



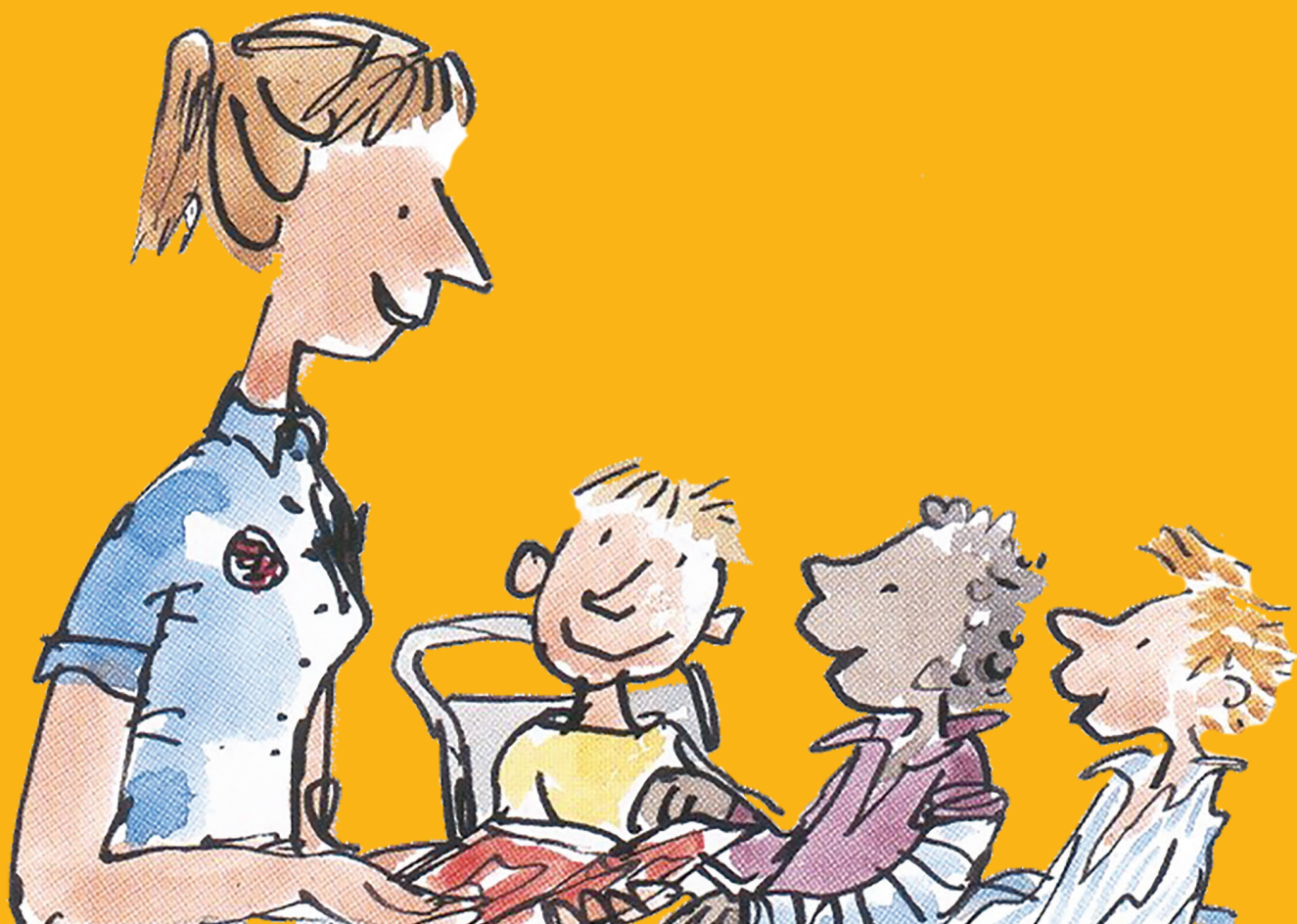
Annual Review

April 2019 to April 2020



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

Cherie, mum to Will



Mission and Vision

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.

A word from our Chair of Trustees, Donald Sturrock

It's been a vigorous and flourishing year at the charity. Our new Chief Executive, Louise Griew, joined us last summer and it has been a joy to watch the team come together under her leadership. They have all worked immensely hard and with great dedication. Our thanks are due to every one of them. The year also saw the launch of our campaign for specialist transition nurses. These nurses are vitally needed by many seriously ill children, who are now growing into young adults with conditions that in the past would probably have been fatal.



I remember one of our teenage sickle cell patients, David telling our 2019 nursing conference how he was shuffled between paediatric and adult services in different hospitals with both denying him treatment for pain so crippling he could hardly speak. Fortunately, he was able to phone his Roald Dahl Transition Nurse, Giselle, and she sorted things out for him.

I am convinced more than ever how vital our nurses are to seriously ill children and their families. Many still don't have co-ordinated access to the specialist treatment, advice and support that they, and their families, desperately need. We continue to work to bridge this gap, by:

- **Establishing Roald Dahl Specialist Nurses in areas of greatest need;**
- **Providing ongoing professional training and development for these nurses;**
- **Fostering nurse-led innovation to improve quality of care and life.**

Every single one of these areas are crucial, but we hope in the coming year to do more to measure the impact of all our charitable work, so we can be certain our nurses are delivering the best possible nursing care. This is harder than it might appear.

Finally, I'd like to thank our Royal Patron, HRH The Duchess of Cornwall whose continued support is so valuable to us, alongside three individuals who have been crucial to the charity since its inception. They are our Presidents, Felicity Dahl and Sir Quentin Blake - both lively octogenarians still backing us in their ninth decades - and Martin Goodwin, my predecessor as Chair, who retired as a Trustee this year. We are very pleased that Martin will become our first official Ambassador.

Welcome from our Chief Executive - Louise Griew

I feel privileged to be writing to you in my first Roald Dahl's Marvellous Children's Charity Annual Review. Since stepping into my role in June 2019, we have started an exciting journey and I am delighted to share with you our accomplishments from the year.

Our Specialist Nursing programme is at the heart of what we do. Everything we achieve is in close collaboration with NHS Trusts who respect our track record of innovation and improving UK paediatric nursing care. This year, our focus has been on transition of care – the point at which a young person moves from children's into adult healthcare services. This is often a frightening and challenging time of uncertainty for the young person and the NHS has identified this as an area that needs vast improvement. We are thrilled to be supporting this important area of healthcare which we have been working in since 2016.

To tackle the gap in NHS transition services, we established two more transition nurses in areas of greatest need and identified a third, working closely with three different NHS Trusts. We will closely monitor the impact these roles have on their communities and the wider NHS Trust services and look forward to sharing the knowledge we gain.

Our 2019 Roald Dahl Nursing Conference was focussed on transition. It was my first opportunity to meet Roald Dahl Specialist Nurses and I was humbled by their dedication, compassion and expertise.

The organisation has been making strides this year to ensure we are demonstrating the impact of our work and the value of our nurses more clearly. We engaged our stakeholders and friends in strategic workshops and our ongoing collaboration with Sheffield Hallam University will enhance the new outcomes framework and measurement plans. We look forward to sharing these with you soon.

Finally, on behalf of thousands of seriously ill children across the UK, I would like to thank again, everyone who currently makes our work possible – including our wonderful and unique team of Roald Dahl Specialist Nurses and the NHS Trusts they work for, our fantastic charity staff, Royal Patron, presidents, patrons, trustees, ambassadors and volunteers.



Roald Dahl's Marvellous Children's Charity Chief Executive, Louise Griew with the Roald Dahl Specialist Nursing team at Addenbrookes Hospital in Cambridge

And of course, we couldn't do it without the generosity of our supporters. We remain hugely grateful to the Roald Dahl Story Company for funding our core running costs. This means in turn that every other donation we raise can go directly to supporting our beneficiaries.

As we look back on the successes of this year, we also look forward into an uncertain future. The world is taking on a frightening new pandemic, which will doubtless test us all in many ways. However, I am confident that we have plans in place and a strong team behind them to ensure that we can serve our charitable beneficiaries even more effectively, whatever the future may hold.

Locations of Roald Dahl Specialist Nurses

Roald Dahl's Marvellous Children's Charity provides specialist nurses and support for seriously ill children living with complex, lifelong illnesses. Our 79 (as of October 2020) Roald Dahl Specialist Nurses are based in hospitals throughout the UK.

Inverness
2 Epilepsy nurses

Aberdeen
Epilepsy nurse

Belfast
Neurological/Head Injury nurse

Leeds
1 Transition,
1 Epilepsy and
1 Neuromuscular nurse

Liverpool
4 nurses, including a
Haematology nurse

Cambridge
3 nurses, including a
Neuromuscular nurse

Birmingham
4 Rare Diseases nurses
including 1 for
Transition of care

Newport
4 Epilepsy nurses

London Area
17 nurses including
4 Transition nurse
specialists

Southampton
4 nurses including a
Neurological/Head Injury nurse



● Locations of Roald Dahl Specialist Nurses

New NHS Trust Partnerships

As part of its ongoing strategy to improve the care for young people with serious lifelong illnesses when they move from children's to adult services (commonly referred to as 'transition of care' by the NHS), Roald Dahl's Marvellous Children's Charity worked with selected NHS Trusts to establish three Roald Dahl Specialist Transition Nurse posts (one post per Trust). The three Trusts were chosen from 17 applications after a formal review and include: East London NHS Foundation Trust (for young people living with complex needs – to start in early summer 2021), Leeds Teaching Hospitals NHS Trust (for young people living with neuromuscular conditions – started in April 2020) and Lewisham and Greenwich NHS Trust (primarily for young people living with haematological conditions and neuro-disabilities – started in February 2020).

We have already established four Roald Dahl Specialist Transition Nurse posts and plan to create further Transition posts in 2020/2021. The Transition posts add to the over 75 Roald Dahl Specialist Nurses who care for seriously ill children across the UK with serious, lifelong conditions. Transition is a key element in all Roald Dahl Specialist Nurses' work as they empower their patients and families to be more independent as they move into adult care.

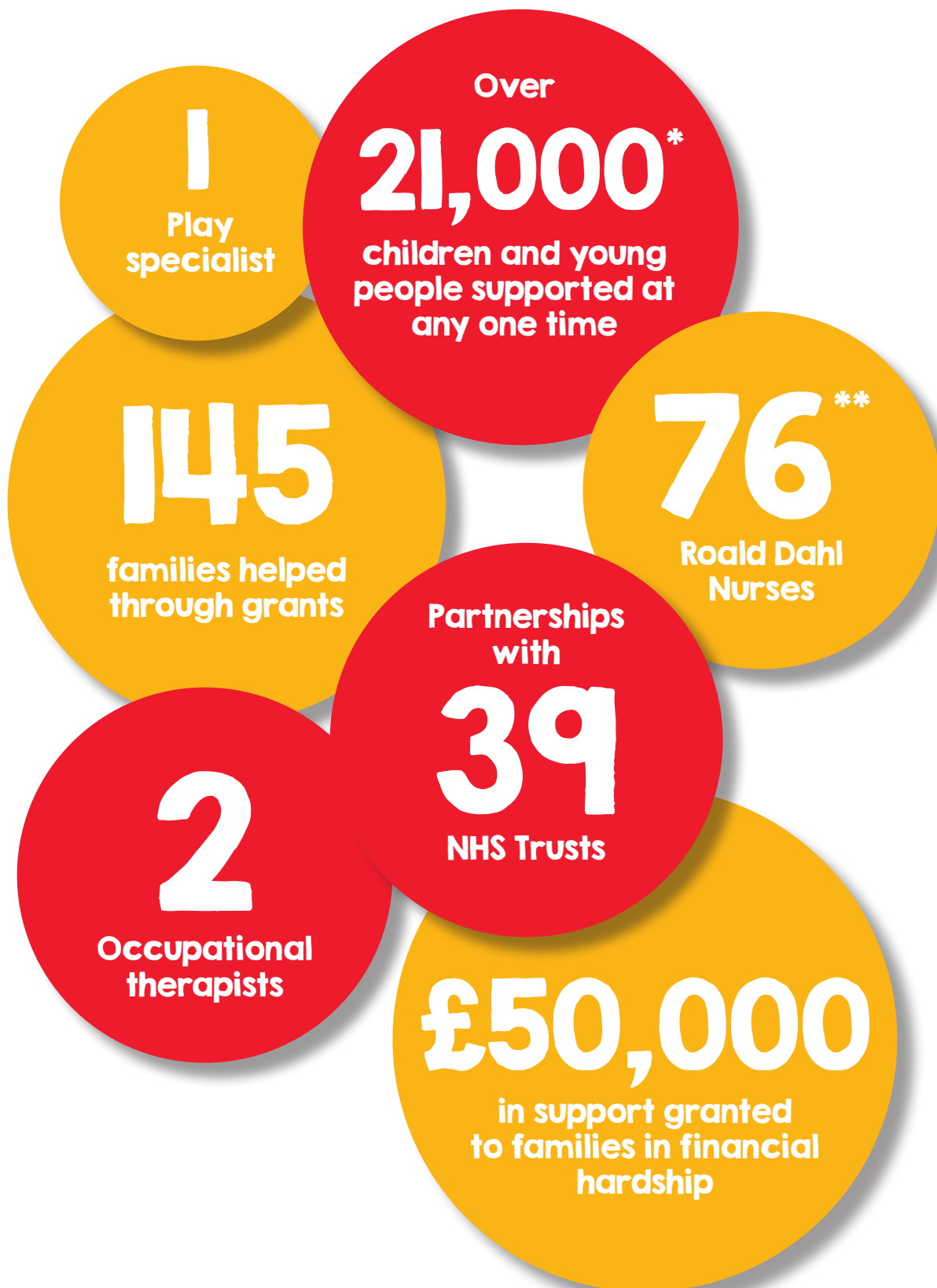


It is widely accepted that Transition needs to be improved in the UK. The NHS Long Term Plan, which is designed to make the NHS 'fit for the future', includes a commitment to, by 2028, "move towards service models for young people that offer person-centred and age appropriate healthcare, rather than an arbitrary transition to adult services based on age not need." It states that "failure to achieve a safe transition can lead to disengagement, failure (of the young person) to take responsibility for their condition and ultimately poorer health outcomes."

Speaking at the 2019 Roald Dahl's Marvellous Children's Charity conference, which was themed around transition of care, Angela Horsley MBE, Head of Children, Young People and Transition NHS England and NHS Improvement highlighted that a lack of focus on transition can lead to unnecessary A&E attendances:

"Children and young people account for 25% of emergency department attendances and are the most likely age group to attend A&E unnecessarily". Angela is leading a national team to improve patient experience and achieve the best possible future healthcare outcomes for young people with long-term conditions. This team wants to see enhanced coordinated care and a cultural shift within healthcare organisations to better meet the needs of young people. These objectives are aligned with Roald Dahl's Marvellous Children's Charity's strategic aims and the charity wholeheartedly endorses the team's desire for a better quality of transition care for young people in years to come.

Our impact - year in numbers



*estimate

**as of 31st March 2020, includes 1 play specialist and 2 occupational therapists

Roald Dahl Nurse Spotlight

Roald Dahl Nurse Wins Healthcare ‘Oscar’!



We are proud to announce that one of our marvellous nurses, Elizabeth Joshua-John, has won a Zenith Global Health Award.

This is widely regarded as the equivalent of an Oscar in the healthcare world! Elizabeth is a Roald Dahl Nurse who specialises in Paediatric Haematology at Luton and Dunstable University Hospital NHS Foundation Trust. She was presented with the Nursing and Midwifery award at a ceremony which showcases healthcare professionals who have excelled in their area of speciality through management, patient care, education, research and innovation.

Judges said: “After carefully reading through the candidates’ supporting statements, the clear winner is Elizabeth Joshua- John. Why? Because she is not only very diverse with her nurse expertise, but very patient oriented with her care plan. She offers support to families and trains nurses. She is very robust and enjoys her job.”

Sophie Dziwinski, Head of Programmes, Roald Dahl’s Marvellous Children’s Charity said: “We are extremely proud that Elizabeth has won this prestigious award. She is a dedicated and caring nurse who goes above and beyond for her patients.”

Elizabeth said: “I am so thankful to each and every one at Roald Dahl’s Marvellous Children’s Charity for providing me with these amazing opportunities. I am so proud to be a Roald Dahl Specialist Nurse!”

Ahuoyzia’s Story - A Mother’s Perspective

Ahuoyzia’s mum, Sarah:

“Ahuoyiza (8) was diagnosed at birth with Sickle Cell Anaemia, an inherited serious condition that affects the red blood cells. When she was three years old, Ahuoyiza had her first Sickle Cell crisis (episode of severe pain). It was very scary, and she still remembers it despite being so young at the time. The doctors appeared from everywhere saying ‘we need oxygen’. It was very frightening as we didn’t know what was going on. Generally, she’s a happy, bubbly girl but when the pain comes on you can see the difference. If we’re not sure what we need to do, we can pick up the phone to our Roald Dahl Specialist Nurse, Elizabeth and she will help us straight away.



Having a child with a lifelong health condition is very stressful as a mum. Sadly, my husband had a stroke in 2016. Straight after he left hospital, Ahuoyiza was in two weeks later with pneumonia. I’d just had a new baby as well so there was a lot going on. Once Elizabeth and the team were aware of that, they were so good and always asking how they could help. It’s very hard. When your child is ill, it floors you completely. You feel so helpless and drained.

Having Elizabeth who always knows what’s going on has made everything so much easier. Ahuoyiza loves Elizabeth too – there’s always a smile on her face when she’s in hospital and she sees Elizabeth – those little things make a big difference. Elizabeth was immediately great at calming Ahuoyiza down and could get her blood tests done in one go. Ahuoyiza quickly got used to her – it’s been very natural, and we see her as ‘our person’.

Roald Dahl Nurses Conference - Transition

On Friday 17 May 2019, Roald Dahl Specialist Nurses and healthcare professionals, along with other marvellous delegates, charity staff and trustees attended a special event - The Roald Dahl 'Transition of Care' Nursing Conference. The event was hosted at the Royal College of Nursing in London and brought together over 50 of the 75 Roald Dahl Nurses who care for in excess of 21,000 seriously ill children, young people and families across the UK.

The theme of the conference was on transition from child to adult healthcare services and the day was hosted by Roald Dahl Specialist Transition Nurses Giselle Padmore-Payne who works at King's College Hospital NHS Foundation Trust and Neil Fletcher, Roald Dahl Specialist Nurse for Teenagers and Young Adults at Barts Health NHS Trust.

Speakers for the day included healthcare professionals and leaders from NHS England and NHS Trusts, as well as young people and parents who are supported by Roald Dahl Specialist Nurses.

Delegates were able to learn about patient experience and share best practice by hearing from Roald Dahl Specialist Nurses and other healthcare professionals about how they support the transition pathways for young people. The delegates were also joined by charity founder and President Felicity Dahl, who set up the charity nearly 30 years ago.



Roald Dahl Transition Specialist Nurses, Neil, Giselle, Janet and Angela

The conference was a wonderful way for Roald Dahl's Marvellous Children's Charity's network of specialist nurses to come together and learn from one another. It was also an opportunity to celebrate their work and how they provide the best possible healthcare to seriously ill children, young people and their families. The day forms part of the Roald Dahl Professional Development Programme- enabling this established community of Roald Dahl Specialist Nurses to develop their service areas and their careers.

The topic of transition was highly valued by all attendees. "Prioritising transition is so important," declared one of our nurses pointedly. "We can do so much more by working together and learning from each other on how to create a great transition experience for young adults".



Professional Development

Roald Dahl Specialist Nurses are often pioneers in their specific field, so it is vital that we provide the training and development support that ensures they remain key leaders of their profession – updating their knowledge, testing new ideas, sharing best practice with their wider hospital teams. That's why each one of our nurses and healthcare professionals' benefits from the Roald Dahl Learning and Development Programme. Through staging the Roald Dahl Nurses' Conference and supporting their attendance at courses and conferences, we ensure they remain up-to-date and continue to develop both their careers and their services.

Roald Dahl Nurse Spotlight - Training

Tracey Bloodworth

Roald Dahl Specialist Nurse – Haemoglobinopathy

Tell us about your role? I look after children with lifelong chronic Haemoglobinopathy conditions, such as Sickle Cell Disease and Thalassaemia. My role encompasses both community and acute clinical. I run nurse-led clinics weekly to perform bloods and review Sickle Cell patients who are on Hydroxycarbamide and need close monitoring for any toxicities. We have patients on regular blood transfusion programmes and co-ordinate all their care and treatments.



How has Roald Dahl's Marvellous Children's Charity helped with your training and progression? I have been very fortunate to complete two courses since starting in this role – Genetic Risk Assessment and Clinical Assessment. These courses have enabled me to assess patients and identify illnesses which will reduce inpatient episodes when identified early. I can identify couples who are at risk of having a child with a significant Haemoglobinopathy disorder and counsel them accurately.

What impact has the training had on you and your patients? The genetic risk assessment and counselling course has enabled me to link up with the midwives in Liverpool and Chester to speak face-to-face with couples who are carriers for Haemoglobinopathy disorders. I have spoken with them about the conditions and modern-day treatments, to give them information on what a child's life may be like living with one of these conditions and what support would be available, to enable them to make an informed choice on the pregnancy. The Clinical Skills course has enabled me to assess children in the nurse-led clinics or at home to identify any illnesses and enable early treatment. This has reduced time attending GP surgeries, Emergency Units or Walk-In Centres for the families as I can visit at home to assess them.

How has the training helped you build your support network of other healthcare professionals? The training has enabled me to meet with the local and regional midwives to counsel couples together and to educate them on the conditions.

Why is training and development important in your role as a specialist nurse? It is important to be able to keep up to date with new therapies and treatments. It is also important to network with others to ensure consistent care is being given to our families. Developing your own knowledge and sharing this with others is essential to progress in your role.

Would you be able to access this kind of training without support from the charity? No – I have worked for 18 years in a previous role and never got the opportunities I have had since starting in this role.

Marvellous Family Grants

Caring for a seriously ill child can take its toll on the entire family, not just emotionally, but also financially. Marvellous Family Grants funded items like physiotherapy, speech and language therapy, hydrotherapy and counselling; play, art or music therapy sessions; specialist equipment, such as specialist seats and walkers and epilepsy monitors.

During 2019/20 we supported 145 families with this vital programme of support. We carried out a thorough review of the programme in autumn 2019 and concluded that while financial support of this kind is clearly important for families in hardship, there are currently other funders providing this and we could probably use our resources to better effect by focusing elsewhere. Consequently, we decided to close the Marvellous Family Grants Programme in February 2020. We are now developing a new programme to support and better equip our families to cope with the immense financial pressures put upon them when you have a seriously ill child. We hope to launch this in 2021.

We are proud of the children and families we have helped through the Marvellous Family Grants programme over the years. One such child is Cameron. Cameron is 13 and suffers with a complex form of epilepsy that has left him with a lifelong disability. When Cameron was younger, he reached the normal milestones, including riding a trike. Cameron's Mum Ann-Marie said, 'he had a Thomas the Tank Engine bike that he loved!' but when he was four, he had his first major seizure and was rushed to hospital in an ambulance. Despite treatment, the seizures got worse – he suffered night terrors and would wake screaming and shaking. He couldn't walk or talk.



When Cameron reached his teens, his condition improved. But he was desperate to be like the other kids in his neighbourhood. His Mum and Dad came up with the idea of getting him a large trike, but they soon discovered that the cost of something suitable was beyond their means.



They applied to our Marvellous Family Grants programme, and his dreams came true. Cameron's Mum told us:

"I happened to mention it to our Roald Dahl nurse Louise, and she suggested she could apply for a grant on our behalf. At first I thought there were other people who need charity more, but I'd recently been made redundant and we realised that it would really help Cameron – he'd put on a lot of weight because of the steroid injections and he wasn't enjoying exercise."

I couldn't believe it when we were successful! And the day it arrived; it was amazing. He was so happy. I was crying. He kept saying "I can ride a bike! It's made a huge difference to Cameron – being able to play with the other children. And it's made a huge difference to our family – if we want to walk the dog by the canal, we just pop the trike in the car and we're off. Normal family life!"

Events and news

Follow Florence

In May 2019, Roald Dahl Specialist Nurse Lesley was joined by her husband Tony on a five-day road trip from Oxford to Rochester in a Citroen 2CV - called Florence. The idea for the fundraising road trip was developed in 2018, from the 70th anniversary of the NHS, the 70th anniversary of the iconic 2CV design and also having 70 Roald Dahl Specialist Nurses in post. Lesley and her husband who are huge 2CV fans, visited hospitals and venues connected to the charity.



Seriously Ill Children Decorate Royal Christmas Tree with Duchess of Cornwall



Five seriously ill children supported by Roald Dahl's Marvellous Children's Charity and their Roald Dahl Specialist Nurses were invited to a magical event at Clarence House by our Royal Patron, Her Royal Highness, The Duchess of Cornwall. The children helped to decorate the Royal Christmas tree after which Her Royal Highness served up bangers and mash for her young guests. The children were also treated to a surprise visit by Santa's reindeers and a gingerbread house decorating experience at the Savoy Hotel with one of their top chefs!

Thank you for giving me a Roald Dahl Nurse

Ten-year-old Lara, who has an undiagnosed genetic disorder, and is supported by Roald Dahl Specialist Nurse, Anna, fronted our 2019 Christmas Appeal in which she imagined a Christmas future where all seriously ill children have a Roald Dahl Specialist Nurse. The video was introduced by David Walliams. Lara also featured in The Daily Mail's Health section in an article, which promoted the charity's Christmas Appeal. It also covered her appearance in the Old Vic's Christmas Carol as one of the three actors to play Tiny Tim.



Roald Dahl Nurses Celebrate Unveiling of Stained Glass Window with Royal Patron

Four of our marvellous Roald Dahl Nurses were among the special guests at Birmingham Children's Hospital for the unveiling of a unique stained-glass window installation featuring some of Roald Dahl's most iconic characters designed by Sir Quentin Blake. The windows were unveiled by Roald Dahl's Marvellous Children's Charity Royal Patron, HRH The Duchess of Cornwall alongside the charity's President, Felicity Dahl, wife of the late author, who devised and led the fundraising campaign for the project.

Year of the Nurse

2020 has been designated the International Year of the Nurse by the World Health Organisation to honour the vital role played by nurses and midwives around the globe. To celebrate, we kicked off the year with a series of videos featuring our nurses talking about why they love being a Roald Dahl Specialist Nurse. Here is a snapshot of some of the videos:



Bethan Williams: Roald Dahl Transition Specialist Nurse, Lewisham and Greenwich NHS Trust

"It is a privilege to be able to improve the pathway for young people with chronic conditions."



Sasha Peacock: Roald Dahl Epilepsy Specialist Nurse, Ninewells Hospital in Dundee

"What I love most about being a Roald Dahl Specialist Nurse, is that I get to see the children I care for regularly. I love that I build and sustain relationships, and that they come to me for expertise and advice. I can only describe my role as a Roald Dahl Specialist Nurse as a privilege that I don't take for granted."



Katrina Cousins: Roald Dahl Neuromuscular Specialist Nurse, Addenbrookes Hospital, Cambridge

"Being a Roald Dahl Specialist Nurse is amazing as it gives you so many opportunities, especially with learning and development. Being a Roald Dahl Nurse for the neuromuscular service is so important because it enables the parents and children to be able to talk to you when they are worried about anything. You're the person they come to, so you build a rapport and they trust you."



Giselle Padmore-Payne, Roald Dahl Transition Specialist Nurse - Sickle Cell and Thalassaemia

"I help young people navigate the complex NHS system to get them ready when they transfer to adult services. I ensure they are confident to speak up for themselves and have the tools to progress in life. Knowing I make a difference to them and their quality of life is what I enjoy the most about being a Roald Dahl Nurse."



Jacquie Hussain, Roald Dahl Rare Diseases Specialist Nurse, Birmingham Children's Hospital

"I absolutely love my role. I love helping the families, building a relationship with them and seeing how they flourish when they've got the help we can provide. It's such a privilege to have the time that Roald Dahl's Marvellous Children's Charity gives us to spend with these families. It's such a marvellous feeling to go home at the end of the day knowing that you've helped these families that are so desperate for some help."

Fundraising thank yous

Our relationship with our supporters is fundamental to our continued success. We are immensely grateful to everyone who contributed in 2019-20. A special thank you as always to the **Roald Dahl Story Company** whose partnership we treasure. We must also mention **David Austin Roses** who have generously been a valued supporter since 2016. We would like to thank the trusts and foundations who have supported us throughout the year. A big thank you also goes to:

- **Zochonis Charitable Trust**
- **Jack O'Donnell Foundation**
- **Coutts**
- **NHS Trusts**
- **Ambassadors Theatre Group**
- **Explore Learning**
- **Auntie Anne's**
- **Newton Investment Management**
- **Sphere Digital Recruitment**
- **Buxted Construction Ltd**
- **Next**
- **Persimmon Homes**
- **BAC Office Equipment**
- **Graham Harris and Chiltern District Council**
- **Fit Club Amersham**
- **Traveltime**
- **De Vere Latimer Estate**
- **Rochester and Cobham Golf Club**
- **The Beacon School, Amersham**
- **National Film and Television School staff and students**

Our finances 2019/20

It continues to be a challenging external climate, but we have been able to maintain our levels of spend on charitable activity*.

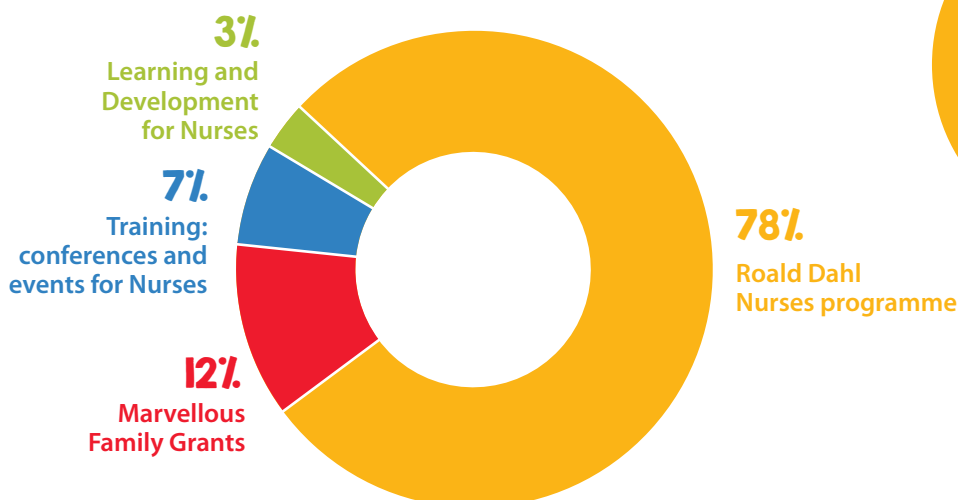
However, as the population of children and young people living with serious illnesses grows, there is a greater need for the programmes we provide and the partnerships we build. In 2019 we received nearly six times the number of NHS Trusts applying to establish new nurse posts with us than we could afford.

With 100% of our income coming from voluntary support, we need your help to meet the growing demand from children, young people and families across the UK.

£891,466
income
generated

£1,222,666
total
expenditure

Charitable Expenditure



*Expenditure exceeded income during 2019/20 as part of a planned reduction to the charity's reserves in order to maintain six months running costs. For further financial information, the charity's full annual report and audited accounts are available from the Charity Commission website.

Who's Who

Thank you to the following individuals who have supported us through the year and made such a difference to the impact we make.

Royal Patron

HRH Duchess of Cornwall

Presidents

Felicity Dahl

Sir Quentin Blake

Patrons

Maddie and Theo Dahl

Joanna Lumley OBE

Tim Minchin

Dame Julie Walters DBE

Claudia Winkleman

Trustees and Directors

Donald Sturrock (Chair)

Jodi Betts

Graham Faulkner

Michelle Johnson

Niels Kirk

Alex Hyde-Parker

Rob Halkyard

Nick Warr

Ben Grist (Joined December 2019)

Robert Paul (Joined December 2019)

Louise Griew (Retired May 2019)

Martin Goodwin (Retired September 2019)

Virginia Myer (retired January 2020)

Looking ahead

The next four years are vital to the progression of our programmes and work with seriously ill children. We know that Roald Dahl Specialist Nurses are crucial to the development of the child and the support of the family and that the areas we work in are underfunded. Our nurses and partnerships with NHS Trusts are vitally important to improving care for these children and we know we can deliver more impact in these areas.

Our strategy to achieve this will be published in 2020 and will go alongside an impact evaluation study that will be launched early in 2021. We now have a very clear pathway to achieving our goals and we look forward to sharing this in 2021 alongside our results from our evaluation study with Sheffield Hallam University.

As we write this, the Coronavirus pandemic has rocked the world and we have seen the effect that this has had on seriously ill children, young people and their families. We have responded to this by supporting Nurses and families more than ever, and we have seen how incredible our supporters have been. While our long-term strategy does not change, we have been flexible and agile in our approach to support families with their urgent needs during this challenging time, helping to ensure that seriously ill children and young people can lead a more marvellous life.



Every seriously ill child deserves a Roald Dahl Nurse



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

Email: enquiries@roalddahlcharity.org



www.roalddahlcharity.org

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