

Muscular Dystrophy Ireland
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RESEARCH OFFICER – MUSCULAR DYSTROPHY IRELAND

JOB DESCRIPTION

CONTRACT: Three-year, fixed term contract

HOURS: Full time

SALARY: Competitive, depending on experience

REPORTING TO: The Chief Executive Officer

LOCATION: 75, Lucan Road, Chapelizod, Dublin D20 DR77

MUSCULAR DYSTROPHY IRELAND (MDI) is a voluntary organisation that provides information, advice and a wide range of support services to people with muscular dystrophy and other neuromuscular conditions, and their families, as well as advocating with them and on their behalves.

MDI's main objectives are:

- Providing information and support to people with neuromuscular conditions and their families through a range of support services
- Advocating for services and entitlements for members; educating and informing society about neuromuscular conditions
- Supporting researchers and clinicians to carry out quality research into neuromuscular conditions.

A key focal point of MDI's 2020-2022 strategy is to create a patient registry for people in Ireland with neuromuscular conditions. Other priorities include research to deepen understanding of neuromuscular conditions and quality of life research.

MDI seeks to recruit an enthusiastic individual with research, computational and communication skills, relevant qualifications and experience for the following position:



Research Officer

Key duties and responsibilities include the following:

Research management and support

- Lead the development and maintenance of a national neuromuscular disease patient registry and a clinical management system. This will include the planning, development and execution of the registry database.
- Facilitate stakeholder and patient involvement in the registry.
- Support researchers and clinicians to carry out quality research into neuromuscular conditions, and manage and support ongoing and future research projects.
- Propose new research projects, in line with the research strategy of MDI.
- Contribute to the research activities and strategy of MDI.
- Act as a point of contact between researchers, patients and clinicians, and support the development of research networks both nationally and internationally.
- Facilitate patient involvement in research into neuromuscular conditions.
- Provide support to members seeking to take part in clinical trials and the use of potential therapies.
- Manage all aspects of the research budget, identify sources of funding and contribute to securing funds for research.
- Develop MDI policies relating to research.
- Lobby and advocate for improved treatments, clinical trials and increased research investment.

Communications

- Work with the relevant stakeholders to develop and implement a communication plan detailing the benefits of the registry to people with muscular dystrophy.
- Keep abreast of research in the field of neuromuscular conditions, current treatments and standards of care and disseminate relevant information to stakeholders, members and staff in a timely manner.
- Represent MDI and contribute to relevant committees at national and international conferences.
- Produce accessible content on all aspects of neuromuscular research.



- Work with MDI Information Officer to organise information events and prepare resources on developments in research and treatment for members and other stakeholders.
- Communicate across all stakeholder groups, helping to inform the wider community in relation to research on neuromuscular conditions.
- Co-ordinate MDI's research committee and provide administrative support.
- Participate in the development and implementation of MDI's research strategy.

Candidate profile

Qualifications and experience:

- Third level qualification in relevant field (e.g. medical/clinical/scientific)
- Previous experience of working in a health research environment
- A minimum of two years' experience in managing and delivering projects while meeting deadlines
- Interest in and understanding of neuromuscular conditions.

Essential skills and attributes:

- Self-motivated, capable of working independently and with a strong work ethic
- Excellent communication skills including, written, verbal and presentation skills and the ability to make complex topics accessible
- Computational skills (including managing databases)
- Ability to work as part of a multidisciplinary team
- Flexibility to travel as required.

This list of duties is not intended to be exhaustive, but to reflect the main duties of the position and is subject to change. Due to the size of the organisation all staff will, from time to time, be required to do duties outside of their job description. Any other duties may be allocated from time to time consistent with the position, operational plan and strategic plan.

Interested candidates should submit a copy of their CV and cover letter to Elaine McDonnell, CEO by Friday, 15th January at 5.00pm via ceo@mdi.ie

Muscular Dystrophy Ireland is an equal opportunities employer.