



NORTHERN IRELAND
**RARE DISEASE
PARTNERSHIP**

CHIEF EXECUTIVE OFFICER Information Pack

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Introduction

Dear Candidate

Northern Ireland Rare Disease Partnership is a charity, with a mission is to ensure that “no one is disadvantaged because of the rarity of their condition”. We bring together those living with a rare disease and organisations representing them, clinicians and other health professionals; researchers, producers of specialist medicines/equipment; health policymakers and academics.

We are looking for a proven leader with a dedication to the evidenced delivery of social impact in their field. You will have the support of an equally impassioned Board of Trustees and lead a small team of staff and volunteers all committed to building on the successful work of the Partnership over the last ten years to meet the needs of service users across Northern Ireland.

If ours is a mission about which you are passionate, and you feel you have the skills and experience to lead our organisation into the next exciting phase of its development, then we would love to hear from you.

Rhoda Walker

Chair

Purpose of the Role

Launched in 2012, the Northern Ireland Rare Disease Partnership (NIRDP) is now ready to appoint a senior leader. This exciting new role is for you if you have experience in co-production, are a team player, and motivated to use your skills creatively to support and represent our members.

Key areas of work include:

- Leading the development and implementation of policies and programmes to meet the needs of the rare disease community.
- Influencing with, and for members locally, regionally, nationally and internationally.
- Developing partnership working with public, private and community sector organisations.

This may be for you if you are:

- Visionary: Experienced in building partnerships and creating new opportunities for people and organisations
- A networker: Someone who understands co-production and achieving stakeholder buy-in, who can enthuse and engage service developers, policy makers and researchers to include the rare disease community voice.
- Self-starting: Keen to take on a challenging, hands-on role in developing and supporting the work of NIRDP. Do you have energy and fresh ideas around the development of services and delivering within a timeframe?
- Passionate: A genuine passion for the wellbeing of others and a drive to improve the lives of individuals and communities.

NIRDP embraces, respects and values the difference in its employees and is committed to creating and maintaining an inclusive environment that consists of fairness, dignity, and caring for everyone, and one that enables every employee to flourish and realise their potential.

This is a new leadership role, with potential for extension and career progression - subject to funding.

Role Specifics

Hours	28 hours per week (job share will be considered)
Base	Home based with some travel requirements
Reports to	NIRDP Chair
Accountable to	NIRDP Board
Salary	£30,000 + Benefits
Contract	Fixed term 12 months with possibility of extension (funding dependent)

What are the benefits of working at NIRDP?

Hours	Agile working - a dynamic and flexible internal culture that gives employees control over the way they work and supports wellbeing.
Annual Leave	A competitive annual leave entitlement of 25 days per year plus public holidays pro rata.
Culture	We are focused on developing a strong team culture that focuses on collaboration. A culture where the Board, staff and volunteers take ownership of our individual contributions but work to each other's strengths in our efforts to achieve our shared vision.
Development	A proactive, positive, and progressive approach to team development. Training and support are available as required.
Pension	NIRDP will contribute 3% of salary and the individual contributes a minimum of 5%. We operate this as a salary exchange and NIRDP also contributes the resulting NI saving into your pension.

Job Description

Reporting directly to the Chair of the Board, the CEO provides leadership and has responsibility for devising the charity's strategic direction in service delivery, administration, recruitment and retention of staff, volunteers and finances.

The CEO supports the overall strategic framework determined by the Board and leads the development and implementation of such strategies that meet the need of the communities in which NIRDP operates, as well as its funders and other stakeholders. The postholder communicates with people inside and outside the organisation to discover which policies, practices, services and marketing strategies are required to help the organisation develop. They will make important decisions intended to enhance the effectiveness of the organisation, its employees and volunteers to deliver the social impact which is its purpose.

1. Strategic Leadership

- Work closely with the Chair of the Board, building a strong working relationship, and building an effective working relationship with all the other trustees/Board members.
- Produce strategic business plans for approval by the Board of Trustees, including a five-year strategy and annual strategic plans that are informed by feedback from a range of stakeholders.
- Monitor and analyse the environment in which NIRDP works, identifying strategic opportunities for growth, and challenges that need managed.
- Work with the Board Treasurer to produce an annual budget for approval by the Board.
- Monitor and evaluate performance against business objectives for reporting to the Board, seeking approval for any contingency measures identified as being required.
- Lead and support strategic and organisational change when it is needed.

2. Governance

- Ensure the organisation fulfils its legal, statutory and regulatory responsibilities

including to HMRC and the Charity Commission NI.

- Work with the Board to manage the annual cycle of monitoring and reporting of regulatory compliance with Charity Commission NI, fulfilment of charitable purpose and compliance with HMRC or its equivalents.
- Provide evidence of best practice and processes that shows NIRDP's resources are being expended efficiently and effectively.
- Maintain awareness of risks and changes in the external environment that affect the organisation, documented by preparing and maintaining a Risk Register as well as Discipline, Grievance and Appeals, and Finance systems.
- Liaise closely with the team to ensure the effective management and supervision of staff and volunteers to ensure compliance at all levels within NIRDP.
- Establish mechanisms for listening to the views of beneficiaries on the charity's performance to contribute to continuous improvement.
- Attend trustee meetings, all internal and external general meetings of the charity as required.

3. Organisation Leadership

- Lead all team members in creating and attaining or exceeding SMART objectives which together form the implementation of NIRDP's strategy and operational goals.
- Work with the operations management and staff in developing NIRDP's operational plans and budgets to ensure compliance with relevant laws and regulations.
- Establish and monitor key performance indicators of the organisation's performance, impact and financial health.
- Provide management information reports on performance against plan and budget and circulate regularly to appropriate stakeholders.
- Actively promote the capture of learning from service delivery to ensure continuous improvement.
- Problem-solve management issues through evidence-based analysis, clarity of action and stakeholder buy-in.

4. Income Generation

- Work to secure funds to meet NIRDP needs and commitments and identify appropriate developments that generate additional sources of funding.
- Cultivate a portfolio of opportunities to generate income from a diverse range of sources which builds the sustainability of the charity.
- Formulate and implement an effective plan for the generation of unrestricted funds.

5. People Management

- Nurture an inclusive, values-driven organisational culture of shared learning and co-operation, of commitment to improvement and high performance, and

to the ongoing professional development of all staff.

- Lead the NIRDP team ensuring the members are empowered and offered the development they need to fulfil their individual roles and cultivating future leaders.
- Develop plans to ensure current and future personnel and volunteering requirements are addressed.
- Encourage and promote areas of innovation and continuous improvement within the staff team that meet the broader organisational vision and aim.
- Recruit and manage contractual relationships with contractors, employees and volunteers.

6. Communications

- Develop and maintain positive working relationships with other organisations and the local community, and liaise with and maintain effective links with statutory, voluntary and professional bodies and other stakeholders.
- Represent the organisation at the highest possible level with regional departments and other bodies (in particular those responsible for Health and Communities) and political representatives.
- Develop and maintain relationships with current and potential funding bodies and delivery partners. The postholder may be required by the Board to undertake such other duties as may lie within the scope of this post to ensure the effective delivery and development of the charity's services.

Person Specification

Experience and knowledge	Essential	Desirable
Hold a third level qualification or equivalent	✓	
A minimum of two years' management experience reporting to Director, Chief Officer-level or to Board	✓	
Experience of producing and implementing strategic and operational plans to include monitoring and evaluation	✓	
Experience of developing/overseeing a programme of income generation to ensure sustainability	✓	
Experience of producing and implementing communication and marketing plans	✓	
Campaigning experience within a non-profit environment	✓	
Experience of all aspects of operations, fundraising, financial management and governance of a small organisation, registered charity, limited company	✓	
Sound knowledge of management structure and systems	✓	
Experience of risk management in a similar environment	✓	
Staff management to include recruitment, management and development of staff and volunteers using an inclusive and empowering leadership style	✓	
An understanding of the needs of people with rare diseases, including children and young people		✓
Experience of the healthcare sector		✓
Experience of service level agreements, contracts, tendering and commissioning.		✓

Skills and Abilities	Essential	Desirable
Exceptional communication skills, drive and enthusiasm	✓	
Strong Leadership - ability to inspire and effectively lead an organisation to achieve best practice	✓	
Strong interpersonal and relationship building skills - to include collaborative working with a diverse set of stakeholders to achieve a common goal	✓	
Organisational skills, attention to detail, ability to prioritise to meet targets and deadlines	✓	
Strong IT and presentational skills with experience of Microsoft Office 365 and online collaboration tools	✓	
Ability to lead change, think strategically and have a commitment to on-going professional development and training.	✓	
Willing to travel to meetings in NI, ROI and UK when necessary	✓	

Application Process

Please forward a CV, maximum three A4 sides, together with a completed Supplementary Questions form to Fiona McLaughlin on secretary@nirdp.org.uk, ensuring you have included relevant contact numbers.

The deadline for submission is **Monday 20 December at 4 pm**.

Note: If you consider yourself to have a disability relevant to the position for which you are applying, please contact Fiona so that we can process your application fairly, make any specific arrangements for your interview, and make any necessary reasonable adjustments or adaptations, and provide any aids to assist you in completing the duties of the post if appointed.

In accordance with the Disability Discrimination Act a person is disabled if they have, or have had, “a physical or mental impairment which has, or has had, a substantial and long-term adverse effect on your ability to carry out normal day to day activities”.

The Interview Stages

You will be asked to give a brief presentation – the topic will be provided at invitation stage.

Candidates will also be assessed against their presentation and the following criteria:

- Commitment to the ethos and values of NIRDP.
- A high degree of personal and professional credibility to engender trust and inspire external stakeholders.
- Ability to lobby and advocate as an influencer to senior representatives in stakeholder organisations.
- The ability to think and act strategically, developing practical and creative solutions.
- High self-motivation, creativity and determination, with the ability to take the initiative and problem-solve effectively.

These will be required and assessed alongside key roles and responsibilities outlined in the Job Description and Person Specification.

Interview will take place week commencing **Monday 3 January 2022**.

Use of Videoconferencing

As a result of the COVID-19 interviews will be conducted by videoconference. Please make sure you have access to adequate broadband speeds, and a mic and camera enabled computer. The videoconferencing platforms to be used may be Zoom or Microsoft Teams.