

Roald Dahl's Marvellous Children's Charity Chair - Candidate Briefing Pack



December 2024

**Trustees
Unlimited**

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 Chief Executive, Louise Grew 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 into 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.

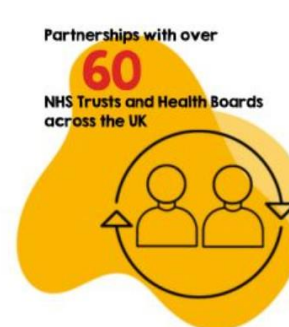
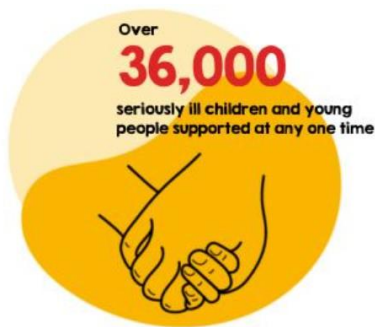
When our charity was set up, no one could have foreseen that it would celebrate its 30th anniversary in the midst of a global pandemic. That was a humbling period for everyone, and we saw just how vital is the support our network of Roald Dahl Nurse Specialists provides to the seriously ill children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

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.

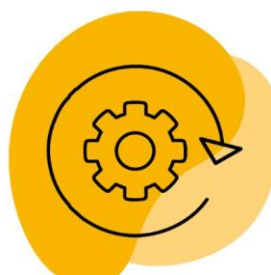
Roald Dahl Nurses' four impact areas



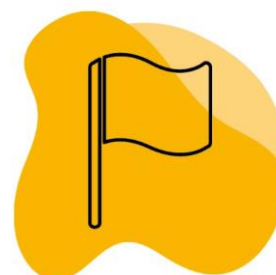
Quality and experience of care



Holistic family-centered care



Efficiencies and cost-effectiveness



Leadership and innovation

The Role

This is an exciting opportunity to lead a talented, collegiate and unified Board.

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

Objective

The Chair will hold the Board and Executive Team to account for Roald Dahl's Marvellous Children's Charity, mission and vision, providing inclusive leadership to the Board of Trustees, ensuring that each trustee fulfils their duties and responsibilities for the effective governance and advancement of the Charity's purpose and values.

The Chair will also support the Chief Executive and ensure that the Board functions as a unit and works closely with the entire Executive of the charity to achieve the agreed objectives. They will act as an ambassador of Roald Dahl's Marvellous Children's Charity, in partnership with the Chief Executive.

Principle Responsibilities

Strategic leadership

- Provide leadership to the charity and its board, ensuring that the charity has maximum impact for its beneficiaries
- Creating the environment for a high performing board team
- Ensure that Trustees fulfil their duties and responsibilities for the effective governance of the charity
- Ensure that the board operates within its charitable objectives and provides a clear strategic direction for the charity
- Ensure that the board is able to regularly review major risks and associated opportunities, and satisfy itself that systems are in place to take advantage of opportunities and manage and mitigate the risks
- Ensure that the board fulfils its duties to ensure sound financial health of the charity, with systems in place to ensure financial accountability

Governance

- Ensure that the governance arrangements are working in the most effective way for the charity
- Develop the knowledge and capability of the board of Trustees
- Encourage positive change where appropriate, address and resolve any conflicts within the board
- Appraise the performance of the Trustees and the board on an annual basis
- Ensure that the board of Trustees, and sub-committees, are regularly refreshed and incorporate the right balance of skills, knowledge and experience needed to govern and lead the charity effectively and which also reflects the wider population
- Work within agreed policies adopted by the charity

External Relations

- Act as an ambassador for the cause and the charity
- Maintain close relationships with key influences and stakeholders
- Act as a spokesperson for the organisation when appropriate
- Represent the charity at external functions, meetings, and events
- Facilitate change and address any potential conflict with external stakeholders

Efficiency & Effectiveness

- Chair meetings of the board of Trustees effectively and efficiently, bringing impartiality and objectivity to the decision-making process
- Ensure that Trustees are fully engaged and that decisions are taken in the best, long-term interests of the charity and that the board takes collective ownership
- Foster, maintain and ensure that constructive relationships exist with and between the Trustees
- Work closely with the Chief Executive to give direction to board policymaking and to ensure that meetings are well planned, meaningful and reflect the responsibilities of trustees.
- Monitor that decisions taken at meetings are implemented.

Relationship with the Chief Executive and wider executive team

- Establish and build a strong, effective and a constructive working relationship with the Chief Executive, ensuring she is held to account for achieving agreed strategic objectives
- Support the Chief Executive, whilst respecting the boundaries which exist between the two roles
- Ensure regular contact with the Chief Executive and develop and maintain an open and supportive relationship within which each can speak openly about concerns, worries and challenges
- Liaise with the Chief Executive to maintain an overview of the Charity's affairs, providing support as necessary
- Conduct an annual appraisal and remuneration review for the Chief Executive in consultation with other Trustees
- Ensure that the Chief Executive has the opportunity for professional development and has appropriate external professional support

Person Specification

In addition to the qualities required of a Trustee of the charity, the Chair must also meet the following requirements:

- Experience of operating at a senior strategic leadership level within an organisation.
- Successful track record of achievement through their career.
- Experience of charity governance and working with or as part of a board of Trustees.
- Significant experience of chairing meetings, events, committees or boards; recognising and leveraging the strengths of the collective, ensuring all voices are heard and guiding decision making when there isn't a consensus.
- Experience of external representation, delivering presentations and managing stakeholders.

Desirable

- Broad knowledge and understanding of the charity sector and current issues affecting it.
- Strong leadership skills, ability to motivate staff and volunteers and bring people together.
- Financial management expertise and a broad understanding of charity finance issues.
- Good understanding of charity governance issues.

Personal Qualities

- Demonstrate a strong and visible passion and commitment to the charity, its strategic objectives, values and cause.
- Demonstrate a commitment to the EDI objectives of the charity.
- Personal gravitas to lead a significant national organisation balanced with being approachable, accessible and visible.
- Exhibit strong inter-personal and relationship building abilities and be comfortable in an ambassadorial role, both internally and externally.
- High degree of emotional intelligence, demonstrating tact and diplomacy, with the ability to listen and engage effectively.
- Strong networking capabilities that can be utilised for the benefit of the charity.

- Ability to foster and promote autonomy and a collaborative team environment.
- Ability to commit time to conduct the role well, including travel and attending events out of office hours.

Terms and Conditions

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| Compensation | Unpaid – Trustees can claim out of pocket expenses incurred in travelling to meetings |
| Time Commitment | <p>Approximately 18 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. • The Chair sits on all of the sub-committees. These meetings take place virtually three times a year. • 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

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| 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 | Sub Committees in May 2025 and Board in June 2025 This will also include an Induction with the Senior Leadership Team (Amersham office) – to be arranged in April/May |
| Other events - TBC | Roald Dahl Nurses Conference 12/13 th May 2025 in Birmingham Possible hospital visit to meet with a Roald Dahl nurse and family Charity events – such as a cultivation event during the Henley Regatta week in July Possible workshop for specific committees |

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 Chair 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