



Spring 2022

Roald Dahl's Marvellous Children's Charity

Impact Newsletter



A message from our Chief Executive

Roald Dahl's Marvellous Children's Charity has been making excellent progress over the last six months. It's thanks to supporters like you that we have been able to establish four new Roald Dahl Specialist Nurse posts in partnership with the NHS in the last few months. Our nursing network and integrated care models have taken steps forward and we are now helping more seriously ill children than ever before.

We currently have 82 Roald Dahl Nurses in our network supporting over 24,000 seriously ill children and their families. I met one mother recently who told me that despite meeting many healthcare professionals "she has never met a nurse like Lisa (her Roald Dahl Nurse)", and that she is "the epitome of family centred care." A really strong testament to how a Roald Dahl Specialist Nurse works with a family and the relationships they build with the parents and children. I am constantly in awe of our nurses and proud of what we achieve through our partnerships with them and the NHS Trusts they work for. You should be too, as it's through your support, money, time, and energy that enables us to help so many seriously ill children and their families.

This newsletter will give you an update on our work, the impact of Roald Dahl Nurses, and introduce you to the families we support. Please do contact me if you ever have any questions or comments.

Best wishes, Louise Griew - enquiries@roalddahlcharity.org or 01494 890465.



Louise Griew
Chief Executive

Roald Dahl Specialist Nurses' four impact areas



**Quality and
experience of care**



**Holistic
family-centered
care**



**Efficiencies and
cost-effectiveness**



**Leadership and
innovation**

30 Years of Being Marvellous!

In 2021 we celebrated our 30th Anniversary - 30 years of providing specialist nurses and support for seriously children, who are living with lifelong, under resourced conditions. Despite restrictions with the pandemic, we were able to create and build partnerships with NHS Trusts, celebrate nurses on International Nurses' Day (May 12), write letters to our younger selves to highlight the need around transition of care from children's to adult services, hold a celebration event in London (picture below), and celebrate with our Royal Patron, Her Royal Highness The Duchess of Cornwall at Clarence House, decorating the Royal Christmas Tree. All of this helped to strengthen the charity through creating future support and partnerships.



Founder, Felicity Dahl, and former Chair of Trustees, Donald Sturrock cut our celebration cake.

Real Life Stories

Owen's Mum, Sharon, talked to us about her son Owen and the difference her new Roald Dahl Transition Specialist Nurse, Angie Godden (took up her role in summer '21), makes to their lives.

"Owen was born in 2004 and there were concerns at the time. Between 3-6 months he was not meeting milestones like other children of his age, and I noticed that his eyes were not right, so had concerns. I spoke to the health visitor that identified an issue with Owen's head circumference and growth. I was advised to go and get Owen checked at A&E at our local children's hospital. From there I was referred to a paediatrician who did lots of tests and examinations."

"Owen is dependent on us for all of his needs."

Owen has very complex needs and as he approaches transition (from children's to adults services as a teenager) his Mum is worried about what is next. "Angie has only recently started in this role but has been to see me at home to chat about transition and what to expect. This was so useful as I was really worried about transition. A small example of how Angie has helped us is her support and flexibility. I was worried about an appointment that was coming up and very apprehensive about going to this alone so Angie came along to support me and was able to advocate for what support I would need. This was with a spinal surgeon, and I was worried about how I would cope with Owen post-operation. Angie brought this up at the appointment and explained why this would be a challenge and the consultant agreed that Owen should be referred to have a four-week residential short break post-operation. This really helped me to make a huge decision that ultimately will be in Owen's best interests and for a brighter future for him."



Owen sharing a smile and a laugh

"I would be lost without Angie"

This shows the impact that Angie has already had on this family. If Angie wasn't there, Owen's Mum would feel "absolutely overwhelmed at what needs to be done and how to manage the next stage of Owen's life. When you are approaching 18 it is so hard to know what to do and what is best and it is great to have Angie there to discuss this with. I would be lost without Angie."

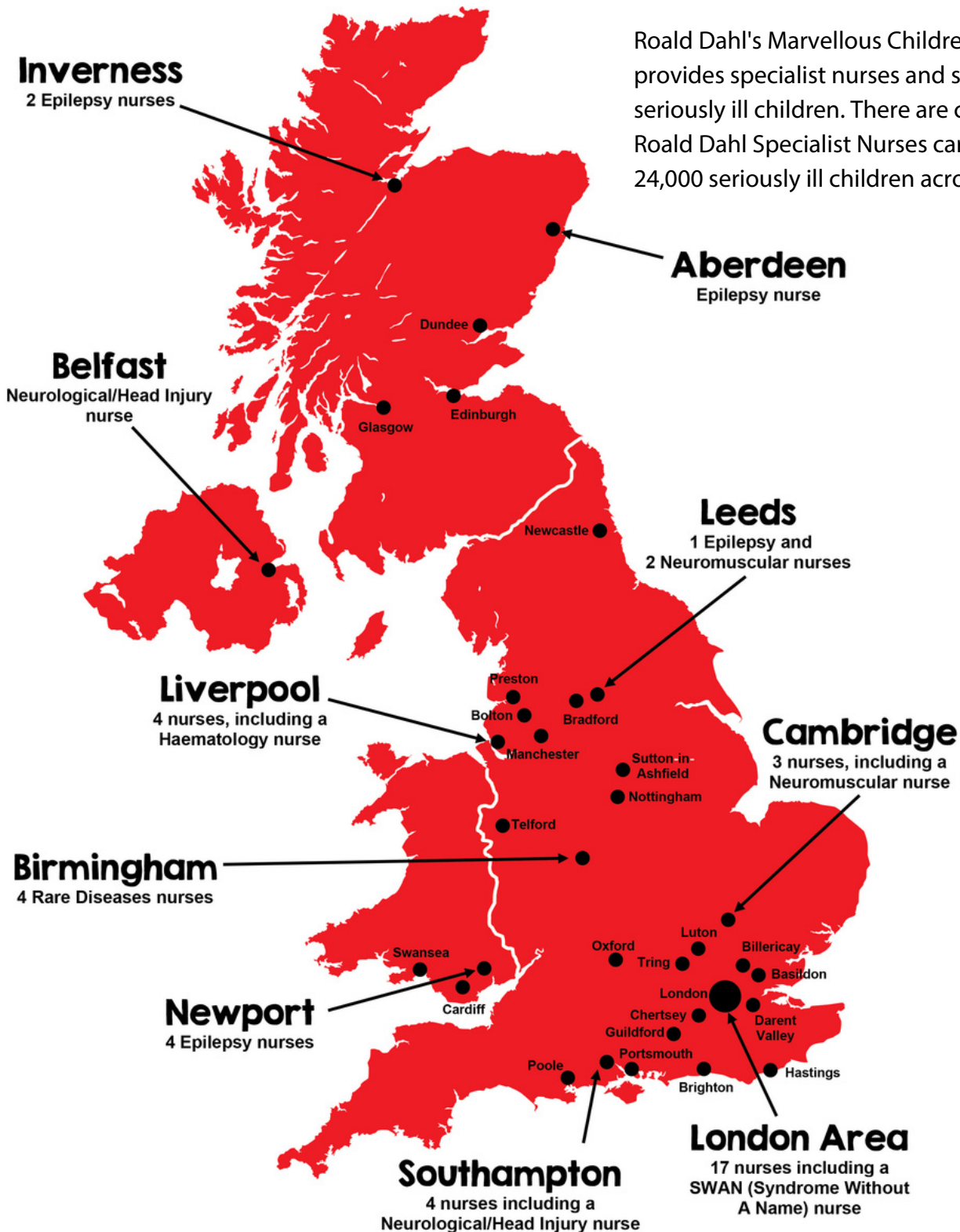


For Owen's Mum, having Angie is now incredibly important. She goes on to thank those that have helped make the new Roald Dahl Transition Specialist Nurse for East Sussex a reality. "Thank you so much – I don't think I can say how grateful we are to have the support of Angie – knowing there is someone there to discuss any concerns or queries about transition into adult services is just so reassuring as it is quite complex to deal with alone."

Roald Dahl Nurse, Angie Godden

82 Roald Dahl Nurses and Counting!

Roald Dahl's Marvellous Children's Charity provides specialist nurses and support for seriously ill children. There are currently 82 Roald Dahl Specialist Nurses caring for over 24,000 seriously ill children across the UK.



A special study of the impact of Roald Dahl Nurses was undertaken by Sheffield Hallam University and the findings were released in October 2021. The evidence of the two-year study showed that Roald Dahl Nurses excelled in four key areas: Quality and experience of care; holistic family-centered care; efficiencies and cost-effectiveness and leadership and innovation (as highlighted on page 2).

[Find out more about impact](#)

Marvellous Family Support Service

Supporting families who face tough times

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 Nurses help their families with the process of applying for financial support as much as they can, but it is extremely time consuming. In response to this need for financial support, Roald Dahl's Marvellous Children's Charity has launched the Marvellous Family Support Service, delivered in partnership with Citizens Advice Cardiff & Vale for families under the care of a Roald Dahl Specialist Nurse.

This service provides financial advice and support to the families, working directly with them to guide and empower them to navigate the complicated benefits system and access the support they are entitled to.

"Services such as this one are priceless"

105 families have accessed the service



Families helped have or will access over £175,000 of benefits

66 families have been referred on to other support services

42 families have so far experienced a positive changes in their finances

Real Life Stories

Hayley, Mum to Cianna (who has sickle cell disease) told us that "The service was extremely useful. The forms can be extremely daunting and confusing and feel to most as though they are almost trying to trip you up with your answers. I found it particularly useful having guidance on the words to use and how to total all of the additional time and care Cianna needs. Services such as the one the Citizen Advice Cardiff & Vale and Roald Dahl's Marvellous Children's Charity are offering are priceless."

Every seriously ill child deserves a Roald Dahl Specialist Nurse

Roald Dahl Nurse spotlight

Fiona Short started in Royal Manchester Children's Hospital in July 2021. Fiona is a Roald Dahl Epilepsy Transition Specialist Nurse and supports children and young people with complex epilepsy between 12 and 25 years old. Fiona is a much needed addition to the epilepsy team in Manchester and she says "I always strive to give the best possible care to patients and their families. During my time in this post, I have taken on the role of lead professional for families ensuring early Multi-Disciplinary Team (MDT) meetings have been held, and that there is a co-ordinated approach to care."

A key part of this role is transition and Fiona has been working with other epilepsy specialist nurses in the region to ensure that transition pathways exist and are managed well for the children and young people. It has meant close working with adult service colleagues and establishing meetings with other nurses to ensure best practice and peer support. Because the relationships with colleagues are building, and the improved communication between the Royal Manchester Children's Hospital and local teams, there is already a reduction of duplication of appointments and identification of named professionals to support the families.



**Roald Dahl Nurse,
Fiona Short**

Improving family resilience

An important objective for a Roald Dahl Nurse is to improve the resilience of children, young people, and families. Whilst it's still early days, Fiona says "I feel that by employing an open and honest approach when working with young people and their families, I can help to set expectations and promote resilience. I always ensure a good level of information is given for young people and their families to feel educated about their condition and signpost to the Marvellous Family Support Service or to other organisations which may be able to offer advice and support. Whenever possible, I will work with young people to explore their beliefs about their condition in order to help them to consider their new "normality".



Fiona is a wonderful ambassador for Roald Dahl's Marvellous Children's Charity and for Royal Manchester Children's Hospital. She says "I am extremely grateful and humbled to be in this post and to hold such a prestigious title. Thank you for supporting the post and recognising the importance of this role."

Thank You

A huge thank you to all of our supporters this year. It's continued to be 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 support and partnership we really appreciate.

The Future

With your support we are continuing to work through our Roald Dahl Specialist Nurses programme and wider support services to improve the quality of care, improve experiences of care, improve the cost effectiveness and cost effectiveness in care and improve the resilience of seriously ill children and their families.

Dates for your diary in 2022



To get involved, or if you have any questions about our work and events, do get in touch.



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