



**Trustees
Unlimited**



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

2023

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 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. She has worked with us to transform the charity, ensuring 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 can achieve this by working in close collaboration with NHS Trusts who respect our track record of innovation and improving pediatric nursing care throughout the UK.

We have now established over 86 Roald Dahl Nurse Specialists in our nursing community and between them they are supporting over 25,000 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 daily. 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 remains 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 last year, 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.

We also provide value to the nurses and the NHS Trusts in other ways; we have a unique online platform which is a safe and private place for our nurses to be in touch with each other across the UK to share best practice, learnings and knowledge and belong to individual specialism groups such as our rare disease nurses group. We also provide our nurses with workshops, professional training, development opportunities and leadership courses for them to continually improve the care and experience of care that 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 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 half a million pounds for these families.

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

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 82 Roald Dahl Nurse Specialists caring for over 24,000 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 the support our network of Roald Dahl Nurse Specialists provides is 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 three years, 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 broaden the skills and recruit new people to strengthen the existing Board and drive Roald Dahl's Marvellous Children's Charity forward.

LOOKING AHEAD: RECRUITING NEW TRUSTEES

Roald Dahl's Marvellous Children's Charity is seeking to appoint at least four new trustees to join its trustee board. **This is a great time to be joining our Board of Trustees**, with interesting challenges and important decisions to be made in the coming months and years.



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**If we didn't have our
Roald Dahl Nurse Anna,
we'd feel completely alone.**

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Salary	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 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. Trustees may be asked to act as Chair or sit on one of the sub-committees. These meetings take place virtually also three times a year. There is 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.
Location	The Charity is registered at 17 Chiltern Business Centre, 63-65 Woodside Road, Amersham, Buckinghamshire, HP6 6AA, however meetings are generally held in London.

All new Trustees should have the following:

- Knowledge of the charitable priorities of the charity and an interest in engaging more deeply with them.
- A willingness to always act 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.

In addition to the above general requirements, the new candidates will bring experience in the specific areas detailed below:

Financial Investment Trustee

Member of the Finance and HR Committee

We want someone able to help us shape our investment policy, contribute to discussions on new funds, and ensure our investment returns are sufficient to support the medium and longer-term financial sustainability of our charity whilst increasing our charitable impact.

We are looking for someone with:

- Current or recent experience of working within the investment management industry.
- Sound judgement and able to contribute to robust discussions, while being able to work as part of a team.
- An understanding of responsible investing for charities

Communications, PR, Media & Marketing Trustee

Member of the Fundraising & Communications Committee

We would like someone to come in with an expert eye to support the team and trustees in developing the strategy to increase the profile of the charity and awareness of the vital work it does.

We are looking for someone with:

- A career of working within the communications and marketing sector.
- Strong ability and creative mindset to utilise the assets of the charity to best effect.
- An understanding of charities and their limited resources and finding best solutions and ways around these.

OUR RECRUITMENT PROCESS

Closing date for applications	Friday 2 nd June 2023
Shortlisting of candidates for interview	Early June 2023
Interviews with the panel	Week commencing 12 th June – dates TBC
Formal invite to the Board	June 2023
To attend board meeting	27 th June 2023

How to apply: All applications should be sent to applications@trustees-unlimited.co.uk with your full name and 'Roald Dahl' in the subject line.

Please include the following with your application:

- A comprehensive CV with the details of two referees
- A supporting statement which outlines your motivations for applying and shows how you meet the criteria.

For a conversation about this opportunity, please contact Melissa Baxter on 07789 985229 / melissa.baxter@russam.co.uk

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 disabilities and people from the LGBTQ+ community.

BEYOND ROLES, RESPONSIBILITIES AND RECRUITMENT: MORE MARVELLOUS LIVES

MEET CARTER

Imagine having to be careful when holding your child's hand because his joints dislocate daily or having to take care when you cuddle him because he bruises so easily. Imagine having to co-ordinate appointments for the ten consultant teams he is under. This is life for 10-year-old Carter and his mum, Laura. Thankfully, they have the support of Roald Dahl Specialist Nurse, Tina who provides both practical and emotional care and helps Laura feel less isolated and alone.

Carter has Ehlers-Danlos Syndrome Type 2 (EDS) which means that he dislocates his joints daily. He's in pain constantly and bruises like a peach at the lightest of contact. He also has Asperger's which is quite a recent diagnosis. **He is cared for by ten different consultant teams including: Rare Diseases, Genetic, Mental Health, Orthotics, Physio, Occupational Therapy, Orthopaedic and Gastroenterology.**

"Carter was diagnosed with EDS around five years ago and we are looked after by Rare Disease Team at Birmingham Children's Hospital. That's when we met the Roald Dahl Specialist Nursing team including Tina, Carter's Roald Dahl Specialist Nurse. **Tina is amazing. She really looks after all of us.** Carter forms very strong relationships and it was hard for him when his main consultant retired. He has become very attached to Tina and having her at his appointments – a face he recognises and feels comfortable with is a massive support for us all. I can text Tina and say, "I'm having a rough day" or "I've had a report from a doctor, and I don't understand it" and she will go out of her way to explain to us in a way we understand.



Carter often doesn't want to communicate with the medical professionals, but Tina will get on the floor with him, listen to him on his level and that's invaluable.

Roald Dahl Specialist Nurses like Tina don't just treat illnesses or injuries, they look after us as a whole family unit including me, dad and Carter's siblings.

Knowing that I can just pick up the phone to Tina when we've had a rotten day, or if Carter has been unwell, makes the world feel a little bit less lonely as a mum. I don't feel as isolated and alone.

I know that I am always going to be Carter's biggest advocate but to know that Tina is in our corner fighting battles, which if we had to fight on our own would feel overwhelming, makes a huge difference.

Tina helps co-ordinate all Carter's appointments, which really mount up as he is under ten different consultants. She also attends all his appointments and helps us to understand everything. One of Carter's favourite things to do is swim as he is completely weightless in water, so Tina sorted out hydrotherapy sessions for him locally to where we live. Half an hour in the pool is amazing for Carter. Even though he is doing physio in the pool, it's great fun for him. Tina came into Carter's school with us because they didn't grasp Carter's condition. She created an entire pack so they could understand in

layman's terms how his condition affects us as a family, and the practical things they could implement so Carter could feel more included at school. No one else would have been willing to do that.

Life has been so much easier since we met our Roald Dahl Specialist Nurse, Tina.

When Carter outgrew his wheelchair Tina immediately got him an appointment to fit for a new one. Tina arranged for an occupational therapist to review and see how they can help us a whole family.



Tina has also helped us secure funding to help with our day to day lives. We were receiving Disability Living Allowance (DLA) but when it was up for renewal, we were then declined. Tina went through the appeals process with us and got consultants to write statements in support of Carter receiving DLA and because of that, we were successful. Receiving DLA makes a massive difference to us as a family.

If we didn't have Tina, I would feel really isolated and alone as a mum.

Prior to us having a Roald Dahl Specialist Nurse, I felt overwhelmed and completely anxious about the future. I worried constantly and struggled to manage appointments while holding down a full-time job. It was hard and affected us massively. I literally felt at times that I had no one to turn to and it was just myself, Carter, and Chris against the world."

MEET KAI

Five days before Christmas 2019, Leanne and her partner Sara were given the news that their five-month-old son, Kai, had **a rare and severe brain injury which affected three quarters of his brain.**

With everything about to close for the festive period, the family might have been left unsupported and unsure where, or to whom, to turn. At that point, the pandemic had yet to take hold in the UK and nobody could predict the full extent of the isolation and impact on seriously ill children and their families. Thankfully, **Roald Dahl Epilepsy Specialist Nurse Stacey was there right from the point of diagnosis**, to make sure both Kai and his mums had everything that they needed, even more so with hospital appointments being cancelled as COVID-19 placed the country on lockdown.

Kai has a complex condition called severe multicystic encephalomalacia. Due to Kai's brain injury **his medical needs are complex.** He has unmanageable epilepsy, an unsafe swallow which means he can't



eat or drink without assistance and is severely physically disabled. Kai is on multiple types of medication to manage his symptoms **and his condition is life limiting; Leanne and Sara do not know how long they have with him.**

Stacey was with the couple while the doctors delivered Kai's medical diagnosis. She explained – in layman's terms – what the diagnosis would mean for Kai and what the next steps might be.

Leanne says that **Stacey is one of the few people she trusts with their son's care.** The family has even decided not to move to a new house (as originally intended) because doing so would take them away from Stacey and this, says Leanne, is too great a risk for them to consider. **Stacey is Leanne's point of contact for all queries the family has about managing Kai's condition, whether medical or emotional.** For example, when **Leanne was asked to sign a no resuscitation declaration for Kai,** she sought Stacey's guidance on whether they should. If Leanne brings up a question about Kai with Sara, she will immediately ask 'what did Stacey say?'. Stacey is an emotional support for the family, as much as their clinical specialist nurse.



Leanne speaks about Stacey as being on 'Kai's Team'. During the COVID-19 pandemic, the family and Stacey developed a strong and trusting bond. When Kai was in hospital for 6 weeks, Stacey was a familiar and friendly face for Kai in what could be an intimidating setting.

The family has grown in confidence so much, and understands Kai's needs so much more, because of Stacey. Stacey often sends Leanne information with a note saying, *'saw this, thought of you, might be beneficial to Kai'*. **Leanne describes Stacey as 'more than a nurse' and says she goes the extra mile in making sure that the family is supported and that they have access to all the answers and resources and connections that they need. Stacey builds bridges and connections between the hospital and community making it easier for complex children.**



Leanne decided to give up work to care for Kai which, having worked all her life, was a difficult transition for her. Leanne's partner Sara has continued to work but it has been hard for the family to adjust to having one income. Leanne was unaware of the benefits to which her family were entitled, but Stacey was once again able to help – this time accessing crucial financial support.

Looking after Leanne's wellbeing as much as Kai's, Stacey helped Leanne with getting Kai into day care, **this year Kai will be starting special needs school two days a week and Leanne is going back to college, working round Kai's needs.** Stacey knew that for Leanne returning to work was important and, has again, gone above and beyond her role as a nurse.

When Leanne was asked how she would describe Stacey, she answered, "flawless".



Roald Dahl's Marvellous Children's Charity
www.roalddahlcharity.org

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