A Day in the Life of Roald Dahl Nurse Edith

Sickle Cell Disease is one of the most common genetic disorders in the UK. Children who have the condition are at risk of a diverse range of backgrounds and can experience life-threatening complications in people with African or Caribbean heritage. Survival rates for children in the western world have improved, however, development and challenges affecting the condition can be a great problem. Sickle Cell is a lifelong condition, although, with the right support, lives can be altered.

The problems associated with Sickle Cell can be prevented through education and support at home, and education for children, and understanding of the importance of healthy diet, health and physical activity. Edith works closely with families to help them communicate messages, including helping to understand some of the misconceptions and different understanding about the condition.

Edith sets up the community, in schools and within health and social environment, including services for families with a comprehensive approach to support and disease. She addresses issues of isolation by providing a sense of community between families. In an ideal world, Edith will treat up to six children and can be seen an average day, Edith will treat up to six children and can be seen when they have had their injections. The story helped children associate with the condition effectively, families are encouraged to treat it at home, and education for children, and understanding of the importance of healthy diet, health and physical activity.

In schools and within health and social environment, including services for families, Edith liaises with the child’s school to provide her recommendations and support and deliver the biggest impact. She addresses issues of isolation by providing a sense of community between families. In an ideal world, Edith will treat up to six children and can be seen when they have had their injections. Her Royal Highness The Duchess of Cornwall, who was the Roald Dahl centenary Patron last year, hosts an annual event for children to decorate the Clarence House Christmas Tree and enjoy a delicious lunch. Five children and their families joined the wonderful festive event from Roald Dahl Marvellous Children’s Charity.

The children had fun adding the finishing touches to the Christmas tree and her Royal Highness spent time talking with the families about their experiences. She also spoke to the Roald Dahl nurses about their specialisms which include Blood conditions, Neurology and Epilepsy.

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Edith says that many of the children and young people she helps struggle with school, including some young people who were thought might not be able to complete their GCSEs. Edith believed in the child’s school to provide her recommendations and they carried out their own research and helped the child understand their condition. They gave the child confidence and it meant they were more able to continue education. Edith has also visited the boy’s school to explain the condition of Sickle Cell and to help the boy cope. She said, “I feel that our work in Sickle Cell means we feel nothing is impossible with Edith on our side.”

The families Edith cares for agree that Edith has made a great difference to their lives, including Lisa, mum to Taye and Tyrell who both have severe forms of Sickle Cell. She said, “Edith is so kind, caring and honest. Edith being there at the end of the phone for advice and support makes me feel better. She is my strength. She has taught me how to manage my condition at home. She gives me confidence and it’s meant that they were more able to continue education. Edith has also visited the boy’s school to explain the condition of Sickle Cell and to help the boy cope. She said, “I feel that our work in Sickle Cell means we feel nothing is impossible with Edith on our side.” The families Edith cares for agree that Edith has made a great difference to their lives, including Lisa, mum to Taye and Tyrell who both have severe forms of Sickle Cell. She said, “Edith is so kind, caring and honest. Edith being there at the end of the phone for advice and support makes me feel better. She is my strength. She has taught me how to manage my condition at home. She gives me confidence and it’s meant that they were more able to continue education. Edith has also visited the boy’s school to explain the condition of Sickle Cell and to help the boy cope. She said, “I feel that our work in Sickle Cell means we feel nothing is impossible with Edith on our side.”

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Roald Dahl Nurse Edith with Taye and Tyrell and her supporters
News from our Marvellous Corporate Partners

Theatre Bucket Collections Raise Thousands

We are delighted to be chosen by the Ambassador Theatre Group for their 2014/15 pantomime season. With bucket collections, appearances from our very own Marvellous Cisabella, a gala night, and our charity at participating theatres, over £48,000 was raised. The fundraising was so successful that they have decided to support us for another two years. Watch this space for more information about the partnership.

In November, we were delighted to be chosen as one of three beneficiaries in the Roald Dahl Children’s Christmas Charity Appeal. The annual campaign, featuring inspiring stories about our Roald Dahl Nurses and the families under their care, generated generous Telegraph readers to donate over £155,000 to our cause during the festive period. Their wonderful support helps us to ensure more seriously ill children have access to essential healthcare in the UK.

Chiltern American Women’s Club

The Chiltern American Women’s Club (CAWC), a Buckinghamshire based social organisation offers numerous ways to support our nurses while supporting local charities through various fundraising events and activities, including their annual Christmas Ball. For four consecutive years, CAWC has raised a fabulous £7,500 for our charity, Paul Showers, co-chair of the CAWC said: “We have always been great friends with our community and are always keen to see the support we had for this great community-focused fundraiser. We are looking forward to our next fundraiser in January 2017.”

Welcome to our New Partners

We would like to welcome our new corporate partners, including SpectroSonic Marketing, BAC Office Equipment, BSC Group, The Big Fundraiser and Dentsu Care. We can’t wait to work with these organisations and look forward to sharing more information about our new friends soon.

Did you know?

Family Grants

During her four years old, her condition can only be managed medically, epilepsy and global developmental delay. It is unable to speak, has a profound developmental delay and is visually impaired. With the support of a child and finds it difficult to regulate emotions, behaviour, and sleep. However, her parents are very proud of her and all she has achieved. Her condition is being managed by a team of healthcare professionals, including a specialist children’s nurse, speech and language therapist, and a psychologist. Her parents have been receiving support from the local Children’s Trust which has helped them to cope with her needs. The team has also provided additional resources and information to help her parents understand her condition and how to support her.

Did you know? News from our Marvellous Corporate Partners

Come together and help raise awareness of developmental delay. We are very grateful to all of our partners who have supported us over the years. Their support has been invaluable in helping to raise awareness of developmental delay and to support those affected by the condition. We would like to thank all of our partners for their continued support.

A Conference With a Difference

Edgewell Personal Care, the company behind household brands such as Wilkinson Sword, turned their annual conference into a day with a difference by opting to raise money for two charities. The event was supported by the RDC Foundation, our Roald Dahl Nurse funders, which was split equally between both charities.

A Trio of Fundraisers

We are happy to see the young and inspiring fundraisers ‘Team Mike Bartos’ otherwise known as Ava, Lucie and George taking part in the Mini Great Manchester Run in May. The boys and girls who don’t have as much as them.

Theatre Bucket Collections

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Conquering Everest Base Camp

Simon Williams, a health and fitness coach is no stranger to exercise, but when he turned forty, he decided he would trek one-hundred and twenty kilometres and over seventeen thousand feet for seriously ill children by reaching the summit of Everest Base Camp. When asked why, he said “I honestly believe that children should have the most magical and amazing childhood possible, and if people like me are able to raise money for the charities, that some children have to spend more time in hospital than anyone should ever have to.” Since completing this challenge of a lifetime, Simon has raised over £42,000 which will all benefit charities and Dementia UK.

Congratulations Simon!

Wallpaper Paste

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Call the Club

Why not join us for a marvellous charity golf day on Thursday 1st September? We will be looking for teams of four to come together and have some fun at the Milton Keynes Golf Club. In return for a golf day, all donations are going towards what we have at the rear, which won’t be. For more information or to register your team, please contact Graeme Milnes at milnes@roalddahlcharity.org or ring the office on: 01908 590 465.