



Roald Dahl's Marvellous Children's Charity

Trustee – Candidate Briefing Pack



December 2024

Welcome from the Chair



Thank you for your interest in Roald Dahl's Marvellous Children's Charity. We are on an exciting journey to help more seriously ill children through our Roald Dahl Nurse Specialists and support that we provide to them and their families. We are looking for like-minded people to join our governance board and support the team with their fundraising skills and experience. I hope the information you find in this pack, encourages you to apply and get involved with this unique and ambitious charity.

Since 2019, we have had our CEO, Louise Griew on board who has worked with us to transform the charity to ensure we are sustainable, have viable plans in place and that the organisation runs efficiently and effectively.

Roald Dahl knew that nurses work magic and can make seriously ill children smile again. It's why he admired them, and it's what inspires us to establish more and more specialist nurses. We are able to achieve this by working in close collaboration with NHS Trusts who respect our track record of innovation and improving paediatric nursing care throughout the UK.

We now have established over 150 Roald Dahl Nurse Specialists in our nurse community and between them they are supporting over 36,000 children who have lifelong, complex illnesses. We are focused on those children who have exceptional health needs which include a multitude of conditions, so they are under multiple consultants and need expert care on a daily basis. This is where our nurses come in. The care they provide is clinical whilst also holistic and families have described them as a "lifeline".

We are proud that almost every single post we have established within the NHS Trusts still remain and that is because we know how important it is to demonstrate impact and how to build on partnerships, so they grow and flourish. On our 30th anniversary in 2021, we launched the research report we had commissioned Sheffield Hallam University to do, to demonstrate the value of our nurses. Please do go to our website and have a look at our highlights report and the latest annual review.

We also provide value to the nurses and the NHS Trusts in other ways; we have an online platform which is a safe and private place for our nurses to be in touch with each other to shared best practice, learnings and knowledge – this is absolutely unique and the nurses also can belong to individual specialism groups such as our rare disease nurses group, so they can really gain from being in touch with others based at other parts of the UK. We also provide our nurses with a robust professional training and development programme including leadership courses and workshops, in order for them to continually improve the care and experience of care, their patients receive.

As we have seen and read from all Roald Dahl's stories, he was an unbelievable innovator and we are proud to continue his legacy through our work, for example establishing the first specialist epilepsy nurse in the UK who we are still in touch with today.

During the pandemic, following research with the families and our nurses, we understood how financially challenging it is to live with a child who is seriously ill and we launched a family support telephone service which looks to practically help families by unlocking



benefits for them. To date, as I write this, we have unlocked over one and a half million pounds for these families. We have also launched and are developing an emotional support service too, to ensure these families don't have to suffer alone.

So, on behalf of thousands of very ill children across the UK, I would like to take the opportunity to thank everyone who applies for this volunteer position. I hope if you get the role, you find it as rewarding as I and my trustee colleagues do.

With warm wishes,

Alex Hyde-Parker

Chair, Board of Trustees, Roald Dahl's Marvellous Children's Charity

About Us: Building on solid foundations

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 Roald Dahl's widow Felicity, shortly after his death.

There are currently over 150 Roald Dahl Nurse Specialists caring for over 36,000 seriously ill children and young people across the UK.

Roald Dahl Nurse are specialists at providing support, information and practical care for seriously ill children and young people, working in NHS Trusts and Health Boards nationwide. They are a key lifeline to the whole family, supporting them clinically and emotionally.

Our nurses work with children and young people affected by complex, lifelong illnesses that are under-funded and under-resourced including epilepsy, rare diseases, sickle cell anaemia, and neuro-muscular conditions. They also support children as they transition in adulthood.

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 for 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.

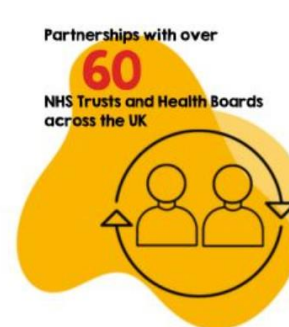
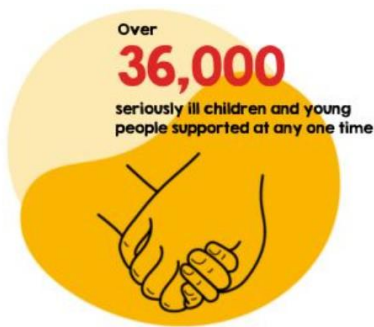
When our charity was set up, no one could have foreseen that it would celebrate its 30th anniversary in the midst of a global pandemic. That was a humbling period for everyone, and we saw just how vital is the support our network of Roald Dahl Nurse Specialists provides to the seriously ill children and families in their care.

In order to better understand the contribution of Roald Dahl Nurse Specialists to children's healthcare, thus informing future investment strategies, Sheffield Hallam University was commissioned to independently explore and evaluate the role and impact of our nurses. [The findings from this research](#) unequivocally highlighted the profoundly positive impact of our nurses and the need for future investment in establishing more of them.

Over the last five years or so, the charity has strived not only to ensure its financial sustainability, but also to convey clarity, focus and purpose in its messaging and activities. We are proud to say that we have achieved this. Now, we look forward to building on these solid foundations and supporting many more thousands of seriously ill children and young people as well as their families.

The future is exciting, and we are keen to ensure we have the skills and recruit a new fundraising trustee to help us grow our income; strengthen the existing Board; and drive Roald Dahl's Marvellous Children's Charity.

Our Impact:



Over 150 Roald Dahl Nurses established

Roald Dahl Specialist Nurses are a vital lifeline to the children and their families, supporting them clinically and emotionally.

Over 36,000 children and young people supported*

"If we didn't have our Roald Dahl Nurse, we'd feel completely alone." Parent of a seriously ill child.

**Seriously ill children supported at any one time. This number is estimated.

Over 65 Partnerships with NHS Trusts and Health Boards

We highly value our relationships with the NHS, creating and innovating seriously ill children's healthcare with them, improving outcomes and making better lives.

9.47 out of 10 - how satisfied families are with their Roald Dahl Nurse

In a recent survey we found that families value their Roald Dahl Specialist Nurses very highly.

"Our Roald Dahl Nurse has been a beacon of light in our darkest of hours." Parent of a seriously ill child.

Over 30 nurse-led innovation projects developed and delivered

We support Roald Dahl Nurses to solve problems creatively. Using a cohort approach, and through forming partnerships we work closely with our nurses to improve healthcare outcomes for children through innovation.

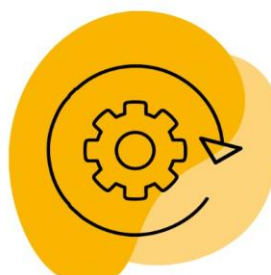
Roald Dahl Nurses' four impact areas



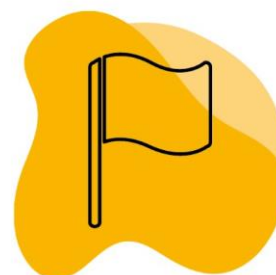
Quality and experience of care



Holistic family-centered care



Efficiencies and cost-effectiveness



Leadership and innovation

The Role

The role of a Roald Dahl's Marvellous Children's Charity (RDMCC) Trustee is to provide strategic leadership and advice in line with the charity's strategic plan and objectives.

Trustees are expected to use their knowledge, skills, and experience to ensure that RDMCC achieves its charitable objectives, represents the interests of all stakeholders, and acts as ambassadors for the charity.

Meet our Trustees here – [Trustees | Roald Dahl's Marvellous Children's Charity](#)

Principle Responsibilities

- **Strategic Leadership:** Provide direction and advice that aligns with the charity's strategic plan and objectives, ensuring we stay true to RDMCC's mission and values.
- **Governance and Compliance:** Ensure effective governance and the smooth running of the organisation, maintaining financial stability and adhering to all legal and regulatory requirements, including those set by the Charity Commission.
- **Financial Oversight:** Monitor the charity's financial health, ensuring strong internal controls, risk management, and financial reporting. Consider the financial impact of new or revised activities, making sure RDMCC operates within its means.
- **Strategic Approval:** Approve strategic plans, budgets, reserves policies, and authorisation limits, ensuring that RDMCC has the resources-both financial and human-to meet its goals.
- **Executive Support:** Recruit, appoint, and support the Chief Executive, delegating the day-to-day management of the organisation to them while providing oversight.
- **Investments:** Ensuring that our funds are invested responsibly and with care.
- **Representation:** Represent the Board at events, engaging with external stakeholders to promote and advance RDMCC's mission.
- **Stakeholder Engagement:** Connect with volunteers, beneficiaries, and other stakeholders to stay informed about our activities and the issues that affect our work.
- **Ambassadorship:** Act as an ambassador for RDMCC, upholding our reputation and promoting our values in all your activities.
- **Remuneration Oversight:** Oversee the remuneration, compensation, and benefits provided to staff, ensuring they are fair and aligned with the charity's policies and legal requirements.

Interested applicants should have worked at least at Fundraising Director level or have undertaken this role prior to moving to a broader role or have already been a trustee leading on fundraising strategy at board level. We are particularly interested in applicants who have an understanding of a broad range of income generation, in a medium-sized charity with multi-million-pound budgets.

We would like someone willing to actively contribute and take action to drive and achieve the charity's ambitious income targets, with a focus on sustainability and growth for the organisation.

Terms and Conditions

Compensation	Unpaid – Trustees can claim out of pocket expenses incurred in travelling to meetings
Time Commitment	<p>Approximately 10 days per year</p> <ul style="list-style-type: none"> Trustees are expected to attend an induction session at our offices prior to their first board meeting. Trustees are expected to prepare for and attend all board meetings which are held three times per year generally in London during normal office hours and normally last approximately three to four hours. Trustee will be asked sit on one of the sub-committees. These meetings take place virtually also three times a year. For this role that would be the Fundraising and Communications Sub-Committee. There can be an additional strategic planning away day when appropriate and it may be a residential event starting one afternoon and lasting the whole of the following day. Trustees will also be asked to attend two to three events per year.
Head Office	The Charity is registered at 17 Chiltern Business Centre, 63-65 Woodside Road, Amersham, Buckinghamshire, HP6 6AA, however meetings are generally held in London.

Our Recruitment Process

Closing date for applications	Monday 27th January 2025
Shortlisting of candidates for interview	February 2025
Interviews with the panel	February 2025
Offers & formal invitation to be a guest at the Board	March 2025
To start the role in the following meetings	<p>Sub Committees in May 2025 and Board in June 2025</p> <p>This will also include an Induction with the Senior Leadership Team (Amersham office) – to be arranged in April/May</p>
Other events - TBC	<p>Roald Dahl Nurses Conference 12/13th May 2025 in Birmingham.</p> <p>Possible hospital visit to meet with a Roald Dahl nurse and family.</p> <p>Charity events – such as a cultivation event during the Henley Regatta week in July.</p>

How to Apply:

Please provide us with:

- An up-to-date CV detailing your relevant experience and including the details of two referees (who will not be contacted without your prior consent).
- A supporting statement addressing the criteria in the person specification and your motivations for applying.

All applications should be sent to applications@trustees-unlimited.co.uk with your full name and RDMCC Trustee in the subject heading.

If you have any difficulty uploading your application or if you would like to have an informal and confidential discussion about the role, alternatively please contact Melissa Baxter on:

melissa.baxter@trustees-unlimited.co.uk | 07789 985 229

Closing date for applications: Monday 27th January 2025

Interviews with RDMCC: 11th/12th/13th February 2025 (TBC)

We actively welcome applications from anyone with suitable experience, irrespective of disability, ethnicity, heritage, sexuality, gender, and socio-economic background. We know that greater diversity will lead to better decision-making and better outcomes. Therefore, we also particularly encourage applications from those currently underrepresented on our Board, including people of different ethnic origins or faiths, younger people, people with