



Charity Update

December 2022





Who's who...

Presidents

Felicity Dahl
Sir Quentin Blake

Royal Patron

Her Royal Highness the former Duchess of Cornwall

Patrons

Dame Joanna Lumley DBE
Dame Julie Walters DBE
Claudia Winkleman
Tim Minchin
Maddie Dahl
Theo Dahl
Donald Sturrock (Retired as Chair 30 March 2022)

Trustees and Directors

Alex Hyde-Parker (Chair from 30 March 2022)
Michelle Johnson MBE (Vice Chair from 30 March 2022)
Rachelle Broadley
Ben Grist
Rob Halkyard
Jodi Johnson
Niels Kirk
Nick Warr

Ambassadors

Martin Goodwin
Rick Oakley
Robert Paul



Welcome from

our Chief Executive, Louise Griew



Louise Griew
Chief Executive, Roald Dahl's
Marvellous Children's Charity

Everyday we hear how immensely difficult being diagnosed with a serious illness is for a child and their whole family.

It's uncertain, overwhelming, scary, and deeply unfair. It can be isolating and take over your whole life. And that's where our marvellous Roald Dahl Nurse Specialists come in – ensuring that heroic children and their families no longer brave their illnesses alone.

Navigating this challenging and complex world can be daunting, particularly when an initial diagnosis is made. The pages of this report are filled with examples of how our Roald Dahl Nurse Specialists have helped seriously ill children and their families.

The support of so many marvellous people and organisations has allowed us to expand our nursing network to 86 Roald Dahl Nurse Specialists across the UK. Since Felicity Dahl founded the charity over 30 years ago, the breath, scale, and impact of our work has never been higher.

Over the past year, Roald Dahl Nurse Specialists have provided over 170,000 hours of support to over 25,000 seriously ill children and families across the UK.

I am truly grateful to all our supporters, and proud of our nurses and wider team for ensuring we achieved so much, for so many people, with the contributions received. It has been a privilege to support so many inspirational children and families this year.

I would like to say a special thank you to our Board of Trustees, and in particular, to Donald Sturrock, who retired as Chair in March this year. I would also like to share our appreciation for our hugely supportive founder and co-president Felicity Dahl, and co-president Sir Quentin Blake for their ongoing support.

We believe that every seriously ill child and their family deserves a Roald Dahl Nurse. And that's why next year we're more determined than ever to meet the rising demand for Roald Dahl Nurse Specialists in the NHS.

To achieve this, we'll need long-term partners to join us on our journey. If you're able to support us in any way, then please do get in touch and learn more about how you can do something marvellous today.



Thank you

from Max and Suzannah



It is hard to put into words how much this charity and our Roald Dahl Nurse Specialist Lisa means to myself and Max.

Max has a real lust for life. Everyone who meets him finds him an absolute joy to be around and he can light up a room with his personality and smile.

Max is diagnosed with GRIN2D-related disorder and epilepsy. This means he is unable to walk, talk, and is dependent on a tube for feeding. He is also registered blind and suffers regular seizures.

Lisa really is the foundation that holds so many things together for us. She has taken us from a place where we were very isolated, overwhelmed, and struggling to get on top of Max's health needs, to a place where we know we are going to be okay.

The care, commitment, and expertise of Lisa and other Roald Dahl Nurses is truly incredible, and I cannot express the full extent of the clinical and emotional benefits they bring.

I am extremely grateful to every person and organisation who has helped ensure Lisa is able to be there for me, Max, and our family over the past 12 months. Your support has made a significant difference to our lives and thousands of others across the UK.

Thank you from the bottom of my heart!

Suzannah, Max's Mum



Maya's Story

Maya's mum Victoria spoke with us about Maya's diagnosis and the impact their Roald Dahl Nurse Specialist has had on the family.

Maya is eight years old and loves ballet and animals (particularly her Cavapoo Flo.)

“ Maya's Diagnosis

Maya had been unwell for about three weeks, and we were concerned as she had a swollen forehead, a high temperature, and had been struggling to eat – it was a very worrying time for us.

Maya was initially diagnosed with sinusitis at our local Urgent Care Centre. After many trips to the GP and A & E, Maya received antibiotics, which did help ease symptoms a little. However, Maya's condition continued to deteriorate. Eventually, we got admitted to the hospital.

The infection from the sinusitis had spread to the brain through a crack in Maya's skull. Doctors began treating this with oral and IV antibiotics, but Maya's condition worsened. Late one Sunday evening, Maya had to have a craniotomy operation to wash out the infection.

Meeting our Roald Dahl Nurse

On the night of Maya's surgery, we met our Roald Dahl Nurse Specialist, Jayne. Jayne spent the time during the operation checking on and reassuring us. The operation lasted 6-7 hours, and as soon as we were allowed to see Maya, Jayne accompanied us to visit her and continued to reassure us by explaining what to expect.



Maya's recovery went well, although she was upset by the severe swelling to her face, which meant that she could not open her eyes. Throughout this, Jayne was on hand to make Maya smile (often by talking about animals) and reassure us about what was happening.

Managing the psychological impact of Maya's condition is challenging as Maya finds it difficult to concentrate and has some ongoing difficulties. Jayne puts Maya at ease and ensures everything is age-appropriate, and handled with kindness and a little humour.

I don't think I could ever put into words how grateful we are for our Roald Dahl Nurse Specialist. Jayne's advice has helped to build our confidence and is very reassuring. Jayne is so central to Maya's recovery.

We will remain forever grateful for the kindness, support, and guidance that Jayne has provided us - she is the most incredible nurse and wonderful human being. Thank you, Jayne, for everything.

Maya says:

Jayne makes everything better. Jayne tries to figure out what is wrong, makes things fun, and makes me laugh.



Impact of our

Roald Dahl Nurse Specialists



Roald Dahl Nurse Specialists are a vital lifeline to seriously ill children and their families, supporting them clinically and emotionally.

The role of a Roald Dahl Nurse is unique and goes beyond traditional nursing care, crossing organisational boundaries to deliver holistic care for their young patients and their families from the moment they receive a diagnosis.



Specialist training allows Roald Dahl Nurses to **co-ordinate complex care needs**, reducing hospital visits for patients and their families.



Roald Dahl Nurses act as an **advocate for the child and family** within the health care system and facilitate urgent hospital care if required.



Roald Dahl Nurses **educate the wider family and schools** about their patient's conditions.



Roald Dahl Nurses **connect patient and families to other families** with similar conditions, reducing loneliness and anxiety.



98%

of Roald Dahl Nurses said:
"because of their support, patients on their caseload have a better knowledge and understanding of their conditions and treatment options."



94.1%

of Roald Dahl Nurses said:
"as a result of their support, emergency hospital admissions have been avoided".



100%

of Roald Dahl Nurses said:
"as a result of their support, patients have a better quality of life".

Roald Dahl's Marvellous Children's Charity provides specialist nurses and support for seriously ill children.



86

Roald Dahl Nurse Specialists



over 25,000

Seriously ill children and young people **supported**



170,000

Hours of nursing care provided from Roald Dahl Nurse Specialists



Over £500,000

Benefits unlocked for families through our Marvellous Family Support Service



51 NHS Partnerships

with NHS Trusts and Health Boards across the UK



1992 

The charity creates the first-ever
**Paediatric
Epilepsy
Specialist Nurse**
post in the UK

Roald Dahl Epilepsy Nurse Specialists

Our charity has been working in partnership with NHS Trusts to establish Roald Dahl Epilepsy Nurse Specialist posts since 1992.

Epilepsy is the most common significant long-term neurological condition of childhood and affects an estimated 112,000 children and young people in the UK.¹

We believe that it is critical that all children and young people living with complex epilepsy across the UK have sufficient access to a full paediatric epilepsy team to increase diagnostic accuracy, improve ongoing management, and provide holistic support to the child, young person, and their family.

With an existing cohort of 40 Roald Dahl Epilepsy Nurse Specialists, our charity is ideally placed to contribute toward reducing the evidenced shortfall of epilepsy specialist nursing across the country, and ensuring that efficient transition pathways exist for children and young people living with epilepsy.

Between April 2021 and March 2023, we committed to establish eight new Roald Dahl Epilepsy Nurse Specialists within NHS hospitals across the UK, to support seriously ill children and young people living with epilepsy.

Over **40**

Roald Dahl Epilepsy Nurse Specialists



¹ Royal College of Paediatrics and Child Health (2020) State of Child Health in the UK. <https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/epilepsy/>

Meet some of our new

Roald Dahl Epilepsy Nurse Specialists

Roald Dahl Epilepsy Nurse Specialists organise and coordinate tests, treatment, and care. They also advise and educate families, ultimately improving their quality of life.



Emma

Roald Dahl Epilepsy Nurse Specialist

Emma started in her role summer of 2022. Emma will provide children and young people living with epilepsy with a single point of contact.

Emma says, "often the children have additional complex needs, and epilepsy is not the only challenge these families face. I am hugely excited by the opportunity here, where I can focus on providing bespoke support to benefit these children and their families".

Natasha

Roald Dahl Transition Epilepsy Nurse Specialist

Natasha also started in her role summer of 2022. Natasha supports children and young people with complex epilepsy.

In her role as an Epilepsy Transition Nurse, Natasha supports children and young people with epilepsy as they make the difficult transition from child to adult health care services.



...before Roald Dahl Nurses I spent hours upon hours, days upon days chasing appointments, medication, explaining my daughter's condition, waiting for a call back. Roald Dahl Nurses have relieved the stress of some of my daughter's care. I feel like I have so much support and advice from them they are invaluable and worth their weight in gold!

Parent of a seriously ill child



Professional Training, Development, and Leadership

Nurse development is key to a Roald Dahl Nurse, improving the care and support they give. We work with Roald Dahl Nurses to offer opportunities to improve their skills, to build a peer network, and to ensure that best practice is shared across the Roald Dahl Nurse community. The charity provides training, workshops, conferences, and peer to peer support through a bespoke online platform, to enhance knowledge, and improve patient care.



92.2% of Roald Dahl Nurses said **experience and quality of care** provided to patients has improved because of them being a Roald Dahl Nurse, and accessing support from Roald Dahl's Marvellous Children's Charity.



96.1% of Roald Dahl Nurses **educate, train, and/or inspire** other professionals (for example teachers, GP's etc), to raise awareness of the needs and challenges faced by patients and their families.

“ The charity has given me access to many learning opportunities that directly impact on the quality of care.

Roald Dahl Nurse

“ I have taken courses which have enhanced my skills and knowledge which is passed on to the families I support.

Roald Dahl Nurse

“ Roald Dahl's Marvellous Children's Charity has opened the door to opportunities, which have increased my nursing skills and access to the network, which has allowed us to communicate and share ideas and resources.

Roald Dahl Nurse

Marvellous Family Support Service

Families with seriously ill children and young people are often unable to access the financial support and benefits they are entitled to. These funds are vital in helping them overcome the life challenges of having a child with a complex, lifelong illness.

The Marvellous Family Support Service pilot launched in 2021 and is available to families supported by a Roald Dahl Nurse. This service gives families practical support to identify and access benefits entitlements, including Disability Living Allowance and Personal Independence Payment applications.



112

families have been supported through the service



£5,210.95

Average per family has been unlocked



Over £500,000

of benefits have been unlocked for families

Feedback from families

Hayley, Mum to Cianna told us:

“ The Marvellous Family Support Service is priceless. Many families with sickle cell struggle to make ends meet, and in most cases at least one parent is a full-time carer and will experience employability concerns due to the amount of time they need to take off for their child's hospital admissions, when they are not well enough to go to school or hospital appointments. ”



Marvellous Fundraisers

Corporate Partners Cobweb and Vuzion complete inflatable race and 10k run

David's daughter Harriet is supported by Roald Dahl Nurse Specialists at Portsmouth Hospital. David's employers, IT companies Cobweb and Vuzion have been taking part in events including an inflatable 5K run, and a 10K run to support our charity and help fund new Roald Dahl Nurses.

“ Without the charity, I am not sure how we would cope with Harriet's epilepsy. Our Roald Dahl Nurses Rebecca and Liz have been simply amazing at helping us as parents feel more in control with what is ultimately an out-of-control experience.

“When I started organising the challenge in May, I did not run and weighed in at over 20 stone. I saw this as a challenge that would push me hard and show how much this charity means to us. I am now able to run 5k in under 32 minutes and have lost a stone already!

“My daughter, Harriet, was waving me round every lap cheering me to keep going which gave me the motivation to keep going. Knowing how much Roald Dahl's Marvellous Children's Charity helps my family and the other thousands of children across the country was the biggest incentive to keep pushing through!

David

”



Dixie's Fundraising

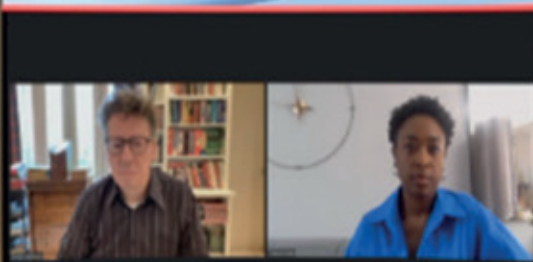
Seven-year-old Dixie has walked over 200,000 steps to help fund more Roald Dahl Nurse Specialists, after experiencing a serious seizure earlier this year.

Dixie had her first epileptic seizure in April 2022 and has since been supported by Roald Dahl Nurse Specialist Kirsten.

“ If I did not have Kirsten as my nurse, I would miss not having a special nurse to ask if I am okay. I would find the doctors' appointments scarier if Kirsten was not there. I did the challenge to help other children, as they may need a special nurse too.

Dixie

”



Celebrating 30 years

of Roald Dahl Nurses

Our Virtual 2021 Nurses' Conference saw our Roald Dahl Nurse Specialists come together to learn, and share ideas and inspiration from each other along with other sector experts. Our Nursing Conference ensures Roald Dahl Nurses are supported in their goal to continuously improve healthcare quality standards, patient safety, and the experience of care for seriously ill children and young people.

Feedback confirmed that the nurses found the conference fascinating. The conference covered topics such as transition of care, mental health in children and young people, as well as informative discussions around how the pandemic affected children and their healthcare.

Thank you to our keynote speakers, which included:



Ruth May
Chief Nursing Officer for England



Anne Sweeney
The first Roald Dahl Nurse Specialist



Emma Wadey
Head of Mental Health Nursing for NHS England



Michelle Johnson MBE MSc
RGN/RSN Queen's Nurse, Chief Nurse,
Whittington Health NHS Trust &
Trustee of Roald Dahl's Marvellous Children's Charity



Professor Sally Shearer OBE
Chair of the Association of Chief Children's Nurses

...amongst many others.

Some dates for the diary



**12th May
2023**

International Nurses' Day

Join us in celebrating nurses on International Nurses' Day 2023. Keep an eye out for our marvellous plans and organise a fundraiser with friends, family, or at work to help establish more vital Roald Dahl Nurses.

Roald Dahl Story Day

Roald Dahl Story Day is the perfect way to inspire pupils through Roald Dahl stories, characters, and worlds. Join us in celebrating Roald Dahl Story Day 2023 and fundraise to support our charity and help seriously ill children lead a more marvellous life.

**13th Sept
2023**



If you would like to get involved there are many ways to support our charity. Visit our website at www.roalddahlcharity.org for more information or contact our fundraising team at fundraising@roalddahlcharity.org

Looking ahead

from our Chair of Trustees



Alex Hyde-Parker
Chair of Trustees
Roald Dahl's Marvellous
Children's Charity

Throughout 2021/2022 we have developed our model to further increase the reach and impact of our work across the NHS.

For the first time in our 30-year history, we introduced opportunities for specialist children's nurses in existing positions to become Roald Dahl Nurse Specialists.

Over the coming year, this initiative will allow more nurses to join our network and receive access to the charity's specialist professional development and peer support services.

This programme will help provide improved clinical and emotional support to more seriously ill children and their families, including access to our Marvellous Family Support Service (see page 9).

Alongside this new route to becoming a Roald Dahl Nurse Specialist, the core of our approach will remain the same. We will continue to pump prime new specialist nursing posts in the NHS, in the areas of greatest need.

As always, to deliver against this ambition will require the support of existing and new partners. We cannot do this alone, although we are confident that this approach has the potential to help thousands more seriously ill children and their families lead more marvellous lives.

Thank you

Our relationship with supporters, funders, and partners is fundamental to our continued success.

We are immensely grateful to everyone who contributed in 2022. Thank you to the companies, Trusts and Foundations, schools, and individuals who have supported us throughout the year. A special thank you also to the Roald Dahl Story Company for their ongoing support.

Every seriously ill child deserves a Roald Dahl Nurse.



www.roalddahlcharity.org



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