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

Director of Research

Position Title: Director of Research
Full-time: 40 hours per week, Monday to Friday (occasional evenings and weekends for events)
Location: Hybrid/Remote
Reports To: Executive Director

About Duchenne Muscular Dystrophy

One in every 5,000 boys are born with Duchenne muscular dystrophy +worldwide, the most common fatal form of muscular dystrophy. More than 800 boys and young men live with Duchenne in Canada. The disease is progressive and relentless. It gradually weakens the body's muscles, deteriorating function of vital organs and ultimately shortening life expectancy. Over the past decade, research into Duchenne has advanced significantly, leading to new insights and emerging therapies. However, major challenges remain in developing safe and effective treatments that can meaningfully alter the course of the disease. We are still very far from a cure. In addition, access to care and treatment across Canada remains inconsistent, particularly within adult care, highlighting an urgent need for more equitable, coordinated, and comprehensive approaches to supporting individuals and families affected by Duchenne.

About Defeat Duchenne Canada

Defeat Duchenne Canada is the country's only national charity dedicated to ending Duchenne muscular dystrophy. Throughout our 31-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.

Position Summary

The Director of 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 Director of 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 Education and Engagement 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.

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Key Responsibilities

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), and the Duchenne Family Advisory Committee (DFAC), 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.

Scientific Expertise

- Provide scientific expertise and oversight to ensure accuracy, clarity, and credibility of all educational and health-related materials.
- Provide scientific input and review to the Education and Engagement team for educational resources, webinars, and family forums, ensuring the Duchenne community's perspective is reflected, and research information is accurate and current.
- Translate complex scientific information into accessible content for a range of audiences.
- Represent Defeat Duchenne Canada at scientific meetings, and conferences.
- Help families find reliable information about clinical trials and research participation in Canada, working with clinicians, patient registries, and trial networks.

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.

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- Serve as a member of the senior leadership team and contribute to organizational strategic planning, budgeting, and risk management.

Knowledge Translation

- Develop research communications, impact reports, success stories, and presentations for fundraising and awareness initiatives.
- Work closely with the communications team to highlight research news, Canadian research leadership and global contributions.
- Prepare research updates 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

Education and Experience

- Graduate degree (MSc or PhD) in a relevant scientific or health discipline (e.g., biomedical sciences, genetics, neuroscience, pharmacology, health research, or related field).
- At least 3 to 5 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 (experience with Duchenne or related fields is an asset).
- Experience working with a health charity, patient organization, or research funder is an asset.
- Experience managing advisory committees and peer review panels is an asset.

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, paper writing, and web materials for both scientific and non-scientific audiences.
- Collaborative and relationship-oriented, 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.
- Ability to work in French is an asset.

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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.
- 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. Accommodations are 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 5th, 2027**