, genetics, neuroscience, pharmacology, health research, or related field)
- Three + years of experience in research program management, grant administration, or scientific project leadership (ideally in healthcare, rare disease, or neuromuscular research)
- Strong understanding of the translational research landscape, drug development processes, and clinical trial design in rare diseases or neuromuscular disorders

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Essential Skills and Competencies

- Proven ability to design, implement, and evaluate research funding programs and initiatives
- Exceptional ability to interpret and communicate complex scientific information to diverse audiences (families, clinicians, funders, and policymakers)
- Excellent project management and organizational skills with the ability to balance strategic priorities and day-to-day operations
- Strong writing and editing skills for scientific and educational content, including reports, grant summaries, scientific manuscripts, and web materials for both scientific and non-scientific audiences
- Strong collaboration and relationship-building skills, with experience fostering partnerships across academia, healthcare, government, industry, families, and donors
- Knowledge of ethical standards, research governance, and best practices in research funding
- Knowledge of the Canadian research funding landscape, including CIHR and provincial health research funders
- Ability to communicate with sensitivity and empathy with families living with Duchenne

Assets

- Proficiency in French (written and spoken)
- Experience with Duchenne or related neuromuscular research
- Experience working with a health charity, patient organization, or research funder
- Experience managing advisory committees and peer review panels

Why Join Us

Joining Defeat Duchenne Canada means becoming part of a small but mighty team driven by purpose, compassion, and a commitment to meaningful impact.

You will:

- Lead the research program for a national organization at a pivotal moment of growth
- Shape a strategy that accelerates research, improves care, and supports families across Canada
- Work alongside a values-driven team that prioritizes collaboration, compassion, and impact
- Enjoy flexibility and trust with a supportive environment that recognizes the importance of balance

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- Contribute to a mission where every dollar raised brings us closer to a future without Duchenne

Compensation and Benefits

Defeat Duchenne Canada offers a competitive and equitable compensation package that reflects the seniority and national scope of this role. The anticipated salary range is $80,000 to $100,000, with adjustments made to account for regional cost of living differences across Canada.

Employees receive comprehensive health, dental, and vision benefits, along with employer-paid insurance supports that promote overall well-being. Paid time off includes three weeks of vacation to start, sick and personal days, and additional paid closure during the December holiday period. Staff also enjoy our Summer Friday program, which provides Fridays off leading into each long weekend between Victoria Day and Thanksgiving.

We offer a flexible work environment with remote work support, a professional development budget to encourage ongoing learning, certification, and sector engagement, and reimbursement for approved travel and work-related expenses.

Inclusion and Accessibility

Defeat Duchenne Canada is committed to an inclusive workplace. We welcome applications from all qualified candidates, including people with disabilities and people with lived experience of Duchenne or other neuromuscular conditions. Accommodation is available on request at every stage of the hiring process.

How to Apply

Please submit your resume and cover letter to careers@defeatduchenne.ca. Applications will be reviewed on a rolling basis. Closing date: January 5, 2027.