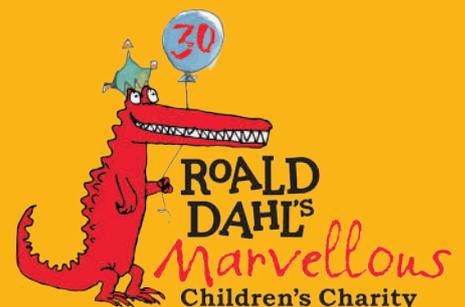


Summer 2021



Roald Dahl's Marvellous Children's Charity

Impact Newsletter



A message from our Chief Executive

The last year has been one of innovation and development within Roald Dahl's Marvellous Children's Charity, we have created new ways of working with our partners and built on our models of integrated care within hospitals, social care, financial support and community services.

We have continued to establish Roald Dahl Specialist Nurse posts across the UK with 80 Roald Dahl Nurses providing support for over 21,000 seriously ill children.

We were able to support seriously ill children and their families with practical and emotional support through the pandemic. Recognising the emerging needs of our children and young people, at a time when hospitals were stretched and worries were high, we changed the focus of our Marvellous Family Grants Programme to support delivery of care at home. Through this, we were able to provide specialist equipment that kept young people out of hospital and safe at home, reducing pressure on families and on a stretched NHS.

In this newsletter, I am delighted to introduce you to Carter and his family, one of the young people we support whose life has been positively impacted through the support of his Roald Dahl Specialist Nurse, Tina. I am also delighted to introduce you to Natalia, our 80th Roald Dahl Specialist Nurse who has now taken up her post in the community in East London and will soon be changing lives for the better.

Louise Griew



How we create impact:

Roald Dahl Specialist Nurses

There are currently 80 Roald Dahl Specialist Nurses caring for over 21,000 seriously ill children across the UK. Roald Dahl Specialist Nurses are a vital lifeline to the children and their families, supporting them clinically and emotionally.



Nurse Development

Training and 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.

Our Charitable Programmes

Marvellous Family Support Service

Our newly launched Marvellous Family Support Service will help families to access their benefit's entitlement. This support service will help families to overcome financial worries, helping to relieve some of their stress and anxiety.



Nurse Led Innovation

We support Roald Dahl Specialist 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 Milestones

2021 marks 30 years since the charity was founded by Roald Dahl's Widow, Felicity Dahl. We kicked off our anniversary year by reflecting on the some of our Marvellous Milestones from the last 30 years.

We currently support over **21,000 children**
But we know there are over **100,000 children** with complex, lifelong illnesses. It is our ambition to provide specialist nurses and support for **every** seriously ill child.

1991
Felicity Dahl, Roald Dahl's widow establishes Roald Dahl's Marvellous Children's Charity



1992
The charity creates the first-ever Paediatric Epilepsy Specialist Nurse Post in the UK



2001
The charity establishes the first Roald Dahl Sickle Cell Specialist Nurse

2001
The 25th Roald Dahl Specialist Nurse is established at the University Hospital of Wales



1999
The first Roald Dahl Specialist Nurse in Wales is appointed

1997
The 10th Roald Dahl Specialist Nurse is appointed

1995
The first Roald Dahl Specialist Nurse in Scotland is established

2004
The first Roald Dahl Nursing Conference took place

2009
Roald Dahl Haematology Specialist Nurse Phil Daly is featured on the cover of 'Nursing Standard'

2014
Felicity Dahl, on retiring as Trustee of the Charity, becomes its Co-President with Sir Quentin Blake

2014
The 50th Roald Dahl Specialist Nurse is appointed

2014
The Marvellous Nurse Inventing Room is launched in partnership with the Burdett Trust for Nursing



2016
To celebrate 100 years since the birth of Roald Dahl the new Roald Dahl rose created by David Austin Roses



2016
The charity creates the first-ever SWAN (Syndromes Without a Name) Nurse Specialist Post in the UK

2016
The charity creates the first-ever Rare Disease Specialist Nurse posts in the UK



2014
The charity creates the first Roald Dahl Neuromuscular Specialist Nurse Post

2017
The first Roald Dahl Neurodisability Specialist Nurse in Northern Ireland is established



2017
The first Roald Dahl Play Specialist Post is created at University College London Hospital

2017
HRH The Duchess of Cornwall officially became our Royal Patron

Photo credit: Ian Turner



2018
Our 70th Roald Dahl Specialist Nurse Katrina Bottle started in post

2020
Sir Quentin Blake creates special illustration to be auctioned off for the charity's Roald Dahl nurses appeal

2020
Roald Dahl Transition Specialist Nurse, Giselle Padmore-Payne wins the RCNi Child Health Award

2019
Roald Dahl Haematology Specialist Nurse, Elizabeth Joshua-John wins Nursing and Midwifery Zenith Global Health Award



2019
The charity creates the first Gastroenterology Specialist Nurse Post



2020
Roald Dahl Nurses are featured on the iconic Piccadilly Lights billboard



2020
20 Roald Dahl Nurses are selected for the Florence Nightingale Foundation Leadership Programme

2021
The 80th Roald Dahl Specialist Nurse is appointed in the charity's 30th anniversary year!



Making Lives More Marvellous Since **1991**

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Illustrations © Quentin Blake

3

Our COVID response

The pandemic brought increased levels of complexity on top of the already complex conditions of the children, and young people under the care of our Roald Dahl Specialist Nurses.

Lockdown affected everyone, and there were additional pressures on NHS hospitals. For seriously ill children and their families the effect was really marked - appointments were postponed, families were worried about attending appointments in hospitals, some nurses were redeployed and consultants were called away.

Roald Dahl's Marvellous Children's Charity's core programmes have continued during the pandemic. Our Roald Dahl Specialist Nurses have adapted their nursing to continue to provide support to seriously ill children, young people, and their families.

We launched our COVID Support Grants early in the pandemic, raising £37,000 to help provide much needed medical equipment to our nurses, families, and hospitals across the UK.

We invited NHS Trusts and individuals to apply for equipment grants to help families and relieve the pressure on the NHS. Here are some of the ways we were able to help:

Providing Vital Equipment

Lockdown during a pandemic is especially hard on a seriously ill child, and even more so when they need to travel urgently into hospital, for instance to monitor levels of oxygen in the blood which may fall at any time of the day or night. The charity provided equipment to measure oxygen blood levels at home.

In addition, to reduce the need for children with Duchenne Muscular Dystrophy and Spinal Muscular Atrophy to stay in hospital for necessary overnight monitoring of carbon dioxide levels in the blood during sleep, the charity was able to provide three TOSCA machines for families in the North West to use at home. This meant the children were able to avoid having to attend hospital thus reducing the stress and anxiety for families and lessening some of the pressure on the hospital teams.

We were also able to provide other vital equipment such as fridges to keep medication at the correct temperature at home, specialist thermometers, blood pressure monitors and epilepsy monitoring kits for seriously ill children, again providing vital equipment and reducing the need to travel and attend hospital.

£37,000

**In COVID-19 grants
distributed to help
families with
medical needs
at home**

Financial support for families

Having a serious illness takes a massive toll on a child and their family. Families with seriously ill children often are not able to access the financial support and benefits they are entitled to. This support is vital in helping families overcome the unique life challenges that come with having a child with a complex, lifelong illness. Getting access to financial support and benefits is extremely complicated and the consequences of financial hardship are far reaching.

Roald Dahl Specialist Nurses help their families with the process of applying for financial support as much as they can, but it is extremely time consuming.

Harriot's six-year-old son, Jacob is supported by our Roald Dahl Specialist Nurse, Stacey. We spoke with Harriot who explained how her family had experienced these issues first-hand. Jacob has a rare and complex form of epilepsy and Harriot, who is separated from her partner, is struggling financially.

“I've been in tears; I cry all the time. When Jacob goes to sleep, I sit there, and think is this it? Before Jacob's Roald Dahl Nurse, Stacey told me that Roald Dahl's Marvellous Children's Charity were looking at helping parents like me with financial struggles, I felt like there was no one that understood. Every time I try to get help, they say no.”

Marvellous Family Support Service

In response to this need for financial support, Roald Dahl's Marvellous Children's Charity has launched a pilot Marvellous Family Support Service, delivered in partnership with Citizens Advice Cardiff & Vale for families under the care of a Roald Dahl Specialist Nurse.

The 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.

The
establishment of the
Marvellous Family
Support Service was made
possible thanks to an
£18,000
grant from
Assura Community
Fund



Roald Dahl Specialist Nurses

During 2020-2021 we continued to establish more Roald Dahl Specialist Nurse posts. There are now 80 Roald Dahl Specialist Nurses providing support for over 21,000 seriously ill children across the UK.

Introducing our 80th Roald Dahl Specialist Nurse

Natalia, who joined East London NHS Foundation Trust (ELFT) this month, is the 80th specialist nurse in the UK to be established by Roald Dahl's Marvellous Children's Charity.

Natalia's role will help seriously ill young people and their families through the transition from childhood to adulthood. Transition is when young people move from children's to adult health and social care systems while also dealing with the challenges of becoming a young adult.

Natalia said: **"I focus on children with special educational needs and disabilities as they start secondary school, preparing the young person and their families for the time when they will enter into adulthood. For a lot of families, this brings a lot of uncertainty and anxiety, especially if they have known one team of healthcare professionals throughout childhood."**

Moving from children's to adult services can be daunting for young people and their families; the services do not always align, the care teams are different and there are different expectations on the patients.

Natalia added: **"Without support, my patients and families would face a very scary adult world where nothing makes sense and where they no longer are entitled to the care that they so heavily relied upon as they were growing up. Some parents may not feel that they have the tools to be able to advocate for their young person. They may not know how to or where to access information from to support the needs of the family."**



Nurse training and development

Training and development is key to a Roald Dahl Specialist 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.

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. Find out more about our nurse training and development and innovation on our website www.roalddahlcharity.org.



Carter's Story

Carter is cared for by his Roald Dahl Specialist Nurse Tina who provides both practical and emotional care for Carter and the whole family. The family are sharing their story as part of our 'Marvellous Thank You' campaign.

Carter's Mum Laura: "Carter (11) has Ehlers-Danlos Syndrome Type 2 (EDS) which means that he dislocates his joints on a daily basis. He's in pain constantly and bruises like a peach at the lightest of contact. Carter was diagnosed with EDS around five years ago and we are looked after by Rare Disease Team at Birmingham Children's Hospital. That's when we met the Roald Dahl Specialist Nursing team including Tina, Carter's Roald Dahl Specialist Nurse. Tina is amazing, she really looks after all of us. Carter forms very strong relationships and he has become very attached to Tina and having her at his appointments – a face he recognises and feels comfortable with – is a massive support for us all. I can text Tina and say, "I'm having a rough day" or "I've had a report from a doctor, and I don't understand it" and she will go out of her way to explain to us in a way we understand."



"Tina supports Carter, she supports Carter's siblings, and she supports my husband and myself. There are never going to be enough thank yous in the world for what Tina does for us and the impact she has had on our family."

As Carter's specialist nurse, Tina brings together consultants, hospital colleagues, community teams and social care. This integrated way of working highlights the multiple people, care agencies that are involved in looking after Carter and the thousands of children who also need long-term care.

Tina said "Children with a rare disease or an undiagnosed condition are usually under multiple professionals, not just within the hospital, but within the community too. Therapy services are often involved - physiotherapists, occupational and speech and language therapists - there could be social workers and schools involved. And so there are an enormous amount of professionals to liaise with. Living with a rare condition can also be very emotionally draining."

Laura said "Roald Dahl Specialist Nurses like Tina don't just treat illnesses or injuries; they look after us as a whole family unit. Knowing that I can just pick up the phone to Tina when we've had a rotten day, or if Carter has been unwell, makes the world feel a little bit less lonely as a mum. I don't feel as isolated and alone. I know that I am always going to be Carter's biggest advocate but to know that Tina is in our corner fighting battles, which if we had to fight on our own would feel overwhelming, makes a huge difference."



"The charity supports over 21,000 children across the UK, there are over 100,000 children like Carter, all of those children deserve a Tina in their lives."

THANK YOU!

A huge heartfelt thank you to all our supporters, this year has been extremely challenging for everyone and we are immensely grateful to everyone who has contributed. A special thank you to the **Roald Dahl Story Company** whose partnership we really appreciate.

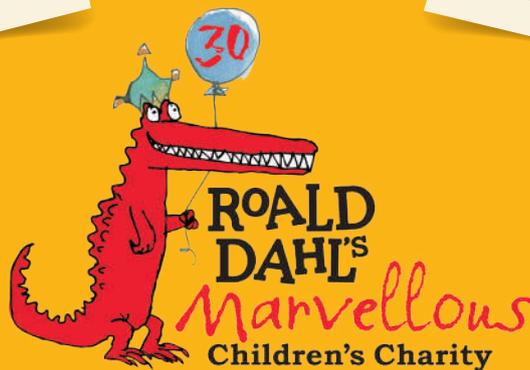
The Future

With your support we are continuing to increase our impact in the following areas for seriously ill children and young people:

- Improved quality of care
- Improved experience of care
- Improved efficiency and cost-effectiveness in care
- Improved resilience of seriously ill children and their families

We are confident that with the backing of you, our fantastic supporters, we can continue to ensure that every seriously ill child has a Roald Dahl Specialist Nurse to help them lead a more marvellous life.

Dates for the diary 2021:



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www.roalddahlcharity.org

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