annual review 2017/18
“We want to keep these patients out of hospital. We want to keep them safe and we want to ensure children here have the same level of care as those in London and the rest of the UK.”

Jennifer Anderson, Roald Dahl Paediatric Neurodisability Nurse, Royal Belfast Hospital for Sick Children, Belfast Health and Social Care Trust.
Introduction

Mission, Vision and Values

Our Mission
Every seriously ill child has the best possible healthcare.

Our Vision and Values

A specialist nurse for every seriously ill child
Every child with a serious illness in the UK should have access to the knowledge, skills and experience required to meet their healthcare needs, no matter where they live. That’s why we create and fund specialist nursing posts within the NHS across the UK.

Quality care for every seriously ill child
It is essential that children’s nurses across the UK are fully supported to develop the knowledge and skills necessary to deliver the best care possible. That’s why we provide professional support to our Roald Dahl Nurses\(^1\) to enhance their skills and foster innovation to improve services for seriously ill children.

\(^1\)The term ‘Roald Dahl Nurses’ is inclusive of other healthcare professions funded by the charity, which encompass seriously ill children’s holistic needs, including psychological needs.
Welcome from our Chair

“ I’m very pleased to share with you our review of 2017/18 – a year in which we touched the lives of more seriously ill children and young people across the UK than ever before.

Working in close collaboration with a number of NHS Trusts, we appointed nine new Roald Dahl Nurse specialists in areas of acute need, including our first ever play specialist - bringing the total number to 62.

We had a particular focus on Sickle Cell Disease during the year - a chronic and lifelong illness that is now the most common genetic condition in England and more prevalent than cystic fibrosis. There is still a stigma attached to the disease and it remains misunderstood and under-resourced in many areas. We produced the first in a series of information films, as well as promoting a new picture book and an app that help children manage the acute pain associated with a Sickle Cell crisis. These were created in partnership with Alder Hey Children’s NHS Foundation Trust and The Burdett Trust for Nursing.

Other highlights of the year included a successful Roald Dahl Nursing Conference in Birmingham, where Professor Dame Elizabeth Anionwu was our keynote speaker. And we were thrilled when Her Royal Highness the Duchess of Cornwall became our Royal Patron in December 2017. We are confident that her support will make a huge contribution to raising awareness of our work.

We recognise that it’s increasingly important to demonstrate the value of what we do as a charity so we also commissioned two new studies, both designed to evaluate the effectiveness of specialist nurses in different ways: ‘Demonstrating the Value of Specialist Nursing’ in collaboration with the Royal College of Nursing and ‘Evaluating the Impact of Roald Dahl Specialist Nurses’ in partnership with Sheffield Hallam University.

We believe that every child should receive the best possible healthcare and yet many seriously ill children still don’t have co-ordinated access to the specialist treatment, advice and support that they, and their families, desperately require. We continue to work to bridge this gap, by:

- Setting up specialist Roald Dahl nursing posts in areas of greatest need
- Providing ongoing professional training and development
- Fostering nurse-led innovation to improve quality of care
- Offering targeted grants to help families living in financial hardship

You can read more about our work in this report, but I would like to take the opportunity to thank everyone who makes it possible – including our very able team of Roald Dahl Nurses, charity staff, trustees, volunteers, patrons and ambassadors. We couldn’t do it without you!

And of course, we couldn’t do it without our supporters. We remain hugely grateful to The Roald Dahl Charitable Trust for funding our core running costs, and this means in turn that every other donation we raise goes directly to supporting our beneficiaries – seriously ill children and their families.

On behalf of the Trustees, I would like to thank every single individual and organisation who supported us in 2017/18.

Donald Sturrock
The year in review

Setting up specialist Roald Dahl nursing posts in areas of greatest need

Roald Dahl specialist children's nurses provide comprehensive support, information and practical care for seriously ill children and young people, and their families. They are highly qualified, senior professionals who work within major hospitals and the community, across the UK – filling critical gaps in health provision and leading change and improvement. They advise on a wide range of medical, emotional and social issues, helping children, young people and their families to navigate the often difficult and complex path of chronic, life-limiting illness.

In line with our ambition to support under-resourced areas of child healthcare, we continued to expand our specialist paediatric nursing programme, committing funds for nine new posts across the UK in 2017-18. During the year we appointed our first play specialist (University College London Hospitals NHS Foundation Trust) and our first specialist transition nurse operating across all complex chronic conditions within a major London Trust (Barts Health NHS Trust). We also appointed three epilepsy nurses, two neuromuscular nurses, and one non-malignant haematology nurse.

Roald Dahl Nurse Spotlight: The Power of Play

Liz Coombs, Roald Dahl Senior Play Specialist, University College London Hospitals

“**I’m the play lady. I’m in charge of all the toys and glitter!**”

She always wanted to work with children but didn’t find her true calling until she came across the role of a health play specialist – ‘a non-medic in a medical environment’. It was perfect.

Having experienced her own health issues as a child, Liz was all-too familiar with the institutional atmosphere of a hospital. She totally understood the compelling need for specialist play support to help young patients and their families minimise stress and anxiety as a result of recurrent treatment.

“As a health play specialist, my job is to take a potentially traumatic experience and make it as positive as possible - so that everyone in the family feels supported in their time of need.”

Like every Roald Dahl funded post, Liz fills a vital gap in care at University College Hospital London:

“The team at University College Hospital are keen to offer pump therapy (an alternative to injections) to those who might benefit. Liz is key in the pathway ensuring children are prepared for the transition.”

Rebecca Martin, Diabetes Nurse Consultant, University College Hospital, London.
Roald Dahl Nurse Spotlight: Transition

Neil Fletcher, Roald Dahl Clinical Nurse Specialist for teenagers and young adults, Barts Health NHS Trust

“This job was perfect – a new post, no legacy, no framework, the chance to really make an impact on the quality of care for young people transitioning from children to adult services.”

Neil is on a mission. He’s passionate about the power of volunteering – both personally and as a tool for change. He’s passionate about young people’s health. And he’s passionate about his job – an innovative new role within a major London health trust that focuses on empowering young people with complex chronic conditions (including hearing and sight loss) across the whole trust.

Most Roald Dahl Nurses specialise in specific clinical areas, but this role is different and when Neil saw it advertised, he jumped at the opportunity.

“The whole idea of transition is that it is a pathway and not a one-off change of care provision. And the reason that’s so important is that if a young person’s first experience of adult healthcare is poor, they are far more likely to disengage”

One part of Neil’s role is to work daily with new admissions for those aged 16 to 18 across four Trust sites. Neil focusses on an assessment of their home environment, education and employment, eating, peer-related activities, drugs, sexuality, suicide and depression, and safety from injury and violence. Barts Health NHS Trust is one of three designated major trauma centres serving the capital. And for Neil this often means teenage victims of violent crime.

“I’m not interested in the issue of criminality; my job is to focus on the fact that I’m working with vulnerable young people...I recently interviewed a 17-year-old who had been stabbed. He was a refugee and the police said he was likely to have been trafficked. He had no family in this country and his English was poor. He was clearly at risk and needed an advocate, so my job was to identify the best route to keeping him safe.”
Providing ongoing professional training and development

Roald Dahl Nurses are often pioneers in their specialist field, so it is vital that we provide the training and development support that ensures they remain in the vanguard 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 Professional Development Package. Through funding their attendance at courses and conferences, we ensure they remain up to date and continue to develop both their careers and their services.

In 2017, we teamed up with the Royal College of Nursing, who created and delivered a bespoke programme of workshops over six months to train our nurses in two key areas – firstly in their roles as leaders in their specialist nursing fields, focusing on effective communications and networking; and secondly to equip them to accurately demonstrate the economic value of their roles to senior NHS business managers.

Some of the results were shared at the annual Roald Dahl Nursing Conference, held in Birmingham, underlining the close association we have with Birmingham Children’s Hospital. The focus of the conference was Sickle Cell Anaemia and Thalassaemia and the keynote address was given by Professor Dame Elizabeth Anionwu, one of the two founders of the first UK Sickle Cell Anaemia and Thalassemia counselling centre in the UK.

Professor Dame Elizabeth Anionwu talked about what was missing in Sickle Cell Anaemia and Thalassaemia care, before she became the UK’s first Sickle Cell and Thalassaemia Nurse Specialist.

“Isolation, despair, a sense of neglect, an urgent need of specialist medical care & information/support expressed by those affected by sickle cell disorders and no local support group”

Our film raising awareness of how Sickle Cell Anaemia affects families and how our nurses support them, was premiered at the Conference and we also launched Marvin’s Marvellous Medals – awards for families with seriously ill children, who, despite their own difficult circumstances, have helped raise wider awareness of their condition. The first medals awarded were presented by Liccy Dahl, our Founder and President, who gave them to George and his Mum and Taye and Tyrell and their Mum for their bravery in supporting other children, young people and families affected by conditions such as Sickle Cell Anaemia.
Roald Dahl Nurse Spotlight: Sickle Cell Anaemia

Elizabeth Joshua-John, Roald Dahl Paediatric Haematology Nurse Specialist, Luton and Dunstable University Hospital

Roald Dahl’s Marvellous Children’s Charity knew a dedicated specialist would vastly improve the life opportunities and experiences for thalassaemic patients in Luton and the surrounding areas.

In 2017, we partnered with the Children’s Haematology team at Luton & Dunstable University Hospital NHS Trust, to fund the establishment of a new Clinical Nurse Specialist for children and young people with non-malignant blood conditions. The aim was to develop a strong, family-centred service and meet the increasing demand for specialist nursing support for children with conditions such as Sickle Cell Disease, Thalassemia and other chronic haematological conditions.

Elizabeth Joshua-John was the ideal candidate. Enthusiastic, motivated and dynamic, she likes to focus on solutions.

“My nature is always to help people as much as possible and try to resolve problems. This role lets me do that... Strong communication skills are vital. I have professional boundaries but good relationships with everyone - patients, their families, consultants and other colleagues.

I liaise with schools to provide training in the community and I also deliver study days for nurses here to educate them about sickle cell and thalassemia.

I think the most important thing is that families have someone they know; they find the continuity really helpful and comforting. They know they can always contact me when they need help or advice - often by text or WhatsApp - and they can leave their children in my care with confidence if they need to.”
Fostering nurse-led innovation to improve quality of care

Roald Dahl was an innovator and we believe that innovation plays a vital role in improving children’s healthcare services. The Marvellous Inventing Room offers a rare place for new ideas to incubate. It is a place where fresh approaches are dreamed up and turned into reality – from new research and training resources to technical and creative products that improve the knowledge and resilience of seriously ill children and their families.

In 2017/18, we focused on Sickle Cell Anaemia, in direct response to the concerns of Roald Dahl Nurses in the field. They told us there is still a surprising lack of awareness and understanding of the condition – amongst the general public, in schools and amongst some healthcare professionals. In response, we launched a comprehensive education pack for children and their families, including a new app and book. Funded by the charity, the project was developed in partnership with The Burdett Trust for Nursing, Alder Hey Children’s Hospital and multi-media charity Twin Vision.

We also produced the first in a series of short films to help increase understanding of the condition amongst the general public, and distributed a new factsheet providing easily accessible facts and advice about Sickle Cell Anaemia and Thalassaemia.

Sickle Cell Disease is now one of the most common serious genetic conditions in the UK, affecting an estimated 15,000+ people, particularly those with African or Caribbean heritage. It is characterised by episodes of intense pain, vulnerability to infection and increased risk of stroke; consequently, children and young people with the condition are in frequent contact with healthcare services and have specific needs, especially for intensive pain relief. Treatment of Sickle Cell Anaemia therefore focuses largely on preventing and treating complications.

When a child is young, their parents or carers take responsibility for managing their child’s healthcare needs - scheduling appointments, managing treatment plans, and making sure their child is eating healthily and sleeping well, to reduce the severity and occurrence of pain crises and other Sickle Cell Anaemia-related health problems. However, as young people enter their teens and mature into adults, the responsibility shifts, and this process is known as transition. During transition, health care provision transfers from child to adult services and young people must learn how to work with their adult healthcare provider to manage their health. It can be a challenging and anxious time. So having dedicated staff with expertise in adolescent care and transition enables a young person to build confidence and feel in control as they navigate towards caring for themselves as independent adults.
Spotlight: David

Finding a new pathway in Transition

David is the oldest of three children. Both he and his younger sister Minka were born with the inherited condition Sickle Cell Anaemia and it’s been a constant worry for their Mum Dorothy – a recently widowed nurse, who works nights at the local hospital.

“I may be a qualified nurse but when it’s your children, you’re their Mum and it’s so scary”

Her son David is a charming, thoughtful 18-year old, currently in his first year at university studying computer technology. Having lived with Sickle Cell Anaemia since birth, David recently made the transition from child to adult healthcare services.

“I’d had the same doctors and nurses that I’d known since birth and then suddenly I can’t access them...They helped me understand Sickle Cell Anaemia and helped me live with it; but then, because of my age, suddenly they’re not there anymore!”

That’s why the charity funded David’s Roald Dahl Transition Nurse, Giselle, to help develop a new transition pathway that makes the move less daunting and dangerous. Giselle is the Roald Dahl Transition Senior Clinical Nurse Specialist & Team Lead for Adult Haemoglobinopathies at King’s College Hospital NHS Foundation Trust, which serves the largest numbers of patients with sickle cell disease in the country.

“When you make the transition it’s like starting all over again at a new school - I don’t think I’d even have found the ward without Giselle and she’s been a lifeline for many teens younger than me, like my sister who’s 16. She’s also helped my Mum. One time, I had a “Crisis” and I was being bounced from adult ward to child ward and back again - in the end my Mum called Giselle and she just sorted it out!”
Offering targeted grants to help families living in financial hardship

Caring for a seriously ill child can take its toll on the entire family, not just emotionally, but also financially. In his lifetime, Roald Dahl gave generously to families in need and the charity continues this legacy today through our grants programme, helping those facing financial hardship while caring for a child with a serious illness. Marvellous Family Grants fund 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 2017/2018 grants totalling £75,425 were made under this programme.

Helping Evie-Jean Take Her First Steps

2 year old Evie-Jean has Noonans Syndrome, a rare disease which means she has physical, learning and communication difficulties. With funding from the Marvellous Family Grants Programme for therapy, she has been attending a specialist centre and can now do many sorting and rolling tasks, turn a wheel when singing ‘wheels on the bus’ and clap. Having learnt to walk with a walker, she took her first steps with little support. These may sound like small things, but to Evie-Jean and her Mum they are a massive achievement.

Evie-Jean’s Mum says the grant has been a great support. She says,

“From learning these new skills, she is a lot more confident and independent. It also helps us as parents feel like we are helping her in some way by providing the best possible opportunity for her. She has made many friends from attending this centre. I have found meeting other parents in a similar situation to us is priceless. Finding something she enjoys has been so satisfying, as she is usually such an unhappy little girl. We have learnt many new ways of helping her, and for that we are forever grateful.”
Evie-Jean takes her first few steps thanks to a Marvellous Family Grant.
Spotlight: A Family Perspective

Expert care for Maddison and her family

Maddison is a 4-year-old with chronic epilepsy and partial-sight. When she was eleven months old, her family learned she'd had a massive stroke when she was born. Two months later she had her first seizure. Mum Kerry never knows when something might happen, which also has a major impact on her other daughter Amelia, who doesn’t understand her sister’s condition.

Roald Dahl Nurse Paediatric Epilepsy/Neurology Nurse Specialist Emily Bell, works at Dartford and Gravesham NHS Trust. She supports children and families like Maddison, Amelia and their Mum. Emily works in the heart of the community, providing training and support to help families manage their child’s condition. She also runs clinics and visits schools to raise awareness of epilepsy and neurological conditions with other children and young people.

“Before Emily, I had a lot of family around me, but I had no-one I could talk to who really understood how I feel. She’s always at the end of the phone. Emily has been my lifeline. I honestly don’t know what I’d do without her!”

Spotlight: A Clinical Perspective

Jennifer Anderson, Roald Dahl Paediatric Neurodisability Nurse and Dr Claire Lundy, Royal Belfast Hospital for Sick Children

Roald Dahl Nurse Jennifer

For many years, Jennifer was the sole Paediatric Neurology Nurse Specialist in the province and in 2017 she joined the recently-established Neurodisability team, becoming the first Roald Dahl Specialist Nurse in Northern Ireland, with an active caseload of about 450 at any one time.

Jennifer’s role has focused on four main areas: pre-assessments of new patients and ongoing medication reviews, including medicine for pain management; family support and guidance, including liaison with community nursing services in Northern Ireland and other centres in England; leading on quality improvement and health promotion; and education and training for both families and local health and social care professionals.

Dr Claire Lundy

The service that Dr Lundy set up supports an estimated 1,000 plus children in Northern Ireland with serious neurological conditions such as complicated movement disorders, severe cerebral palsy and brain and spinal injuries. She initially managed to secure funds for physiotherapy and occupational therapy roles, but a small pilot highlighted the immense value a specialist nursing post could bring to the service. So when Dr Lundy heard about the charity, she applied for funding and now feels totally vindicated by Jennifer’s contribution to the team.

“Jennifer leaves us in awe sometimes. She’s a steady hand and a great support to us all. The team has gone from strength to strength. And as a sole practitioner, my peer group is in London, so having a colleague to support me from a medical perspective is fantastic. Plus, our families are astute enough to know what she’s capable of, which frees me up for other clinical commitments.”
Spotlight: Urte and her Family

Urte’s rehabilitation

Urte is 7 years old. Several months ago, she tripped and fell down the stairs at home – resulting in an acquired brain injury that has also left her weak down one side. It was every parent’s nightmare and the impact is visible on her mother Girda’s face as she reflects on the last few months.

“It was a life-threatening injury and for a time we didn’t know if she would pull through.”

Thankfully she did and following a period of intensive care, she is now receiving neurorehabilitation before she can be discharged home. Roald Dahl Nurse Jennifer’s role, in this post-acute stage, is to help to co-ordinate Urte’s care both in hospital and following her discharge, when she will continue to attend neurodisability clinics as an outpatient.

Working closely with Dr Lundy, Jennifer ensures Urte has the best possible healthcare package to support her and her family over the long term as they make the transition back in to the community.
Our impact

Our dedicated team of staff, Roald Dahl Nurses and all who have supported Roald Dahl’s Marvellous Children’s Charity have contributed towards our work in 2017/18. It is with the help and commitment of all these parties that we can have a tremendous impact on the lives of seriously ill children, young people and their families.

Here is the year in numbers:

- **Over 18,000** children & young people supported at any one time
- **59** Roald Dahl Nurses
- **2** Occupational Therapists
- **39** Partnerships with NHS trusts
- **142** families helped through Marvellous Family Grants
- **£75,000** in funds available to support families in financial hardship
- **1** Play Specialist with plans for more
An economic assessment of a Roald Dahl Children’s Epilepsy Nurse Specialist role

In 2017, we teamed up with the Royal College of Nursing to provide Roald Dahl Nurses with training to help them demonstrate the benefits of their service for the children and families in their care, the healthcare sector, and the wider community. Kirsten Johnson is a Roald Dahl Sapphire Epilepsy Nurse Specialist at Sherwood Forest Hospitals NHS Trust and she undertook an economic assessment of her role as a children’s epilepsy nurse specialist.

Epilepsy in children can be distressing for children and for their parents so NICE (National Institute for Health and Care Excellence) recommends that children, young people and their families have access to specialist nursing support. The ability to contact a specialist nurse at the point of need improves the management of the condition and service user’s satisfaction; it can significantly improve the well-being of the child, reduce parental stress and avoid the use of other parts of the healthcare system, including acute services.

However, prior to Kirsten’s economic assessment, little was known of the economic benefits of a Clinical Nurse Specialist-led service other than these quality benefits. Through rigorous analysis of her records, Kirsten demonstrated that just one aspect of her service - her telephone and advice line - has saved £84,778 in costs for her trust in just one year. This feature of her service has also contributed to her trust meeting its 18-week waiting time target. Her analysis clearly demonstrated why the advice line should be incorporated into the service tariff to increase her trust’s income and enable further service development.

“As a Roald Dahl Sapphire Epilepsy Nurse Specialist the partnership between myself and the children, young people, parents and carers enables me to recognise the benefits of the service provided. This is demonstrated by improved health outcomes, reduced use of acute services, increased participation and customer satisfaction. Presenting these benefits to persuade further investment allowing the service to further develop and improve without compelling evidence of their economic value is a challenge.”
Fundraising

Our relationship with our supporters – funders and partners, volunteers and advocates – is fundamental to our continued success. We are immensely grateful to everyone who contributed in 2017-18, including:

- Alleyn’s Junior School
- Ambassadors Theatre Group
- Bax and Bay
- BGC Partners
- The Big Feastival
- Busy Bees
- Buxted Construction Ltd
- Miss Daisy’s Nursery
- David Austin Roses
- The Dragon Sale
- Edgewell UK
- Explore Learning
- The Grant Foundation
- Jack & Jill School
- NSB Trust
- JELF Group
- Money
- The Wixamtree Trust

And many other generous individuals, fundraisers, and community groups.

“A big thank you”
FINANCIAL SUMMARY
Our Marvellous Numbers

Income 2017/18: £1,195,540

- Investments: 4%
- Donations and gifts: 50%
- Fundraising activities: 40%

Expenditure: £1,724,515*

- Marketing
- Overheads
- Fundraising
- Marvellous Family Grants Programme: 6%
- Roald Dahl Nurses Programme: 70%
- Governance

*Expenditure exceeded income during 2017/18 as part of a planned reduction to the charity’s reserves. The majority of the increase in expenditure benefits the Roald Dahl Nurses Programme. For further financial information, the charity’s full annual report and audited accounts are available from the charity commission website.
Looking Ahead

Roald Dahl’s Marvellous Children’s Charity is firmly rooted in Roald Dahl’s legacy as a philanthropist who had a keen and personal interest in supporting sick children and their families. As we look ahead, the pressures on the health service are growing daily and it is increasingly difficult for NHS Trusts and Clinical Commissioning Groups to fund new, specialist posts – even where they are desperately needed. The strain on budgets also means there is limited resource available for professional development.

Our aim is to address this gap in care by pump-priming new roles, funding new initiatives and demonstrating their value in terms of impact and savings. Over the next 12 months we plan to:

• Fund a minimum of five new posts, based in areas of greatest need
• Establish a fresh evaluation process for all new Roald Dahl healthcare specialists
• Introduce a new professional development programme
• Carry out a review of our family grants programme
• Work in partnership with our existing team of healthcare professionals to raise the profile of specific diseases and generate innovative ideas for improving care

In order to support this activity, we will continue to focus on building a wider national profile and to engage proactively with health professionals, families, companies, grant giving bodies and the general public in all parts of the UK.

Who’s who

Royal Patron
Her Royal Highness The Duchess of Cornwall

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Maddie and Theo Dahl
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