



Annual Review

2022 - 2023



Contents

Introduction	1
Our Impact in Numbers	2
Our Impact: Anaiyah's Story	3
Key Programmes	4
1. Roald Dahl Nurses	5
Establishing more Roald Dahl Nurses	6
Our Impact: Charlie's Story	7
2. Professional Training and Development	8-9
3. Marvellous Inventing Room	10
4. Marvellous Family Support Service	11
Marvellous Moments	12-13
Get Involved	14
Our Impact: Isaac's Story	15
Looking to the Future	16
Our Team	16
Thank You	17

“ Our Roald Dahl Nurse has been a beacon of light in our darkest of hours. ”



Introduction

This year the charity hit another incredible milestone.

For the first time in our 31-year history, there are over 100 Roald Dahl Nurses providing specialist care for children with complex, lifelong health conditions across the UK.

Over the past 12 months, Roald Dahl Nurses coordinated the care of over 32,000 children and young people. Their specialist knowledge resulted in thousands of reduced hospital admissions, emergency visits to A&E and consultant appointments.

The pages of this report tell the story of how our Roald Dahl Nurses coordinate complex care needs, advocate for children and families and educate the wider community about patients' conditions.

We also continued to focus our programmes and services on supporting the children and families under the care of Roald Dahl Nurses. Our Marvellous Family Support Service provides financial support for families and young people, and we continue to grow our Professional Leadership and Development offerings for Roald Dahl Nurses.

Despite the charity's recent growth and renewed focus, some things remain constant. The kindness, dedication and skill of Roald Dahl Nurses continue to be inspirational. Their impact continues to be life-changing.

Roald Dahl Nurses continue to be a vital lifeline to families. As one parent told us:

"In our darkest moments our Roald Dahl Nurse has been an absolute rock. I simply do not know how we would have coped without her."

Next year's focus will be on establishing new Roald Dahl Nurse posts to support children and families living with some of the most complex conditions. These children represent some of the most vulnerable across the UK.

As always, delivering against this ambition will require the support of existing and new partners. If you can support us in any way, please get in touch and learn more about how you can do something marvellous today.

Finally, we would like to say a marvellous thank you to our Co-Presidents, Licky Dahl and Sir Quentin Blake, and our Royal Patron, Her Majesty The Queen, whose continued support is immensely valuable.



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

over **100**
Roald Dahl Nurses

32,000+
children and young
people supported

Our Impact in Numbers*



*April 2022 - March 2023

Our Impact: Anaiyah's Story

Meet Anaiyah, an incredible 5-year-old whose sense of fun shines despite the challenges of complex epilepsy and severe autism.

Water is very calming for Anaiyah and her favourite activities are playing with water, taking baths and water activities at school.

The family's world turned upside down when they first noticed Anaiyah had started to have unresponsive absences. Then one evening the family awoke to Anaiyah having a terrifying seizure which lasted over three hours.

Meeting their Roald Dahl Nurse

The family met Lynn, their Roald Dahl Nurse for the first time after receiving Anaiyah's diagnosis of epilepsy. Lynn provides practical and emotional support for the whole family.

Anaiyah's Mum Rebecca says:

“ Lynn reduces our stress and anxiety, her knowledge and support have also made us more confident to manage Anaiyah's epilepsy at home. The reassurance of having Lynn's support has had a huge impact on our whole family.

Without Lynn, I would feel lost. There are so many what-ifs. What happens next time? What if I'm not watching? Having someone to listen and someone to help fight our battles has been life-changing. Thank you, Lynn. Thank you for being there and for being my voice.

”

Key Programmes

Every child with a complex, lifelong condition deserves a Roald Dahl Nurse to help them lead a more marvellous life. To achieve this we provide:

1 **Roald Dahl Nurse Specialists**
Our Roald Dahl Nurses work in NHS hospitals across the UK and are a vital lifeline for children, young people and their families living with complex, lifelong conditions.

2 **Nurse Professional Training and Development**
Through training, workshops and conferences we focus on improving the quality of care and leadership across our network of Roald Dahl Nurses.

3 **Marvellous Inventing Room**
We provide opportunities for Roald Dahl Nurses to explore innovative ways of improving the healthcare outcomes and resilience of seriously ill children and young people.

4 **Marvellous Family Support Services**
Our Financial Support Service is available for families supported by a Roald Dahl Nurse. The service offers families practical support to identify and access benefit entitlements, including Disability Living Allowance and Personal Independence Payment applications.

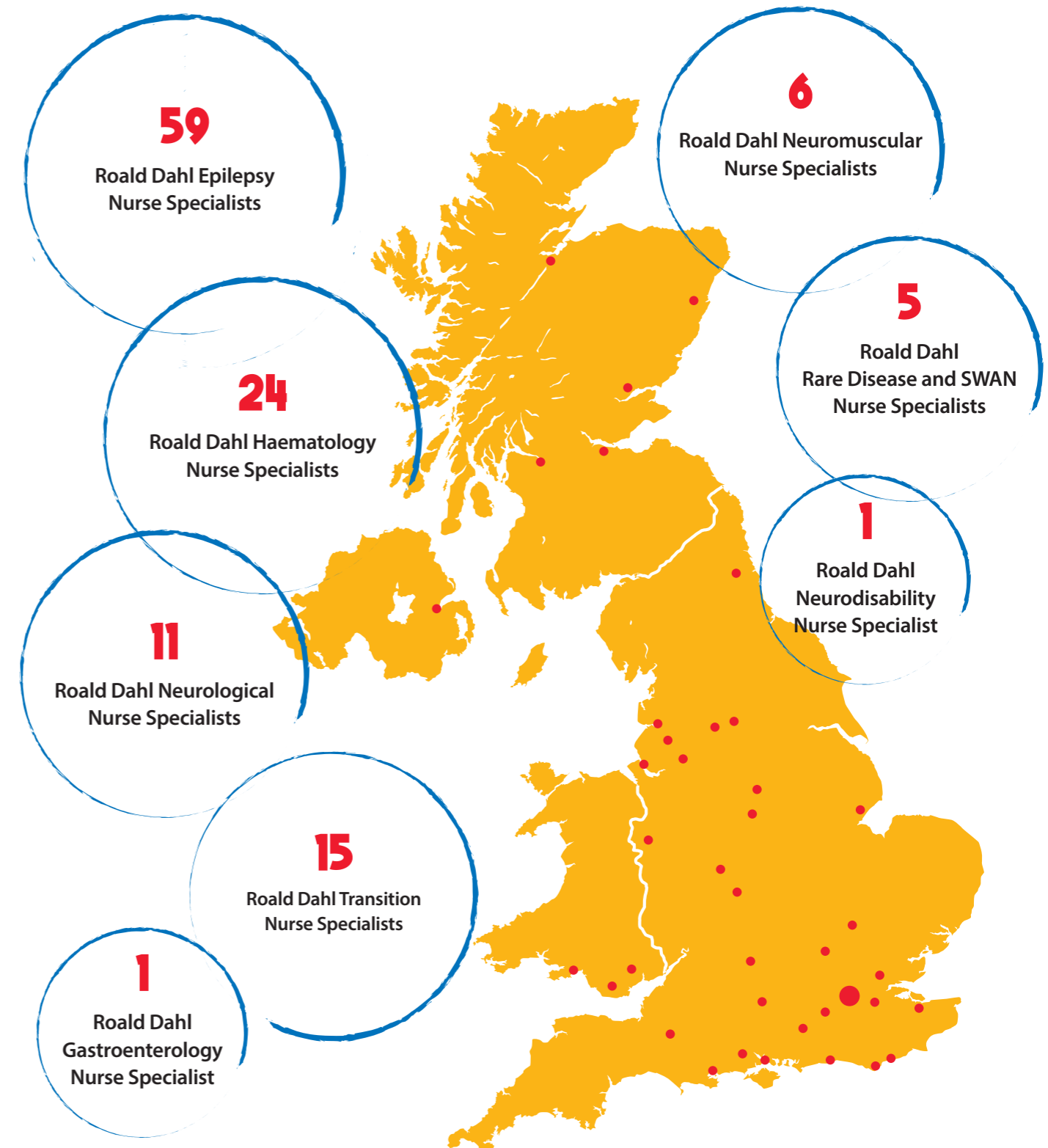


“ Our Roald Dahl Nurse provides us with emotional and practical support when no one else is available. It’s really a lifeline sometimes when you feel lost, confused and sad. **Parent** ”

1. Roald Dahl Nurses

Roald Dahl Nurses provide care that focuses on the whole family. They go beyond traditional nursing boundaries to support families in every possible way. This includes offering emotional support, providing consultations, arranging sibling support and organising events for families to connect with others who share similar experiences.

There are many children with complex conditions who don’t have access to a Roald Dahl Nurse, and we want to change this.



Establishing more Roald Dahl Nurses

Roald Dahl's Marvellous Children's Charity is committing to raise £1 million over the next two years to establish eight new Roald Dahl Nurse Specialists to care for children with some of the most serious, complex and lifelong conditions across the UK.

Over the last three decades, working in collaboration with over 50 NHS Trusts and Health Boards nationwide, the charity has successfully used a 'pump priming' model to establish Roald Dahl Nurse Specialists.

Using this model, the charity commits to raising funds to pay for the salary of these nurses for two years, with commitment from the relevant NHS Trusts and Health Boards to fund a further three years.

These new Roald Dahl Nurses will join the network of over 100 Roald Dahl Nurses across the UK and will benefit from the charity's professional development programme and peer support network.

Children with medical complexity (CMC) are often under the care of several health professionals and the pressure placed on their parents and carers is relentless. Roald Dahl CMC Nurse Specialists will help coordinate these appointments, provide vital healthcare support and improve the quality of care for these children.

Families under the care of Roald Dahl Nurses can also access the charity's financial and emotional support services.

The charity is now reaching out to supporters to help raise the £1 million required to deliver this mission.



“ Our Roald Dahl Nurse has made a dramatic impact on our lives, and we really don't know how we would get through so many days without her support and dedication. **Parent** ”



The charity needs to raise **£1 million** to establish eight new Roald Dahl Nurses in the next two years.

Our Impact: Charlie's Story

Charlie is a brave fifteen-year-old who has complex epilepsy and severe learning disabilities due to an underlying mitochondrial disorder.

Charlie depends on others for all personal care and mobility and has an unsafe swallow and feeds via a jejunostomy, for which his Mum does routine tube changes.

Due to Charlie's complex condition, he is under the care of multiple health professionals. Charlie's family would benefit from the consistent presence of a Roald Dahl Nurse Specialist, who would be involved in decision-making and ensure the family's wishes are listened to and respected.

Charlie's communication needs add additional vulnerability. Consistent care from a Roald Dahl Nurse who understands him and the subtle signs he may display when becoming unwell will enhance his safety and the quality of care delivered to Charlie and his family.

Support from a Roald Dahl Nurse would also help to reduce the length of Charlie's hospital stays and minimise readmission, positively impacting Charlie, his parents and his younger sister.

Charlie is in the early stages of transitioning from children's services to adult healthcare services, adding to future uncertainty. The family would have peace of mind knowing that a Roald Dahl Nurse was available to liaise with and advise the adult teams as they become involved in his care.



Charlie's Mum Dawn says,

“ Having a Roald Dahl Nurse there within acute areas would help the flow of communication, support and advocacy which is very important for Charlie's care. ”



2. Professional Training & Development

We work with Roald Dahl Nurses to offer a robust programme of training and development. This provides opportunities to develop their skills, build peer networks and ensure that best practice is shared across the Roald Dahl Nurse community.

We provide a variety of training, workshops and conferences, and offer peer-to-peer support through a bespoke online platform.



152.5 hours
of professional training
for Roald Dahl Nurses.



92.2 %
of Roald Dahl Nurses said their
quality of care has improved because
of professional training.

Examples of training and professional programmes provided in 2022/2023



Leadership Programme

The Florence Nightingale Leadership Programme creates opportunities for nurses to explore and discover their own **leadership style** and develop the essential skills to be courageous and confident leaders.

“ The charity has supported me with my professional development and training opportunities. These opportunities have made me a more driven and dynamic nurse leader. The charity has opened the door to new opportunities and experiences. ”
Roald Dahl Nurse



Makaton Training

Makaton is the UK's leading **language programme for adults and children** with learning or communication difficulties. Makaton is a unique language programme that uses symbols, signs and speech to communicate.

“ Having support from the charity means that I can access training, such as mental health, transition and Makaton. This increases my knowledge and skills and makes me a better nurse for the young people and their families. ”
Roald Dahl Nurse



Mental Health Training

To support Roald Dahl Nurses in offering simple, **evidence-based assistance** to patients within their professional role.

“ I value the support the charity gives to our continued professional development, which in turn enhances patient care. ”
Roald Dahl Nurse

3. Marvellous Inventing Room

We provide opportunities for Roald Dahl Nurses to explore innovative ways of improving the healthcare outcomes and resilience of children and young people.

Roald Dahl Nurses identified a gap in available resources for educating children on what sickle cell disorder means and how to manage it.

As a solution, a group of Roald Dahl Nurses worked closely with our charity and Focus Games Ltd, to develop interactive games to help children with sickle cell disorder better understand and manage their condition.

The suite of games includes a board game, card game and online game.



Play our online game here:



A group of Roald Dahl Nurses developed interactive card, board and online games to help children with sickle cell disorder better understand and manage their condition

4. Marvellous Family Support Service

Many families who care for children and young people with complex, lifelong conditions face unique life challenges, including financial pressures.

To support families under the care of a Roald Dahl Nurse we launched the Marvellous Family Support Service pilot in 2020 to offer one-to-one expert advice.

The service offers families practical financial support to identify and access benefit entitlements, including Disability Living Allowance (DLA), Personal Independence Payment (PIP) applications, assistance with submitting grant applications for medical equipment and much more.



282
families referred to the service



£5,133.90
Average per year gained by families



Over £800,000
of benefits have been unlocked for families

Figures correct at April 2021 – March 2023

Family Story

Rhiannon lives with her husband and their three children. Their daughter Lola, aged 11, has Epilepsy and Tuberous Sclerosis.

Rhiannon was referred to the Marvellous Family Support Service by her Roald Dahl Nurse for support with applying for grants.

The expert advisor assisted Rhiannon with completing child DLA for Lola and was able to signpost the family to other useful information.

The family was awarded the highest care rates for DLA which has provided them with an additional £186.55 a week, which is a total annualised amount of £9,700 to support Lola's care needs.



Marvellous Moments



We welcomed guests to our Marvellous Gala Dinner

Gala Dinner

In June 2022, we welcomed nearly 200 guests to our Gala Dinner at the Banqueting House in London. The evening was full of magic and attended by some famous faces and our marvellous Patrons, including Dame Joanna Lumley DBE, Jane Asher, Geraldine James OBE and Sir Tony Robinson.

The evening was a fantastic success and raised enough to establish a new Roald Dahl Nurse!

Host Dame Joanna Lumley



We visited Clarence House to

decorate the royal Christmas tree

Clarence House

A highlight of the charity's annual visit to Clarence House is helping to decorate the Royal Christmas tree with our Royal Patron, Her Majesty The Queen.

Six families and their Roald Dahl Nurses were delighted to attend the annual visit to Clarence House.

Thank you also to Prestat for putting on a great chocolate making event afterwards, and to Stagecoach for providing the transport for the day.

BBC Lifeline Appeal

We were delighted to feature in February's BBC Lifeline Appeal to raise awareness of the charity's vital work.

Renowned presenter, and our charity patron, Claudia Winkleman presented our appeal. In the film, we met some of the marvellous children and their families under the care of our Roald Dahl Nurses.

Family from BBC Lifeline Appeal

Emmeline's Story

In the appeal, we meet brave Emmeline (two years old), who was born with a rare condition called Goltz Syndrome. Emmeline, her mum Anna and the whole family now receive vital support from Tina, their Roald Dahl Nurse.

Tina has been vital in helping to coordinate appointments and provide emotional and practical support for the entire family. Anna says, "Tina puts everything into perspective, reassures me and gives me confidence. She has reduced my anxiety and supported myself, Emmeline and the whole family."

Claudia Winkleman



Emmeline's Mum Anna says:

“ The Roald Dahl Nurses have had a massive impact, especially during my pregnancy. Knowing that whatever condition Emmeline did have, I had somewhere to go and someone to talk to. Having that was huge and helped my and my baby's well-being. ”

Get Involved

Corporate Fundraising

Our work would not be possible without the generous support of our corporate partners.

If you would like to find out more about how your company can get involved, please contact our Corporate Partnerships team on:

 partnerships@roalddahlcharity.org



Challenge Events

Taking part in a challenge event is a great way to raise money to establish vital Roald Dahl Nurses. There are lots of exciting events happening across the country.



Please visit our [website](http://www.roalddahlcharity.org) for more information.

www.roalddahlcharity.org



Roald Dahl Nurses' Conference 2023

On 12th October we are delighted to be hosting our first in-person conference in four years.

We are excited to bring together over 100 Roald Dahl Nurses from across the UK to engage in discussions about tackling health inequalities and learn from industry professionals.



For all other fundraising enquiries please contact:  fundraising@roalddahlcharity.org

Our Impact: Isaac's Story



Isaac is a very clever four-year-old who enjoys puzzles and reading.

Isaac was born with a rare disease called Spinal Muscular Atrophy which affects his entire body, including his breathing and swallowing. Isaac and his family have been supported by their Roald Dahl Nurse Vicki from a very young age.



Isaac's Mum Kerry says:

“ If we did not have Vicki, I would have to spend a lot of time on the phone trying to coordinate appointments. I don't think I would have been able to go back to work and I would be very lonely. Without Vicki, I would not have anyone to turn to. ”

Looking to the Future



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

Since we were founded in 1991, our mission and guiding principles have remained the same. We will adapt to where the greatest need exists and where specialist nursing can have the greatest impact.

We have decided that our focus for the coming years will be on establishing more Roald Dahl Nurses to support children with the most serious and complex needs across the UK.

These will often be children with multiple health conditions and are some of the most vulnerable children in the UK. Due to their complex needs, several medical specialities are frequently involved in their care.

These Roald Dahl Nurses will work across traditional boundaries and enable proactive, holistic and inclusive services centred on the needs of the child and family.

Support from a Roald Dahl Nurse will reduce hospital admissions, shorten hospital stays, improve communication, improve resilience, enhance relationships between families and professionals and improve the wellbeing of families.

As always, we will rely on our supporters and partners to help us meet the urgent need that exists. We hope that you will join us on this exciting and vital journey.

Our Team

Presidents

Felicity Dahl
Sir Quentin Blake

Trustees

Alex Hyde-Parker (Chair of Trustees)
Michelle Johnson MBE
Rachelle Broadley
Ben Grist
Rob Halkyard
Jodi Johnson
Kath Evans
Mike Marsh
Claire Hollands
Grace Andrews
Helen Thomson
Dr Sanjiv Sharma
Suzannah Goodchild
Niels Kirk (Retired as Trustee 2023)
Nick Warr (Retired as Trustee 2023)



Royal Patron

Her Majesty The Queen

Patrons

Dame Joanna Lumley DBE
Dame Julie Walters DBE
Claudia Winkleman
Theo and Maddy Dahl
Tim Minchin
Donald Sturrock

Ambassadors

Martin Goodwin
Rick Oakley
Robert Paul

Thank you

We would like to say a sincere and heartfelt thank you to our marvellous celebrity patrons, ambassadors and Board of Trustees for your commitment and support. We would also like to thank all of the marvellous corporates, schools, individuals, Trusts and Foundations who support our work.



A huge thank you to everyone that supports the charity, you can take pride in knowing your generosity has enabled the families we support to enjoy being parents. The generosity of the wonderful supporters enables us to take pressure off the parents, offering emotional, psychological and practical support to these families. [Roald Dahl Nurse Specialist](#)



@roalddahlfund



@roalddahlcharity



@roalddahlcharity



@roalddahlcharity



www.roalddahlcharity.org

17 Chiltern Business Centre
63-65 Woodside Road
Amersham
Buckinghamshire
HP6 6AA

Email: enquiries@roalddahlcharity.org
Phone: **01494 890 465**

Roald Dahl's Marvellous Children's Charity. Registered Charity No: 1137409. Company Limited by Guarantee in England and Wales. No: 7340518. Illustrations © Quentin Blake. Roald Dahl is a registered trademark of Roald Dahl Nominee Ltd

