



Roald Dahl's Marvellous Children's Charity Trustee Recruitment Pack September 2020

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WELCOME FROM THE CHAIR

Thank you for your interest in the Roald Dahl's Marvellous Children's Charity. The charity is thirty years old next year, and it is on an exciting journey. Currently we are looking for like-minded people to join the board of trustees and support it with their skills and experience. In particular we are looking for a trustee with an intimate knowledge of the charity world, who is also familiar with the healthcare sector and its public policy context.

Our Chief Executive, Louise Griew, has been at the helm of the charity for a year now and she has gathered a small but dedicated team around her. They are smart, committed and passionate about what they do. This energy and talent is reaping dividends for the charity. Our CoVid Nurses appeal in May was a big success and fundraising is currently significantly ahead of expectations – sadly something that few small charities can say just now.

My fellow trustees and I are more convinced than ever that our charity has a significant role to play in looking after seriously ill children and their families. It almost goes without saying that every child should receive the best possible care and yet many seriously ill children still don't have co-ordinated access to the specialist treatment, advice and support that they, and their families, desperately need and deserve. We work to bridge this gap, by:

- **Setting up specialist Roald Dahl nursing posts in areas of greatest need**
- **Providing ongoing professional training and development for these nurses**
- **Fostering nurse-led innovation to improve quality of care**
- **Offering support to help families living in hardship**

In the last year we have focused more clearly on what we want to achieve, which is of course to serve the sick children and families we look after, by providing them with the best possible nursing healthcare. Internally however we are also committed to trying to become the best children's nursing charity in the UK. And we are working hard to determine the areas of greatest need in specialist paediatric nursing. This is proving surprisingly complex.

Going forward, we want to be more focused in measuring the value of our nurses and what they do. We want to hear more from, and work directly with the children and their families to ensure we understand and meet their needs. We want to listen and respond.

I have been hugely inspired by meeting children, families and our 78 Roald Dahl Specialist Nurses. Their stories spur us all on to helping the NHS ensure that every seriously ill child has access to a specialist Roald Dahl Nurse. We have a long way to go. But we have made a wonderful start. I hope that our next thirty years will see us build on that success and grow into a powerful voice for children and children's nursing in the UK and possibly beyond.

I hope the information you find in this pack, encourages you to apply and support the charity.

Donald Sturrock, Board Chair

Who we are

Roald Dahl believed in the importance of children and in helping them overcome life's toughest challenges. He was one of the world's most imaginative and loved storytellers and he left a marvellous legacy - Roald Dahl's Marvellous Children's Charity. Roald Dahl's Marvellous Children's Charity, which provides specialist nurses and support to seriously ill children, was established in 1991 by his widow Felicity, shortly after his death. Today, there are currently 78 Roald Dahl Specialist Nurses caring for over 21,000 seriously ill children across the UK. Roald Dahl Specialist Nurses are a vital lifeline to the children and their families, supporting them clinically and emotionally. The charity supports children affected by complex, lifelong conditions that are underfunded, under-resourced and under-recognised including Rare Diseases, Sickle Cell Anaemia, Neuro-Muscular Conditions and Epilepsy.



Our Vision

Every seriously ill child deserves a Roald Dahl Specialist Nurse to help them lead a more marvellous life.

Our Mission

To provide specialist nurses and support to seriously ill children living with complex, lifelong conditions.

Key Strategic Charitable Aim

To improve the healthcare outcomes and resilience of seriously ill children and their families living with complex, lifelong, and under-funded conditions.

Summary of outcomes to achieve:

- 1) Improved quality of care
 - 2) Improved experience of care
 - 3) Improved efficiency and cost-effectiveness in care
 - 4) Improved resilience of seriously ill children and their families
- (see supporting document for our outcomes framework)

Meaning of serious illnesses supported by RDMCC:

Long-term (lifelong/chronic), complex conditions which are incurable and potentially life-limiting. In particular, those conditions which have been historically underfunded/under-resourced and not prioritised, such as non-malignant blood disorders, rare diseases and undiagnosed conditions.

The illnesses targeted are those which are often 'invisible' and those which still carry with them a stigma which leave a child and their family isolated, frightened and alone.

The charity defines serious chronic lifelong conditions in the following two ways:

- Progressive conditions without curative treatment options (e.g. Batten disease, mucopolysaccharidoses etc.)
- Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (e.g. Sickle Cell Anaemia, epilepsy, various neurological conditions, haemophilia etc.)



What makes a Roald Dahl Specialist Nurse so special

- They are experts in their field, specially trained in one disease area, and dedicated to a group of individual patients.
- They work in fields that are under-funded, under-recognised and under-resourced. Epilepsy, sickle cell disease and rare diseases are three key areas of focus.
- They look after both patient and the family. Online, by telephone and in person. At home, at school and in hospital. They are a single consistent presence from diagnosis to transition to adult services. They advise. They reassure. Often they are the only medical practitioner the sick child trusts. Roald Dahl Nurses are viewed as a life-line by their seriously ill patients and their families.
- Their specialist training allows them to co-ordinate complex care needs, reducing hospital visits for child and family. They liaise between local healthcare professionals such as Paediatricians, Physiotherapists, Occupational Therapists and Community Nurses.
- They connect patient and families to other families with similar conditions.

Our charitable programmes

To achieve our key strategic charitable aim, over the next four years, we will increase the impact and reach of the Roald Dahl Specialist Nurse programme by:

- Creating further Roald Dahl Specialist Nurse posts within the NHS
- Developing, promoting and supporting children's specialist nurse leaders and role models
- Championing specialist nurse-led innovation in children's healthcare
- Providing additional support to seriously ill children and families.

VALUES

Child focussed

- Ambitious to help as many children as we can
- Children are at the heart of what we do
- Listening to and respecting the voice of children

Kind

- 'I think probably kindness is my number one attribute in a human being... to be kind, that's it.' Roald Dahl.
- We value and respect each other (colleagues, beneficiaries, trustees, supporters)

Empowering

- We are honest and transparent
- Promoting independence for families, children, young people, nurses and our people.

Resourceful

- Being innovative problem solvers
- Appreciating the value of money

Sparky

- We are determined, resilient and dynamic.
- Our energy and liveliness makes us stand out.



THE ROLE OF THE BOARD OF TRUSTEES

The Charities Act 1993 defines charity trustees as those responsible under the charity's governing document for controlling the administration and management of the charity. This is the case regardless of the terminology used to describe the role by Roald Dahl's Marvellous Children's Charity.

The trustees must always act in the best interests of Roald Dahl's Marvellous Children's Charity, exercising the same standard of duty of care that a prudent person would apply if looking after the affairs of someone for whom they have responsibility. The trustees must act as a group and not as individuals.

We are keen to broaden our skills and recruit new people to strengthen the existing Board and drive Roald Dahl's Marvellous Children's Charity forward. We seek to ensure diversity in its board of trustees and consideration will be given to ways in which groups, skillsets and experience that are under-represented on the board might be reached and encouraged to apply.

Roald Dahl's Marvellous Children's Charity is seeking to appoint new trustees to join its trustee board and be formally appointed as soon as practicable after the recruitment process is complete.

DUTIES OF A TRUSTEE BOARD MEMBER

The duties of a trustee board member are to:

- Ensure that Roald Dahl's Marvellous Children's Charity complies with its governing document (its constitution), charity law and any other relevant legislation or regulations.
- Ensure that Roald Dahl's Marvellous Children's Charity pursues its objects as defined in its governing document.
- Ensure Roald Dahl's Marvellous Children's Charity applies its resources exclusively in pursuance of its objects. For example, it must not spend money on activities which are not included in the objects, however worthwhile they may be.
- Contribute actively to the board of trustees by giving firm strategic direction to Roald Dahl's Marvellous Children's Charity, setting overall policy, defining goals, setting targets and evaluating performance against agreed targets.
- Safeguard the good name and values of Roald Dahl's Marvellous Children's Charity.
- Ensure the financial stability of Roald Dahl's Marvellous Children's Charity.

In addition to the above statutory duties, each trustee should use any specific skills, knowledge or experience they have to help the board of trustees reach sound decisions. This may involve leading discussions, identifying key issues, providing advice and guidance on new initiatives, and evaluating or offering advice on other areas in which the trustee has particular expertise.

TIME COMMITMENT

- Approximately 10 days per year.
- Trustees are expected to attend an induction session at Roald Dahl's Marvellous Children's Charity prior to their first board meeting. (Currently virtual)
- Trustees will be asked to undertake training in such areas as safeguarding and will be required to submit a DBS check.
- Trustees are also expected to prepare for and attend all board meetings which are held four times per year during normal office hours and normally last approximately three to four hours.
- There is an additional strategic planning away day each year and it may be a residential event starting one afternoon and lasting the whole of the following day.
- Roald Dahl's Marvellous Children's Charity will have additional sub-committees and a trustee may be asked to act as a Chair for one of the sub-committees.
- Trustees will be asked to attend two to three events per year.

OUR PROCESS FOR RECRUITMENT:

- Closing date for applications: 2nd October 2020
- Shortlisting of candidates for interview: 5th October 2020
- Interviews with the panel (depending on availability either): Week of 12th October(tbc)
- Formal appointment of new trustees: 3rd November 2020
- If successful, to attend board meeting: 2nd December 2020

If you are unavailable for some of these dates but are interested in the role, please let us know so that we can try to be flexible

Salary: Unpaid – Trustees can claim out of pocket expenses incurred in travelling to meetings

Time Commitment: Approximately 10 days per year

Location: The Charity is registered at Montague House, 23 Woodside Road, Amersham, Buckinghamshire, HP6 6AA, however meetings are generally held in London or currently virtually

How to apply: Louiseg@roalddahlcharity.org / 01494 890465

PERSON SPECIFICATION

All Trustees should have the following plus we are specifically looking for experience and expertise in the charity sector and on policy in the health sector:

- Knowledge of the charitable priorities of the charity and an interest in engaging more deeply with them.
- A willingness to act at all times in the best interests of the charity and the children and young people it exists to serve, and to act with selflessness and integrity.
- The ability to operate effectively and credibly at a strategic level regardless of their own background and to contribute to collective decision making.
- The intellectual capacity to grasp issues outside personal experience and to contribute to discussions around such issues.
- Excellent communications skills including the ability to listen closely and openly to others and to discuss differences of opinions clearly, calmly and with respect and good humour.
- Good networking skills including relationship-building and tact.
- Adequate numeracy skills, with the ability to understand budgets and charity finance.
- The ability to digest and retain information.
- A good understanding of corporate governance, charity trusteeship and risk management.
- Clear understanding of the difference between Executive and Non-Executive roles at Board level.
- Discretion and an ability to maintain high levels of confidentiality.
- An ability to commit the necessary time to be a helpful and effective member of the Board of Trustees.
- Specific skills and experience currently required include finance; legal/charity governance; medical and support with introductions for fundraising.

Thank you very much for your interest in Roald Dahl's Marvellous Children's Charity. We will be in touch.