



Annual Review

April 2020 to March 2021





“

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

”

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.

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.

Presidents

Felicity Dahl
Sir Quentin Blake

Royal Patron

Her Royal Highness The Duchess of Cornwall

Patrons

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

Trustees and Directors

Donald Sturrock (Chair)
Jodi Betts
Ben Grist
Rob Halkyard
Alex Hyde-Parker
Michelle Johnson
Niels Kirk
Robert Paul
Nick Warr
Rachelle Broadley (joined 3 December 2020)
Graham Faulkner (retired March 2021)

Ambassadors

Dr Night Arif
Martin Goodwin
Rick Oakley

A welcome from our Chair of Trustees, Donald Sturrock

This has been a difficult time for everyone, but especially so for the seriously ill children we support and the Roald Dahl Specialist Nurses that care for them. Yet I am pleased to report that the charity staff team, trustees, volunteers, supporters and, above all, our nurses pulled together to ensure that our vital work was not affected and indeed went from strength to strength. I am very proud of them all.

As a result of the pandemic, many of the seriously ill children in the care of our Roald Dahl Nurses had to shield at home and were therefore unable to access crucial hospital medical treatment. The charity responded by setting up an emergency Covid fund to support families with urgent medical equipment to be used at home, while our nurses responded by creating innovative ways to support their children and families in this difficult period. The charity also created a financial support line for families in the care of Roald Dahl Nurses to access benefits advice and other practical help. As the financial impact of the pandemic unfolds, the charity believes this will continue to be a vital resource.

It has been a stressful year for many charities. We have been fortunate that our supporters have stood by us in this testing period and the charity's beneficiaries have not suffered. I would like to record a special note of appreciation to Graham Faulkner, who retired as a Trustee this year. Graham has been involved with the charity for nine years as Trustee and most recently as Deputy Chair. He has been a wise, thoughtful and vital ingredient in whatever successes we may have had during this time and his experience and good judgement have been a massive help to me personally in my time as Board Chair. He will be hard to replace. I would also like to note the departure of our Head of Programmes, Sophie Dziwinski, who in one way or another has worked for the organisation for almost twenty-five years. Roald Dahl Nurses, past and present, will I am sure treasure their memories of Sophie's passionate

and seemingly boundless energy in support of them. We are greatly indebted to her. She too will be a difficult act to follow.

On behalf of the trustees, I would like to thank all the charity's supporters, who had helped us through these tough times. There are now so many of them that it is probably invidious to single out individuals. Nevertheless I would like to mention Dame Julie Walters, Claudia Winkleman and David Walliams who all gave up their valuable time to help us. I would also like to thank our Royal Patron, HRH The Duchess of Cornwall, whose continued support is so immensely valuable. She has made a huge personal impact on those children, families and nurses she has met this year.

Finally, we are indebted as ever to our two marvellous Presidents, both of whom are now in their ninth decades. Our founder Licky Dahl and Sir Quentin Blake continue to startle us with their imaginative vision and generosity. Last winter, for example, in the middle of lockdown, Quentin donated several of his paintings to us. These were auctioned at Christies in London by another of our wonderful patrons, Joanna Lumley. Joanna brought her distinctive glamour, wit and sense of fun to the auctioneer's rostrum and wielded her gavel to memorable effect. The auction raised over £25,000 and provided a welcome ray of light in the pandemic gloom. I hope the coming year will be full of more of such moments and I am confident that the charity is in good shape to handle whatever challenges the coming year may throw at it.



Donald Sturrock



Roald Dahl Specialist Nurses

Roald Dahl Specialist Nurses are a vital lifeline to the children and their families, supporting them clinically and emotionally. They co-ordinate care and are often there for them until adulthood. Although Roald Dahl Nurses operate across a number of different specialisms, they are all specialist nurses who make a huge difference to children and families.



Nurse Development

Nurse Development is key to a Roald Dahl Nurse improving the care and support they give. We work with our 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 network. We also work with our nurses on leadership and service improvement, making them incredibly valuable to their services.



Nurse Led Innovation

We support Roald Dahl Nurses to solve problems creatively. Using a cohort approach, and through forming partnerships we work closely with our nurses to improve healthcare outcomes for children through innovation.



Marvellous Family Support Service

Our Marvellous Family Support Service helps families to access their benefit entitlements. This support service helps families to overcome financial worries, helping to relieve some of their stress and anxiety.

2021 is our 30th year

Here are some important milestones in our 30 years of helping seriously ill children lead more marvellous lives.



1992

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



The First Roald Dahl Nursing Conference took place

The charity now holds a conference for its nurses
every two years

2004



2014

The Marvellous Inventing Room

is launched in partnership with the Burdett Trust for
Nursing to promote nurse led innovation

Launch of the Marvellous Family Support Service

A free helpline service that allows families of seriously ill
children to access expert one-to-one benefits advice

2021



A word from our Chief Executive, Louise Grieve

Our charity has risen to the incredible challenges presented to it by the Covid-19 pandemic and I am really proud of everyone involved, particularly the executive team. We agilely moved to working digitally, created new fundraising partnerships, launched an emergency fund for our nurses' patients and continued to establish and support new specialist nurses posts in the NHS (creating 3 new posts this year). Roald Dahl Specialist Nurses are more important than ever to the children and families they help and care for. One key role our nurses play is to coordinate the care the children receive when they may have multiple doctors, nurses and therapists to deal with because of the complexity of the care they need. This need has been heightened during Covid with our nurses playing a vital role to take the pressure and burden off the parents and families. The fact that the nurses are 'beacons of light' in a families 'darkest hour' could not have been truer this year.

The year would not have been as successful without the tireless and combined efforts of our whole team, our Board of Trustees and of course supporters like you, so a huge thank you from us all.

Our Specialist Nursing programme is at the heart of what we do and everything we achieve is by working with NHS Trusts, who respect our track record of innovation and improving UK paediatric nursing, through an integrated model of 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 service, which is often a frightening and challenging time of uncertainty for the young person. The NHS has identified this as an area that needs vast improvement across the UK.

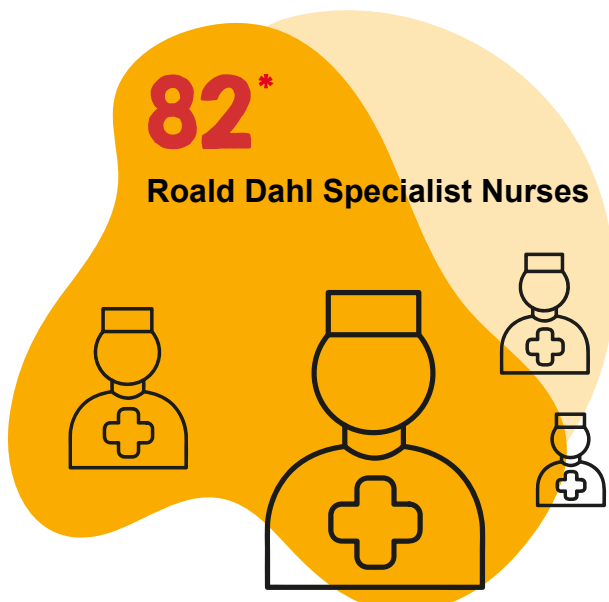
I would like to thank everyone who currently makes our work possible – including our marvellous dedicated and caring team of Roald Dahl Specialist Nurses and the NHS Trusts they work for, charity staff, Royal Patron, presidents, patrons, ambassadors and volunteers.

We remain hugely grateful to the Roald Dahl Story Company for providing their generous support which helps cover our core running costs whilst also providing their expertise and skills to increase the capacity of the charity. This means in turn that every other donation we raise can go directly to supporting our beneficiaries. We also want to thank all our valued ambassadors and supporters for their generosity and those who have given their time and support for us over the year – it is really appreciated.

The future is exciting as we look to support more seriously ill children and young people than ever before. You will see demonstrated, many times over, in this annual review, how impactful our work is and how important it is that we continue to push forward and grow what we do. With your help, we can do that, and I am really looking forward to go on the journey together.



Number of Roald Dahl Specialist Nurses around the UK



* Includes 1 play specialist and 2 occupational therapists.

Number of serious ill children supported by Roald Dahl's Marvellous Children's Charity



** estimate

The Impact of Roald Dahl Specialist Nurses

Roald Dahl Specialist Nurses are experts in their field, specially trained and dedicated to a group of individual patients. They work within the NHS in fields such as epilepsy, brain injuries, Sickle Cell Disease and Rare Diseases.

While the specialties of our Roald Dahl Nurses appear to be extremely diverse, the common thread is that the children and young people looked after by these nurses are all living with complex lifelong conditions that are under-funded, under-resourced and under-recognised. These conditions include progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe disability.

Children and young people under the care of Roald Dahl Specialist nurses:

27.9% Require round the clock care

29.9% Attend a school catering for special educational needs

Many of these children and young people have very complex conditions exhibiting multiple organ system disorders; consequently, they are under the care of several different consultants, often associated with different NHS Trusts and healthcare organisations.

Ultimately, our experienced 82 Roald Dahl Specialist Nurses are a vital lifeline for over 24,000 seriously ill children and young people as well as their families. They are also an invaluable asset for the NHS Trusts and Health Boards where they work, the medical teams and the community at large.

The role of Roald Dahl Specialist Nurses is unique and goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for their young patients

The co-ordination of their care is highly complex and often exhausting for the parents, with many patients also having significant additional needs beyond healthcare for example in education, social services and housing.

Roald Dahl Specialist Nurses are a consistent presence in the child's life from initial diagnosis through to the child's transition to adult services. They advise, they reassure, and they become "part of the family." Their specialist training allows them to co-ordinate complex care needs, reducing hospital visits for child and family. They act as an advocate for child and family within the health-care system and can facilitate urgent hospital care if required. They educate both the family, other health professionals and school about their patient's condition. They connect patient and families to other families with similar conditions. They help ensure that the children in their care receive benefits to which they are entitled.

Our child is currently under 24 teams between several Trusts

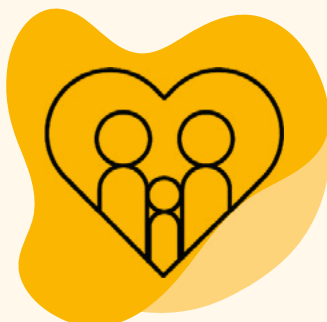
and their families. This role is not easy to step into and fill and Roald Dahl Specialist Nurses require a particular skill set and set of attributes beyond their clinical expertise to equip them for this role.

Roald Dahl Specialist Nurses exhibit a high degree of insight into their role beyond the clinical care that they provide including passion, empathy, motivation and 'a willingness to go the extra mile'.

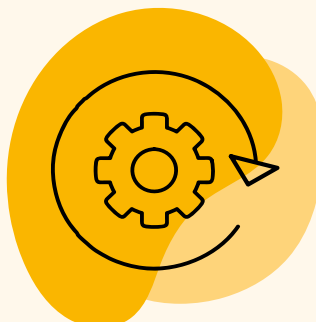
Roald Dahl Specialist Nurses' four impact areas



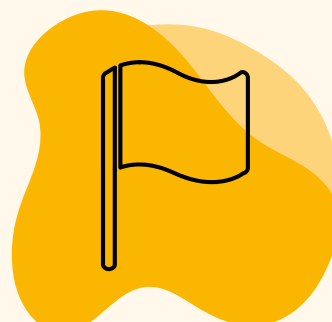
Quality and experience of care



Holistic family-centered care



Efficiencies and cost-effectiveness



Leadership and innovation

Reduction



- Consultant appointments
- Emergency visits to A&E
- An urgent visit to GPs
- Admission to hospital
- Pressure and burden on consultants
- Patients and families levels of stress, anxiety and isolation

Improved



- Quality of care
- Accessibility of care and support
- Experience of care
- Patient satisfaction
- Patients safety
- Condition's management
- Patient's confidence to cope with and manage their conditions
- Patient's knowledge and understanding of their conditions and treatment options
- Compliance with treatment
- Support when transitioning from Children's services to adult services
- Holistic support
- Coordination of care
- Access to services beyond healthcare (E.g. counseling, sibling support, housing, benefits, etc)
- Effectiveness and efficiency



Result

Better health outcomes and quality of life for seriously ill children and young people

Seriously ill children and young people lead a more Marvellous life

Parents have described the profound impact a Roald Dahl Nurse has had on their family

great
professional
helpful beyond and above
support **a 'fixer!'**
invaluable
utterly vital
friendly face **reliable** **inspirational**
efficient **caring** best support
welcome
amazing
understanding

Sheffield Hallam University (SHU) has recently evidenced the highly valued role and profound positive impact of Roald Dahl Specialist Nurses. The findings of SHU's research support the future establishment of further Roald Dahl Specialist Nurses across the UK. To find out more about the impact of our Roald Dahl Specialist Nurses, please [click here](#).

Meet our new Roald Dahl Specialist Nurses



Bethan

Roald Dahl Transition Specialist Nurse Lewisham and Greenwich NHS Trust

Bethan started in post at Lewisham and Greenwich NHS Trust in February 2020 and is the first Roald Dahl Transition Specialist Nurse post at the Trust. Bethan will review current processes for transitioning children to adult services and implement a new and improved transition process for young people.

Transition is all about preparing young people for adulthood by empowering them and ensuring they have the correct knowledge and skills to help them live their life to the fullest potential despite their complex conditions. Bethan will work closely with the multi-disciplinary team within all specialities to improve Transition Service.

Bethan says 'I hope to ensure that no families have a poor experience in the future and that young people with serious, complex conditions feel fully prepared for adulthood.'

Lisa

Roald Dahl Neuromuscular Transition Specialist Nurse Leeds Teaching Hospitals NHS Trust

Lisa started in post April 2020 at Leeds Teaching Hospitals NHS Trust. Lisa supports up to 100 young people aged 12-25 from across West and North Yorkshire and the Humber with serious neuromuscular conditions, such as Duchenne Muscular Dystrophy and Spinal Muscular Atrophy.

The children and young people Lisa cares for are often in a lot of pain, experience extreme fatigue and have difficulties walking. Lisa is here to make life less scary for them and easier to navigate for their families, by providing dedicated support.

Lisa says "My role provides young people and their families with a go to person who can help fill the space between paediatric and adult services, ensuring young people do not slip through the net. The role will empower patients, maximising their potential and living a more marvellous life!"



Natalia

Roald Dahl Transition Specialist Nurse East London NHS Foundation Trust

Natalia started her post with the East London NHS Foundation Trust in March 2021. Natalia will be solely focussed on helping young people with epilepsy, sickle cell anaemia and other life-long health conditions 'transition' from children's to adult health and social care services, while also dealing with the challenges of becoming a young adult.

Natalia said: "From speaking to many parents/carers, the fear of their young person moving into adult services is almost crippling for them. Through my role, I hope to reduce that fear and anxiety by preparing the families for transition. Working with professionals to start thinking about transition earlier, to start having those conversations and to think about how we can all work better together with adult services to prepare these young people and their parents/carers for adulthood."

As part of our ongoing strategy to improve the care for young people with serious lifelong illnesses, we are establishing two new much needed transition nurse posts in 2021 in Manchester and East Sussex.



Location of our Roald Dahl Nursing Posts

Our 82 Roald Dahl Specialist Nurses are based throughout England, Wales, Scotland and Northern Ireland and support over 24,000 seriously ill children and young people living in every corner of the UK.

There should be more Roald Dahl Nurses employed, they make a big difference to people's lives.

Inverness

2 Epilepsy nurses

Aberdeen

Epilepsy nurse

Belfast

Neurological/Head Injury nurse

Dundee

Glasgow

Edinburgh

Newcastle

Leeds

1 Epilepsy and
2 Neuromuscular nurses

Liverpool

4 nurses, including a
Haematology nurse

Preston

Bolton

Bradford

Manchester

Sutton in
Ashfield

Cambridge

3 nurses, including a
Neuromuscular nurse

Telford

Nottingham

Birmingham

4 Rare Diseases nurses

Swansea

Oxford

Tring

Luton

Billerica

Basildon

Newport

4 Epilepsy nurses

Cardiff

Chertsey

Guildford

Portsmouth

Poole

Brighton

Hastings

Southampton

4 nurses including a
Neurological/Head Injury nurse

London Area

17 nurses including a
SWAN (Syndrome Without
A Name) nurse

They do an amazing job from all aspects...more need to be employed as they make big differences.

Henry's Story



Henry has an extremely rare, inherited blood condition, Diamond-Blackfan Anemia (DBA) and is cared for by his Roald Dahl Specialist Nurse Clare. We spoke with Henry's Mum, Zoe about the difference their Roald Dahl Nurse has made.

When Henry was four months old, he was referred from our local hospital in Colchester to Addenbrookes in Cambridge, which is where our Roald Dahl Specialist Nurse, Clare is based. Henry had a bone biopsy and it came back that he had the extremely rare, inherited blood condition, Diamond-Blackfan Anemia (DBA), which affects the ability of the bone marrow to produce red blood cells.

Henry absolutely loves his Roald Dahl Nurse Clare! Despite all of the horrid things that happen to him, he loves going to hospital and seeing Clare. His face lights up when he sees

Clare and that's really lovely. It's so important – I couldn't wish for better care. I would find it difficult taking him to hospital if he didn't have such a good relationship with Clare and the team.

Whatever I need and whenever I need it, I can phone our Roald Dahl Nurse, and she'll get it done. Knowing she is there and is our person of contact is like having someone as a security blanket. She is always there, and she always knows the answer.

Henry has to go to a number of different hospitals and specialist teams. Having to work with all of the different teams was a nightmare before we had Clare. She will pull everything together and book all his appointments under one roof.

We'd just be completely lost without our Roald Dahl Nurse. She's our person and we go to her when we need anything. I don't know what we would do without her. She's an instrumental part of our hospital lives.

Having a Roald Dahl Specialist Nurse to guide us through all of it, stand with us and fight for what we need is amazing. I don't know what we'd do without her.

Dáire's Story



Dáire is supported by Roald Dahl Nurse Jennifer. His mum told us: In 2010 when Dáire was two 2 years old he suddenly became very unwell and we rushed him to our local hospital in Bristol. A scan showed he had a lot of pressure on his brain due to a malignant brain tumour, which was removed during a long 12 to 14-hour operation. A few months later we travelled to Jacksonville in Florida so Dáire could receive special proton beam radiotherapy. Throughout this time he had to relearn to sit upright, walk and talk.

In August 2016, Dáire suffered a devastating stroke. He lost all the function on the left side of his body. He also had difficulty in hearing, speaking and swallowing. In 2017 Dáire met his Roald Dahl Specialist Nurse, Jennifer. At this point, it was difficult for Dáire to engage with therapy given his frustration with his condition and being on steroids. They introduced lots of different ways to engage

Dáire by using techniques such as magic therapy. They really understood that he was a child who experienced lots of medical interventions and had become weary of them. They engaged him in a way that was acceptable to Dáire, which was so important as his rehabilitation was a slow process taking place over two years with long stretches of time in hospital.

Our Roald Dahl Nurse, Jennifer has been a great support to us by turning Dáire's mundane rehabilitation therapy and many appointments into a positive experience.

It's important for healthcare professionals like Jennifer to delegate aspects of the recovery to the parents and the child. They take a situation and make positive steps for parents to be able to manage their child's situation confidently. It's important that Dáire is confident and needs to own his rehabilitation and Jennifer has given him a great start in preparing him for all these interventions.

Roald Dahl Nurses have a positive psychological and emotional impact on the child and family's mental health. When a child experiences a traumatic event, if they don't engage, there will be no rehab and no progress, and ultimately a demotivated unhappy child. Jennifer and the team motivated him in a way that I will be forever grateful.

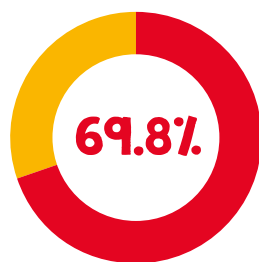
To find out more about the children and young people we support, please [click here](#).

Professional Development

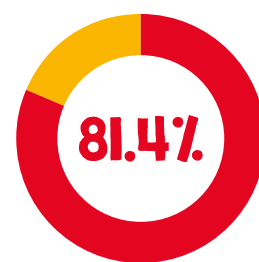
Roald Dahl Specialist Nurses operate at an advanced level - delivering high levels of clinical reasoning, decision making and critical analysis - which require a particular set of skills and core attributes. It is therefore necessary that Roald Dahl's Marvellous Children's Charity continues to support the training, education and continuing professional development of these nurses. In a recent survey of Roald Dahl Nurses:



of nurses educate, train, lead and/or inspire other professionals - e.g. teachers, other nurses, play specialists, community practitioners



of nurses have mentored another healthcare professional



of our nurses have delivered teaching, training or educational programme/session to other healthcare professionals

Florence Nightingale Foundation Leadership Programme.

Twenty Roald Dahl Specialist Nurses based at NHS Trusts in England were selected to take part in the highly regarded Florence Nightingale Foundation Leadership Programme between October 2020 to March 2021, thanks to funding support by Health Education England. The Florence Nightingale leadership development programmes create opportunities for nurses to explore and discover their own leadership style and develop the essential skills to be courageous and confident leaders.

Liz Fenton, Deputy Chief Nurse, Health Education England says: "Health Education England were delighted to be able to support the development of this cohort of Roald Dahl's Marvellous Children's Nurses as leaders.

I'm confident that their learning and development will not only benefit the nurses themselves, which it undoubtedly will, but will also have a positive impact on their teams and importantly on the children and families they care for."

All nurses on the programme completed quality improvement projects which focused on demonstrating the value and/or impact of the nurse's role and the service they provide to the children and families in their care.

The Florence Nightingale Foundation Leadership Programme will culminate in a celebration day, where the nurses will present their quality improvement projects and celebrate becoming Florence Nightingale Foundation alumni.

Feedback from the programme

“Amazing experience which has helped me develop as a leader”

“I feel the Florence Nightingale Leadership Programme has provided an outstanding level of support and opportunities to achieve the best from myself and others in my workplace and home life”

Roald Dahl Specialist Nurse wins prestigious Royal College of Nursing Award (RCNi)

Roald Dahl Specialist Nurse Giselle specialises in the transition of care and support young people with sickle cell anaemia and thalassaemia as they move from children's to adult services at King's College Hospital London.

In 2020 Giselle was nominated for and won the Child Health Award at the prestigious Royal College of Nursing Institute Awards. These awards celebrate the best in nursing across the UK, from innovative projects to inspiring examples of patient care.

RCN Chief Executive, Dame Professor Donna Kinnair congratulated Giselle and praised her for "not only helping young people with Sickle Cell navigate the journey from child to adult services but also using her model to improve other services."



Nurse Led Innovation

Nurse led innovation is an important part of improving the quality and experience of health care. we work closely with our Roald Dahl Specialist Nurses to encourage creativity in problem solving and to ensure that there is space to bring ideas into reality.

One project involved us working in partnership with Royal Holloway University and Story Futures. Nurses, young people, and other stakeholders were involved in an exciting innovation process that led to a prototype being created. Dragon Legends is an Augmented Reality (AR) card game capable of supporting seriously ill young people adjusting to, and communicating with their carers and nurses about, the movement from children's to adult services.

This challenge was rooted in the need to help young people (aged 13 to 16) and their families addressing the anxieties and concerns they face around transition of care, so they fully engage with their illness and it's likely impact on their lives as they move into the adult world. This Research & Development was informed by a multidisciplinary team spanning clinical psychology, interactive writing and games design. Key to this was a

shared understanding of the young people at the heart of the project: that they were 'teenagers first, patients second'. Young patients are young people first and are negotiating all of the usual adolescent transitions whilst additionally adjusting to taking more responsibility for their health condition and adapting to changes in their caring system.

Teenagers can feel overwhelmed by the complexity, enormity and impact of their health conditions alongside the everyday challenges of growing up and becoming an adult that every young person faces such as school/college/further education, the world of work, drugs, sexuality and sexual health. The additional worries around the COVID-19 pandemic have heightened young people's anxieties and so the need for open discussion for young people with complex lifelong conditions is even more important in helping to empower them to live the most marvellous life they can.

Whilst this project is still ongoing, our nurse led innovation remains a key part of improving the experience of care that children and young people have, and we will continue to develop innovation projects over the coming years.



Marvellous Family Support Service

Families with seriously ill children often are not able to access the financial support and benefits they are entitled to. These funds are vital in helping them overcome the unique life challenges that come with having a child with a complex, lifelong illness.

The consequences of financial hardship are far-reaching, impacting families' mental health and often leading to further ill health for their already seriously ill child. Roald Dahl Nurses help their families with the process of applying for financial support as much as they can, but it is extremely time-consuming.

These challenges were increased during COVID-19 and in response we have launched the pilot Marvellous Family Support Service, to provide one-to-one, practical support for families supported by Roald Dahl Nurses to apply for funding and where necessary help them appeal rejections.

One family who has faced financial anxiety is Harriot and her six-year-old son, Jacob. Jacob, who is supported by Roald Dahl Nurse, Stacey, has a rare and complex form of epilepsy and Harriot, who is separated from her partner, is struggling financially. She talked to us about the impact this is having on her and Jacob and how the Marvellous Family Support Service would help.

"Jacob (6) has been having seizures since he was one. Between the ages of one to three, he would have around 12 focal seizures a month plus three to four generalised seizures a month. We have just got back from a period in hospital as his case is so complex and he was having 30 - 60 seizures a day.

I don't get any maintenance support as Jacob's dad looks after him every other week. I am on Universal Credit as I recently got sacked from my last job because of Jacob's needs. I was constantly losing jobs here there

“

I've been in tears; I cry all the time. When Jacob goes to sleep, I sit there, and think is this it?

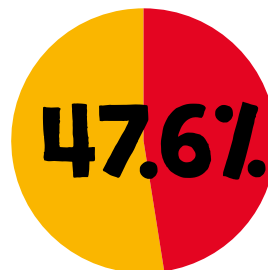
”

and everywhere no matter how I was trying to bring in money when he was unwell.

I haven't got money to take him anywhere. It makes me feel like a bad mother – I can't provide what he needs in his daily life – I've tried to apply for DLA, but I keep getting rejected, I have appealed the decision but not heard back. I feel like they don't understand how complex Jacob is without the extra support. We struggle all the time.

Before Jacob's Roald Dahl Nurse, Stacey told me that Roald Dahl's Marvellous Children's Charity was looking at helping parents like me with financial struggles, I felt like there was no one that understood. Just making sure the bills are paid and food is on the table would take a lot of stress off.

The pilot Marvellous Family Support Service will help families to identify which benefits they could be entitled to, support them with completing applications and appeals, support with grant applications for medical equipment and much more.



of the families supported by Roald Dahl Nurses experience financial hardship as a direct or indirect result of their children's conditions



Events and News

May 2020 - International Nurses' Day and launch of the Roald Dahl Nurses appeal.

On International Nurses' Day 12th May 2020 we launched the Roald Dahl Nurses appeal, to raise donations to enable Roald Dahl Specialist Nurses to continue their vital work and help seriously ill children lead a more marvellous life. The appeal was supported by charity Patrons, Claudia Winkleman and Julie Walters as well as David Walliams and Tony Robinson.



Roald Dahl Nurses and the seriously ill children they support were illuminated on the iconic Piccadilly Lights screen to celebrate International Nurses' Day 2020 and to the Roald Dahl Nurses Appeal.

Fundraising from this appeal provided urgently needed equipment to monitor seriously ill children at home during the pandemic and helped to establish more Roald Dahl Nurses across the UK.

April 2020 - Families, Roald Dahl Nurses and charity supporters take part in the 2.6 challenge in aid of Roald Dahl's Marvellous Children's Charity

A nationwide campaign, the 2.6 challenge launched in April 2020, after the cancellation of fundraising events including the London Marathon which was postponed due to COVID 19. The challenge encouraged people to take part in an activity of choice around the number 26 and fundraise for their charity of choice. Many of our Roald Dahl Nurses, supporters and the marvellous families supported by a Roald Dahl Nurse took part in the challenge, from building 26 Duplo pirate ships to tying 26 bowline knots and building a rocket out of 26 household items and raising over £10,000 for the charity.



September 2020 Charity appoints Dr Nighat Arif as Ambassador for the charity.

Dr Nighat Arif is a resident GP for BBC Breakfast and This morning. A family GP, Dr Arif is based locally to the charity's headquarters in Amersham, Buckinghamshire. Dr Arif is also a medical educator and provides teaching to local trainee GPs as well as at national conferences. She works as an outreach clinician, meeting with doctors, nurses, community teams and residents to discuss the unmet health needs for Pakistani communities who are less likely to engage with health professionals.

Commenting on her appointment as ambassador to the charity Dr Arif said "I am thrilled to become involved and support Roald Dahl's Marvellous Children's Charity and look forward to building the awareness of its work across the health sector, my colleagues and patients."

I know first-hand how important specialist nurses are to families dealing with a child who has a serious, lifelong illness and as a GP, specialist nurses are a godsend as they help take the pressure off everyone. It is a fantastic cause and I am truly delighted to get involved."

9th December 2020 Joanna Lumley OBE hosts a special auction at Christie's Auction House in aid of Roald Dahl's Marvellous Children's Charity.



The auctioned lots included one-of-a-kind illustrations and pieces designed by the charity's Co-President and world-renowned illustrator, Sir Quentin Blake. Highlights included two stunning stained-glass window panels featuring Willy Wonka, Charlie and the BFG.

Other lots in this unique auction included four original Sir Quentin illustrations of the charity's mascot, Marvin the Marvellous Crocodile, alongside a Roald Dahl Specialist Nurse and children in their care.

Marvin's Marvellous Club

Marvin's Marvellous Club

In January 2021 the charity launched Marvin's Marvellous Club, the exclusive digital club for children and siblings supported by a Roald Dahl Specialist Nurse. Marvin's Marvellous Club was launched to create a valuable community for children supported by a Roald Dahl Specialist Nurse.

Alongside fun activities and competitions the club will teach children about other Roald Dahl Nurses across the country, who are also caring for seriously ill children.

Working in partnership with Fun Kids the charity has created an exciting eight-page welcome magazine which includes fun activities, games, and competitions, plus information about the charity and the work of Roald Dahl Specialist Nurses.

Each month one member of the club will be selected at random to win a fantastic prize.

Thank you to the Roald Dahl Story Company and Yoto Player, who kindly donated prizes for these competitions.



Henry was thrilled, it actually arrived on a morning that we were due to head over to the hospital, so he took his magazine with him and read it while he was there. He can't read too well as yet so we double teamed it but he loved the hospital eye-spy game and really loved that he got his own membership card too. He's looking forward to the next one already?

Feedback from a member of Marvin's Marvellous Club



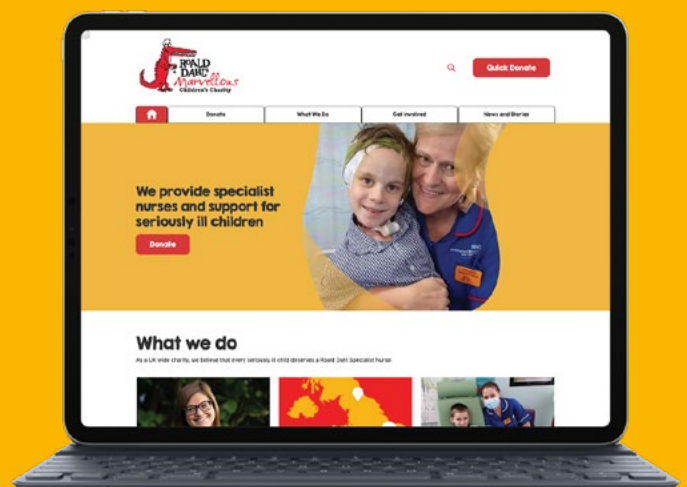
Digital Transformation

In January 2020 the charity began working with some incredible partners on the digital transform project to update the website and customer database. Thanks to Holograph Digital who are currently building and developing the website, which is due to launch in summer 2021.

The new charity website will be interactive and informative including information about the vital role of Roald Dahl Nurses, nurses' training and development and the charity's impact.

An interactive nurses' map will highlight where Roald Dahl Specialist Nurses are based across the UK and quick donate button will make it quicker and easier for supporters to donate.

As part of the charity's digital transformation, Beacon will be supporting with updating the CRM database. This will improve digital systems, safeguarding and the collection of personal data.



Visit our new website:
www.roalddahlcharity.org

We are so grateful to all of our fundraisers, below are just a few fundraisers from 2020 - 2021.

BGC Partner's Charity Day September 2020

This event takes place every year to commemorate BGC's 658 colleagues and the 61 Eurobrokers employees who lost their lives in the World Trade Center attacks in 2001.

Celebrities including David Walliams, Claudia Winkleman and Julie Walters took part in the BGC Partners' 16th annual Charity Day in September 2020 to help raise donations for charitable causes including Roald Dahl's Marvellous Children's Charity.

They join a star-studded lineup including Rod Stewart and Penny Lancaster, Stephen Fry, Jose Mourinho, Jodie Comer, Holly Willoughby, Davina McCall, Jason Mount, Sir Mervyn King and Cherie Blair.

Newton Investment Management's virtual Round-The-World-Challenge

A round-the-virtual-world trip which involved colleagues from Newton Investment Management (Newton) running, swimming, yoga-posing and even shimmying between their global offices, raised a marvellous £10,000 for our charity.

248 international colleagues from the team at Newton collectively covered 20,000 miles in a virtual race starting in New York and going via London, Pune, Hong Kong and back to New York.

Colleagues clocked up mileage for the trip by walking, running, cycling, doing home workout sessions, swimming and even snow-shoeing.

Logan's Charity Football Match

Logan is under the care of Roald Dahl Rare Disease Specialist Nurse, Sarah at Birmingham Children's Hospital.

Logan's family took part in the 2.6 challenge earlier in the year to raise money for the charity and Sophie, Logan's mum wanted to do more, saying "without Sarah and her team, we would be lost.

The charity football match took place on a very wet and rainy Saturday in October 2020, but spirits were high with each player from each team donating to take part. The family raised an incredible £2,610.



Roald Dahl Specialist Nurses say thank you

"Many thanks The funding enables children and young people and their families to have access to specialist care and support in managing their diagnosis. This is a Marvellous contribution and a valuable resource and helps to improve health outcomes across many serious conditions."

Karen

"Please continue, without your support, the nursing posts would be lost over time and the care and support the children receive would be a major loss"

Linda

"Thank you so much for all your support and donations without your kind generosity we would not be where we are today."

Lisa

"Supporting a charity who work tirelessly for patients suffer long term medical condition. Your work is greatly appreciated"

Elizabeth

"A huge thank you! Without your support, I would not be able to help empower young people to live a marvellous life, of their choosing, WITH their health condition and not feel limited, restricted or different BECAUSE of it."

Bethan

Our finances 2020/2021

Whilst it was an incredibly challenging year for everybody, we were able to increase our income, and gifts in kind. We have also been able to maintain our levels of charitable spend for the third year in a row.

As the population of children and young people living with serious illness continues to grow, there is a greater need than ever before for us to continue to provide specialist nurses and support. We are grateful to all of our partners across the charity, including NHS Trusts and Health Boards, funders and other supporters for working with us to ensure the stability and growth of the charity.

Because we ran at a surplus in 2020/21 this has enabled our reserves to remain in the 6-8 months running costs bracket, which is our policy. During the turbulent times

of this pandemic period, Trustees feel that ensuring our reserves remain at this level, it gives us stability to ensure that we can continue to deliver our programmes, and meet our fundraising and communications targets.

£1,423,449
income generated

£1,221,868
total expenditure

Thank yous

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 2020-21. A special thank you as always to the Roald Dahl Story Company whose partnership we treasure. We would like to thank the companies, and trusts and foundations who have supported us throughout the year.

A big thank you also goes to:

- Alison Hillman Charitable Trust
- AMC Networks
- Assura Community Fund
- Auntie Anne's
- Barnett Waddingham
- Barratt Developments PLC Charitable Foundation
- BGC Partners
- Bridgepoint Charitable Trust
- Britford Bridge Trust
- Buxted Construction
- Card Factory Foundation
- Charities Aid Foundation
- Childwick Trust
- Clara E Burgess Charity
- Coutts
- Cytiva
- David Family Foundation
- Dixon Wilson
- DontSendMeACard
- E B M Charitable Trust
- Explore Learning
- Florence Nightingale Foundation
- Garfield Weston Foundation
- Holograph Ltd
- Jack O'Donnell Foundation
- John Laing Charitable Trust
- Landsec
- LifeSearch
- London & Capital and the Daniel Freedman Foundation
- London Freemasons Charity
- Newton Investment Management
- Novartis
- Pantheon Charitable Trust
- Royal Holloway, University of London
- Sheffield Hallam University
- Sphere Digital Recruitment
- St James's Place Charitable Foundation
- Talbot Village Trust
- The City Bridge Trust
- The Hospital Saturday Fund
- The LEGO Foundation
- The Medicash Foundation
- UCB
- Valentine Charitable Trust
- Webb Family Charitable Trust

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.

We have been able to prove the value of specialist nursing through an impact evaluation study conducted by Sheffield Hallam University. This has formed the cornerstone of our future work. We now have a very clear pathway to achieving our goals.

The Coronavirus pandemic continues to change 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.

Our strategic focus will turn to epilepsy as this has been identified as a strong need both by NHS Trusts and Health Boards, and national studies like Epilepsy 12. The establishment of new epilepsy nurse specialists will be the cornerstone of our programmes work, but we will also continue to support the financial wellbeing of families and will be looking at further support around the mental health of children and young people.



I feel incredibly privileged to be a Roald Dahl Nurse.

I know the difference that Clinical Nurse Specialist make. We are the professionals that go on a journey with Children, young people and their families, and have the opportunity to support them, advocate for them and care for them. We are often pivotal to improving and shaping services. Roald Dahl Nurses make an incredible difference to the quality and experience of care for a child, young person and their family.

More Roald Dahl Nurses are needed so even more children and young people who are seriously ill can be supported on their journey too.

Roald Dahl Specialist Nurse Stacey



How to get involved and support us

A huge thank you to everyone who has been involved over the last year. In the toughest of years our supporters have been incredible. Thank you.

If you would like to get involved there are many ways to do that. All are featured on our website at www.roadddahlcharity.org or contact us on fundraising@roadddahlcharity.org for more information. Add these dates to your calendar:

Free Wills month March 2022

Our supporters can access our free Wills scheme online, and once you've looked after your family and friends, consider leaving a gift to support children.



International Nurses' Day 12 May 2022

We will be celebrating our incredible Roald Dahl Nurses with fundraising activities to ensure we can establish more nursing posts.



Roald Dahl Story Day 13 September 2022

Get your school or work place involved in Roald Dahl based fundraising activities.



TCS London Marathon 2 October 2022

Take part in the world's greatest marathon by running the iconic 26.2 mile course and raising vital funds.



Every seriously ill child deserves a Roald Dahl Nurse



17 Chiltern Business Centre, 63-65 Woodside Road, Amersham, HP6 6AA
Email: enquiries@roalddahlcharity.org



www.roalddahlcharity.org

Registered Charity No: 1137409. Illustrations © Quentin Blake. Roald Dahl is a trade mark of Roald Dahl Nominee Ltd.
Company Limited by Guarantee in England and Wales No: 7340518