Kirsten’s role is running a telephone hotline service so parents and children can call in confidence. The course helps nurses like Kirsten to recognise the benefits of working to support families at Sherwood Forest Hospitals NHS Trust.

Nikki’s involvement in the economic evaluation of the role has reinforced the value of the role to other bodies, also affecting her NHS Trust. She has worked with staff from multiple departments, expanding communications understanding of the importance of her post and what support she provides. It has also developed her confidence and now she feels more empowered to talk about the Specialist element of her role. A filmed version of Nikki’s evaluation work is now available to view now here, with the Royal College of Nursing’s Youtube Channel.

We are thrilled to hear of the new nurse specialist position in Roald Dahl Nurse Kirsten has been appointed. She has been mentored and supported by the very successful Roald Dahl Nurse Specialist Fran Schlich under whose leadership the Roald Dahl Nurses have rapidly expanded. It is fitting that this position was funded thanks to the Roald Dahl Charitable Trust, which provides grants in line with its charitable objectives and has historically provided support to our work.

HR and Administration Officer Karen Win

Karen joined the charity in December 2018. She manages the running of the office on a day-to-day basis, Karen has been described by a colleague as the office fairy Godmother. No day is the same for Karen, she could be answering queries from the general public or taking minutes at Trustee Board Meetings.

Karen is very excited to learn that the charity is launching a new Roald Dahl Nurse Specialist position to support young people moving from child to adult healthcare services. As a Mum with a child who has a rare condition Karen knows how valuable these new roles will be to families that need that support.

Karen is also incredibly honoured to be the Senior Representative at the charity’s annual fundraising Gala at The Savoy this Spring. Karen has contributed more to the team using her professional and personal experience.

Karen says “Although I have only been here a short while, all the staff have made me very welcome and I feel like part of the team already.” Welcome to Team Marvellous Karen!
Serious illness children and families attend Clarence House

In December, Her Royal Highness The Duchess of Cornwall, Roald Dahl’s Marvellous Children’s Charity’s Royal Patron invited five seriously ill children, family members and Clinic Nurse Louise Cope from the Royal Gwent Hospital to Clarence House to enjoy the Christmas tree and a special lunch. The children, along with their Roald Dahl Nurse, made the Royal Christmas tree. Her Royal Highness offered a delicious lunch for her guests to enjoy and the children were treated to a surprise visit with some of Santa’s reindeer.

Among the guests were Adam, aged 4, who was diagnosed with epilepsy when he was just 2 years old. He is supported by Roald Dahl Nurse Karen who was in post for 20 years and has just retired. Roald Dahl Nurse Katie Spender-Taylor, whose partner is Jessica Anderson, our first Roald Dahl Nurse in Northern Ireland who cares for children with neurological conditions, was delighted to be able to attend the event. She told us "We are thrilled to have attended the support of our Royal Patron. It was a wonderful way for the Charity to celebrate their 20th anniversary and to continue to tell the story and the work that we do to the tens of seriously ill children all year round.

“Roald Dahl nurses do to support in so many different ways, from fundraising to delivering specialist support to the families in her care. Louise provides both medical and emotional support and can be seen attending home visits, answering calls from worried parents and carers, education for other healthcare professionals and the wider community, such as schools. Louise also ensures that the children and young people in her care can easily access treatment to help manage their condition more effectively. She is a true ambassador for the Roald Dahl Nurses, and their valuable work in providing support to those in need.”

Louise has been a Roald Dahl Nurse for 11 years and works in the heart of the community to deliver specialist support to the families in her care. Louise provides both medical and emotional support and can be seen attending home visits, answering calls from worried parents and carers, education for other healthcare professionals and the wider community, such as schools. Louise also ensures that the children and young people in her care can easily access treatment to help manage their condition more effectively. She is a true ambassador for the Roald Dahl Nurses, and their valuable work in providing support to those in need.

Another example is Cameron. Despite his health issues, Cameron is determined to be just like other children, reaching210 cm in height—meaning that his coordination is challenged, and he is prone to falling over easily. Frequent seizures have resulted in a permanent weakness on the right side of his body, which limits his mobility.

Roald Dahl Nurse Louise Provides Invaluable Support to Cameron and his Family

Cameron, aged 13 from Wales, has a complex form of benign Rolandic epilepsy, where seizures begin in the part of the brain called the ‘Rolandic’ area, leaving him with a lifelong disability. Education, health, socially and emotionally. Cameron benefitted from this development. Regular seizures have resulted in a permanent weakness on the right side of his body, meaning that his coordination is challenged, and he is prone to falling over easily.

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