

# Marvellous Nurse Inventing Room

## Haemophilia Selfies - Alder Hey Children's Hospital, Liverpool

Haemophilia is a rare, lifelong blood clotting disorder which can cause episodes of bleeding. In order to manage the condition effectively, families are encouraged to treat it at home, starting with parents and carers. Children are also encouraged to learn how to self-inject their treatment when they are ready and able to do so, with varying levels of success. The 'Haemophilia Selfies' project was developed by Cathy Benfield, Haemophilia Nurse Specialist at Alder Hey Children's Hospital, Liverpool to help these children feel supported. It also provided an opportunity for families to connect and share their experiences.

## The Superhero Kit - South Warwickshire NHS Trust

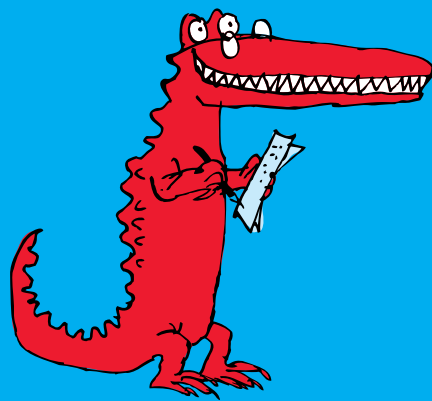
For children with juvenile arthritis, having painful injections is something many of them have to contend with. 'The Superhero Kit' project which was overseen by Joe Holder, Clinical Lead for the community children's nursing team and play specialists in South Warwickshire Foundation Trust, was designed by Play specialist Tracy Lole. She wrote a story about a superhero who has juvenile arthritis and lost their superpower, but regained this when they had their injections. The story helped children associate with the superhero and understand how the injections would help them feel better in the end and reduce fear. 'The Superhero Kit' was then created and children received a superhero storybook, a doll to provide comfort and identify where they might feel pain, as well as a superhero cape. The kits were introduced to the children by their nurses and play specialists, including four-year old Maisie-Grace who benefited from the project. She said, *"Mummy and me have sat and read my story before I had my injection. My brothers now know about my arthritis and we talk about it."*



### The project saw great results including:

- Increased confidence for children self-administering injections
- Siblings and classmates felt more informed
- Healthcare professionals can now develop the kit further for children with other conditions

## Get in touch



Want to receive our Marvellous News by email? Sign up to receive our email newsletters. Visit:

[www.roalddahlcharity.org](http://www.roalddahlcharity.org)

Whether you want to fundraise, donate, apply for our help or ask us a question, get in touch with our team using the contact details below.

Don't forget to follow us on Twitter @RoaldDahlFund and like our Facebook page [facebook.com/roalddahlcharity](https://www.facebook.com/roalddahlcharity) You can also find us on YouTube and LinkedIn.

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# A Day in the Life of Roald Dahl Nurse Edith

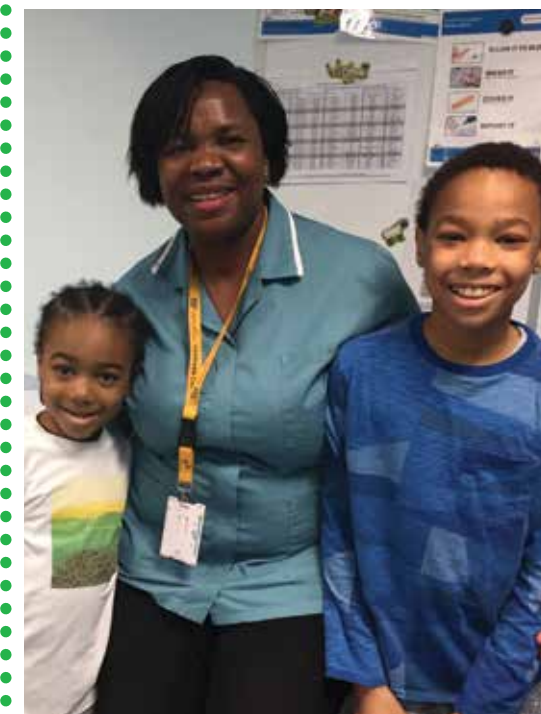
Sickle Cell Disease is one of the most common genetic disorders in the UK. Children who have the condition are from a diverse range of backgrounds and it is particularly common in people with African or Caribbean heritage. Survival rates for children in the western world have greatly improved, however development and schooling for children affected by the condition can be a great problem. Sickle Cell is a lifelong condition, although, with long-term treatment it can be managed.

The problems associated with Sickle Cell can be prevented through simple, low cost care at home, and education for children and families is the key to maintaining health. Edith works closely with families to deliver key health messages, including helping to overcome cultural barriers or misunderstanding about the condition.

Edith works within the community, in schools and within health services to ensure there's a comprehensive approach to support and deliver the biggest impact. She addresses issues of isolation by providing a sense of community between families. In an average day, Edith will treat up to six children and can be seen doing anything from administering blood transfusions to providing pain management and advice. Every single day is different for Edith but she works hard to ensure that all the families she cares for feel supported.

Edith says that many of the children and young people she helps struggle with school, including one young person whom it was thought might not be able to complete their GCSEs. Edith liaised with the child's school to provide her recommendations and they went on to complete their studies. Edith thoroughly enjoys her work and couldn't imagine doing anything else. She says, *"The best thing about my job is knowing that I've made a difference. I have an incredible sense of fulfilment."*

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 live with severe forms of Sickle Cell. She says *"Edith's an expert - she's so patient, caring and honest. Edith being there on the end of the phone for advice and support calms me down. She gives me strength. She has taught me how to manage my boys' condition at home. She's given me confidence and it's meant that they spend less time in hospital. Edith has also visited the boys' school to help the staff and pupils understand about Sickle Cell. She knows the boys so well, we feel that nothing is impossible with Edith on our side!"* We think Edith is a marvellous example of the dedication and commitment that is demonstrated by Roald Dahl nurses in helping seriously ill children and their families.



Roald Dahl Nurse Edith with Taye and Tyrell who she supports

Supporter Newsletter

Issue 7 - Spring 2017

# Marvellous News



## Welcome from the CEO

I am delighted to welcome you to the Spring edition of our supporter newsletter. We are incredibly grateful to have received wonderful support from many individuals and organisations in the last few months. What's more, we are very excited to work on growing our marvellous community of Roald Dahl specialist children's nurses.

I hope that when you finish reading, you are as inspired as I am by the invaluable efforts of all the wonderful people who have helped our NHS heroes provide the best possible healthcare for seriously ill children in the UK.

Jane Miles

## A Royal Day to Remember

It's not every day that we get a call to invite some of our marvellous Roald Dahl specialist children's nurses and families they support to Clarence House, so when the phone rang, we knew it was a special occasion.

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 wonderfully festive event from Roald Dahl's Marvellous Children's Charity.

The children had lots of 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.



Jane Miles, Chief Executive of the charity was thrilled to attend the event, she said, *"We are overjoyed that Her Royal Highness The Duchess of Cornwall, who has shown fantastic support for Roald Dahl's Marvellous Children's Charity, invited us along to this special event. We truly value the kindness that Clarence House has shown to our hard-working Roald Dahl nurses and the children and families affected by a serious illness."*

As part of the treat for families, leading London hotels offered a place to stay to remember. We would like to say a special thank you to The Stafford, The Dorchester, The Grosvenor House Hotel and The Goring for their support.

It was a fantastic opportunity for Her Royal Highness to learn more about the hard work and dedication of our Roald Dahl nurses and the resilience of the families who attended and we want to say a marvellous thank you to Clarence House for having us.



Images: Ian Jones Photography



## Did you know?

### Family Grants

Daniel is four years old and has cerebral palsy, microcephaly, epilepsy and global development delay. He is unable to speak, has the developmental age of a younger child and finds it difficult to regulate his emotions. We awarded Daniel a grant of £500 to fund ten sessions of play therapy at school to help him express his feelings. Daniel's mum says that he really enjoys the sessions which have helped to build his confidence. The play therapy has also provided Daniel's school with the tools to calm him down quickly, enabling him to learn more easily as a result.



All Star Photography

## Raising Awareness for Blood Conditions

Come together and help raise awareness for blood conditions that are supported by Roald Dahl specialist children's nurses, including Haemophilia and Sickle Cell.

**World Haemophilia Day - 17th April**

**World Sickle Cell Day - 19th June**

## What it means to be a Roald Dahl Nurse

Roald Dahl nurses are specialists in their field. We ensure they are fully supported so that they can continue to enhance the knowledge and skills necessary to deliver quality care. As part of their training and development, our Roald Dahl Nurses are invited to attend an annual conference, offering a chance to meet other healthcare professionals and share best practice. The most recent conference was held on 18th November 2016 at Alder Hey Children's Hospital in Liverpool. The location was very special as this is where the first-ever Roald Dahl specialist children's nurse, Anne Sweeney, started in post twenty-three years ago.

Anne has recently retired, having provided excellent care and support to many children and young adults affected by epilepsy in her career which has spanned forty-six years. Her dedication and service to those she has helped was celebrated at the conference. A whole host of speakers delivered inspirational talks and specialism hubs were held, which encouraged discussion about the different challenges faced by healthcare professionals. The conference was also an opportunity for project leaders from the Marvellous Nurse Inventing Room, our collaboration with the Burdett Trust for Nursing, to celebrate the impact of their projects.

We asked Roald Dahl nurses what it means to be a Roald Dahl nurse. Nurse Jo who

specialises in head injury says it means being *"Supporting, keen, an educator, innovator and something to be proud of."*



Roald Dahl nurse Giselle who specialises in haematology says being a Roald Dahl nurse means you're *"Kind and compassionate. We provide knowledge, support and wellbeing for patients and their families. It's a privilege."*



Whether a Roald Dahl nurse is a friend, an expert in their field, or someone at the end of the phone, they are all working hard to improve services for seriously ill children in their care.



Roald Dahl nurses and Charity President Felicity Dahl enjoying the 2016 Roald Dahl Nurses Conference.

## News from our Marvellous Corporate Partners

### Theatre Bucket Collections Raise Thousands

We are delighted to have been chosen by the Ambassador Theatre Group for the 2016/17 pantomime season. With bucket collections, appearances from our very own Marvin the Marvellous Crocodile and a special film about our charity at participating theatres, **over £80,000 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.



### 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 UK headquarters is based in Buckinghamshire and their staff felt it was important to support local organisations.

Eight teams competed against each other to see who could raise the most awareness and money in one day. From fancy-dress tandem cycles to climbing the O2 centre, selling goody bags at a market and hosting a tea party at a local primary school, staff from Edgewell also came up with some very creative team names including the 'Giant Peaches', the 'Fund-Raizors' and 'Pledgewell'. Their gallant efforts resulted in a **spectacular fundraising total of over £18,000** which was split equally between both charities.



### Telegraph Christmas Appeal



In November, we were delighted to be chosen as one of the three beneficiary organisations for The Telegraph's 2016 Christmas Charity Appeal.

The annual campaign, featuring inspiring stories about our Roald Dahl Nurses and the families under their care, motivated 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 members a chance to network while supporting local charities through various fundraising events and activities, including their annual Christmas Bazaar.

Marvin the Marvellous Crocodile helped to open this popular and well-attended event, which hosted over seventy artisan stallholders and **raised a wonderful £7,550 for our charity**. Pam Showalter, co-chair of the CAWC said, *"We have always been about giving back to the community and once again it was marvellous to see the support we had for this great community-focused holiday shopping opportunity with a charitable aspect to it."*



### Welcome to our New Partners

We would like to welcome our new corporate partners, including Splendiferous Marketing, BAC Office Equipment, JELF Group, The Big Feastival and Denta Care. We can't wait to work with these organisations and look forward to sharing more information about our new friends soon.

A big THANK YOU to all our...

## Fantastic Fundraisers

### 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 filled with love and laughter. It pains me to think 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 £2,000** which will be split between us and Dementia UK.

### Congratulations Simon!



### A Trio of Fundraisers

We are very happy to see the young and inspiring fundraisers 'Team Mini Bartons' otherwise known as Ava, Lucie and George taking part in the Mini Great Manchester Run in May *"for boys and girls who don't have as much as them."* **They have raised over £100 so far.**

### Good luck to all three of you!



### Dahlicious Dress Up Day Delight

Schools and groups across the country have been dressing up as their favourite Roald Dahl characters and donating £1.00 to our charity to celebrate the world's number one storyteller. **These marvellous donations have now raised over £100,000** and we couldn't be more delighted. Thank you to everyone who has made the Dahlicious Dress Up Day a great success once again. If you would like to find out how you can hold your own Dahlicious event, visit:

[www.roalddahl.com/dahlicious](http://www.roalddahl.com/dahlicious)



## Diary Dates

### Take Part in Your Own Marvellous Challenge

Are you looking to get fit this year? Take on a new challenge or try something fun with friends while raising money.

### Some of the marvellous events taking place this year include:

#### 1st May

Milton Keynes Half Marathon

#### 7th May

Tough Mudder, Henley on Thames

#### 11th June

The Colour Run (5km), London

#### 22nd July

The Gauntlet Games (5km), Cardiff

#### 29th July

Great Yorkshire Run (10km), Harrogate

#### 26th August

Great Scottish Swim (various distances), Loch Lomond

#### 1st September

Trek Machu Picchu, Peru

There are lots of events to choose from, you could even organise your very own cake sale or coffee morning in the office or at school. Get in touch at: [fundraising@roalddahlcharity.org](mailto:fundraising@roalddahlcharity.org)

### Calling all Golfers

Why not join us for a marvellous charity golf day on **Thursday 21st September**? We're looking for teams of four to come together and have some fun at Harewood Downs Golf Club in Buckinghamshire in what's set to be a great day out.

For more information or to register a team, please contact [partnerships@roalddahlcharity.org](mailto:partnerships@roalddahlcharity.org) or ring the office on: 01494 890 465.