

Marvellous Nurse Inventing Room

Our Marvellous Nurse Inventing Room has been full of creative research projects which aim to improve medical care for children and young people. See what discoveries were made.

Investing in Happiness

Great Ormond Street Children's Hospital

Using creative research methods to explore happiness, fulfilment and build resilience in children with rare diseases, and their families, this project has sought to give a voice to children living with a rare disease. Using a 'Bank of Happiness' to store happy moments they could draw on during difficult times, the children were encouraged to identify, reflect on and capture their happy moments. Parents' experiences were also explored and those that participated enjoyed the study. It was a great opportunity for the families to think about happiness and revisit happy moments in the future.



Get Ready Cos Here We Come

Alder Hey Children's Hospital

This project aimed to improve the quality of care in relation to transition from child to adult health care services for children and young people with epilepsy. Epilepsy is recognised to be the most common neurological condition in adolescence and it can impact on the formation of independence with social, educational and emotional consequences. Through the medium of art, including storyboards, hand-made character models and a film, the participants informed those undertaking the study that a modern tool to aid the process of transition would be beneficial. Anne Sweeney, Roald Dahl's Marvellous Children's Charity's first Roald Dahl Nurse (and the first paediatric epilepsy specialist nurse in the UK) has marvelled

in the project. She says, "I know that this project has had a positive impact in many ways including improving the quality of life for those who have epilepsy." The study and the film were recently presented at the National Transition Conference and were well received by those that attended. Watch out for the film which is coming soon on our YouTube channel.



A Road Less Travelled

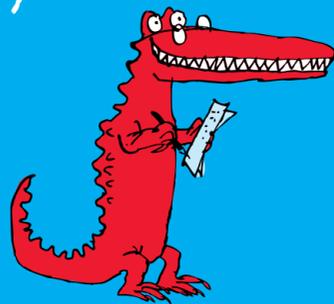
Bristol Royal Hospital for Children

Mapping emotional journeys following moderate to severe burn injury, this project sought to identify child and parent perspectives on the psychological journey following a burn injury and what helps or hinders their recovery, which is currently poorly understood. After conducting interviews, a film was produced to map the experiences of the participants

and assist practitioners and patients in co-creating service improvements. Co-design is important to the charity and we often work closely with those we support to help design new Roald Dahl nursing posts.



Get in touch



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

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A Day in the Life of Laura and her Roald Dahl Nurse

It's hard to imagine being told that your young child has a diagnosis of a rare type of epilepsy. For parents like Laura, it became a harsh reality. When her daughter Olivia, now seven years old, was just a toddler, she started having seizures. Although prescribed medication to help control them, they sadly just increased in frequency. Further hospital visits revealed that a Ketogenic diet could improve not only Olivia's epilepsy, but also her learning and development. The diet which is low in carbohydrates and high in fat has been hard to get used to. Laura found it a challenge at first, but now it's a little easier to manage. She is proud of how well Olivia manages her diet and says, "We have a lot of trust in her, knowing she is going to make the right decision. She's like a twenty one year old and she's only seven."



When Olivia is unwell, her diet can become ineffective. That's when having a Roald Dahl Nurse like Roz really makes a difference for children like Olivia. Based at University Hospital Wales in Cardiff, she is always on hand to give advice, support and information and mum Laura can't praise her highly enough. She says, "I don't think we would have been able to cope in the way we have over the years without Roz. She's always there if I need her."

For Roald Dahl nurses like Roz, helping Olivia is all about empowering children with epilepsy. With over 700 children in her care, she knows how important it is to enable them to feel they can all be children and not be defined by their condition. Roz is incredibly dedicated to her post and ultimately wants every child with epilepsy to live their lives to the full. She says, "I like being able to make a difference to children's lives when they're suffering with a condition that doesn't need to affect them as much as it can sometimes."

When Laura isn't managing Olivia's diet or looking after her son Bailey, she can be found running a Facebook support group called 'Epilepsy – the Ketogenic Way'. She set this up for parents to share recipes and provide a platform for other parents who share similar experiences. Over 800 members from all over the world have now joined Laura's group, showing how important parent support can be.

Olivia will have to be on her special diet for the rest of her life, but with help and support from Roald Dahl nurses like Roz, Olivia can focus more on her much-loved hobbies like gymnastics and one of Roald Dahl's favourites, writing.



Supporter Newsletter

Issue 6 - September 2016



Celebrating Roald Dahl 100

Tuesday 13th September marks Roald Dahl's 100th Birthday and we're celebrating 100 years of the world's number one storyteller with some marvellous events including the **Roald Dahl Day party**. You can join the fun and receive a **FREE Party Pack** so you have everything you need to hold your party. Sign-up by visiting: www.roalddahl.com/party. Schools across the country will be taking part in the **Dahlicious Dress Up Day**, by dressing up as their favourite Roald Dahl character and donating £1 to the charity.

There's also Roald Dahl's Tremendous Adventures at **Tatton Park**, which is playing host to many Roald Dahl inspired events until the end of the year. Find out more at: www.tattonpark.org.uk/roald-dahl



You can also feast your eyes on the David Austin™ **Roald Dahl Rose**, a peach coloured, tea-scented flower which is on sale now. Buy your own beautiful bloom

from: www.davidaustinroses.co.uk £2.50 from the sale of each rose will be donated to us. Why not visit our sister charity **The Roald Dahl Museum and Story Centre**, who are hosting The Museum of the Unexpected on 17th September? Book your tickets at: www.roalddahl.com/museum. You can also venture to Roald Dahl's birthplace, Cardiff for the **City of the Unexpected** on 17th and 18th September for plenty of magic, fun and invention for all ages.

What's more, Professor Tom Solomon, who provided medical care for Roald Dahl, has written a unique book entitled '*Roald Dahl's Marvellous Medicine*' which examines Roald Dahl's fascination with the medical world. Some of the proceeds from the sale of the book will be donated to our charity.

We've already celebrated the launch of *The BFG* this summer with the **Dream Jar Trail**, where 50 marvellous Dream Jars, which captured the dreams of celebrities, landed in London and beyond for human beans to find. We were thrilled that 4 of the jars, which contain the dreams of **Sophie Dahl, Her Royal Highness, The Duchess of Cornwall, Sir Quentin Blake and Tim Minchin**, were auctioned in aid of our charity, with the total over £10,000 and rising at the time of going to print.



The end of 2016 also marks the 25th anniversary of the charity and we're proud of our achievements over the last 25 years. Make sure you visit: www.roalddahl.com/25years to find out how we'll be celebrating in the coming year.

Did you know?

Family Grants

Since April, our marvellous family grants have helped 86 families, totaling £32,790 including four year old triplets Hazel, Sara and Patrick who received funding for new mattresses and bedding. The children were born prematurely and Hazel has had health difficulties ever since. Weighing 11lb 2oz at birth, she was in intensive care for six months and suffers from chronic lung disease and vocal cord palsy. Mum, Esperanza says "The children now have a beautiful, colourful, joyful bedroom and comfortable mattresses. They sleep very well now, which makes mum and dad very happy."



Roald Dahl Nurse supports more children with Sickle Cell

Since the charity was founded twenty five years ago, we have supported children with Sickle Cell Disease. The condition which affects the red blood cells in the body can cause many problems from early childhood and specialist lifetime care is required.

Thankfully, help is on hand from Roald Dahl nurse Rachael who works at St Mary's Hospital in London. She provides direct support for children and their families affected by Sickle Cell and associated conditions and is another of our marvellous nurses who dedicates her time to giving those in her care the help they need.



Why we champion underdogs and their brothers and sisters!

Roald Dahl's stories famously champion underdogs. From Charlie Bucket to Matilda, you can be sure that these characters always prevail. But how about the real-life underdogs and what about their brothers and sisters? Many of the seriously ill children we support have incredibly brave siblings, and just like Sophie in *The BFG*, they face frightening and uncertain circumstances with courage.

It can be increasingly difficult for families to provide their other children with the attention they need, and siblings are all too often the unsung heroes of the family, providing care for their ill brother or sister and missing out on time with their parents and friends. Renata, mum to Dominic, Elliot and Lilia would agree. Dominic, aged nine, has a rare condition and has spent a lot of time in and out of hospital since he was born. Renata says "They sacrifice so much for their little brother both when he is in hospital and when we are home. They accept that we cannot do what their friends do and that nothing is ever 'definitely' going to happen, as you never know with a child like Dominic, and they have been disappointed too many times."

Recently, we invited Renata and her family to attend the UK premiere of *The BFG*. It was a great opportunity for the whole family to spend some quality time together and enjoy a special outing.

No doubt, life will continue to be difficult for siblings like Elliot and Lilia, but we want to say that we think you are all truly marvellous!



Overcoming barriers during play

In order to best support our Roald Dahl nurses, we provide training grants to enable their professional development, increase innovation and encourage leadership within paediatric care. Tamsin, one of our two Highly Specialist Occupational Therapists based at King's College Hospital in London has recently undertaken a course in relationship-based therapy. It is founded on the belief that every child is a genius with buckets full of potential and all it takes is a connection through relationship building to unlock it. This child-centred approach encourages children to engage through play regardless of whether they have a behavioural, emotional or physical disability.

Tamsin has been able to apply her skills to ensure that every child can play and their sessions can be adapted to suit their individual needs. The families Tamsin supports often face a barrier when wanting to play with their children, mostly due to their levels of stress from having to manage a serious illness in the family.

Tamsin works to empower parents so that they too can connect with their children despite difficulties they may face. Positive results have been seen as a result of the training and Tamsin now holds a worldwide certification as a Floortime Specialist and couldn't be happier to have gained new skills. She says "It was amazing, I learnt so much. Childhood is about fun and children want to play. It's not about what they do, but how and who with that makes it meaningful."

News from our Marvellous Corporate Partners

Calling all Bake-off fans!

We are delighted to have been chosen as the charity partner for **The Cake and Bake Show 2016**, Britain's Biggest Baking Show, featuring Nadiya Hussain and many more celebrity chefs and authors. It has plenty to offer for all of the family, including demonstrations, classes and competitions to market stalls, displays and show-stopping installations. You can visit the shows at ExCel London from 7th to 9th October and EventCity Manchester from 10th to 13th November. Pop in to see us at the Children's Corner and pick up your very own **limited edition Marvin the Marvellous Crocodile cookie cutter!**

For more information visit: www.thecakeandbakeshow.co.uk



Design your own Marvellous T-shirt

Are you looking for an ethical present for the person who has everything or something different for a child's birthday? Now you can create your very own, personalised Marvellous Marvin T-shirt from **T-Shirt Booth**. Choose your favourite design and colour, upload a photo or logo, add a name and – hey presto – you've just created a unique T-shirt and donated £3 to the charity in the process! You can even create a special birthday T-shirt for ages 2-6! T-shirts come in children's, ladies' and men's sizes. Visit: www.t-shirt.net

Explore Learning

Explore Learning staff have thrown themselves into our partnership with huge enthusiasm. In addition to taking on all manner of athletic challenges to raise funds for us, they have been volunteering at our family events at Birmingham Children's Hospital and Cardiff, where they helped with all sorts of children's craft activities and workshops.

As if that wasn't enough, Explore Learning is offering **20 free English and Maths tuition places to children under the care of a Roald Dahl Nurse or in receipt of one of our Marvellous Family Grants**. This generous offer also includes these children's siblings. For more information please contact Clare Eynon, Corporate Partnerships & Trusts Manager at: claree@roalddahlcharity.org



A big THANK YOU to all our... Fantastic Fundraisers

A Rock 'n' Roll Success

Emily and Catherine from Explore Learning, who have taken part in various fundraising activities, have exercised their boundless energy and have successfully completed the Liverpool Rock 'n' Roll Marathon, raising over **£1,100**. Well done to you both!



A Family of Fundraisers



Two sisters, Caroline and Isy Mead have raised over **£2,200**. From a delicious cake sale to running 26.2 miles in the London Marathon, these two fantastic fundraisers have worked incredibly hard (and proven that running can be fun and rewarding too!) Thank you both for your support and congratulations on your achievements.

The Longest Try

Have you ever dreamt of running 1,800km carrying a rugby ball? One man has! Robbie Dolan is currently training to complete The Longest Try. In 2017, he will attempt to carry a rugby ball across 3 states of Australia, running nearly 42km a day, over 42 days, just in time for the final stages of the Rugby League World Cup. Robbie has been training hard ahead of his endurance challenge and has already run hundreds of miles as part of his training. Find out more by visiting: www.thelongesttry.com



ROALD DAHL 100 Diary Dates

The Roald Dahl centenary celebrations are well under way. What better way to celebrate the world's number one storyteller than with some marvellous events.

Fantastic Mr Fox

Roald Dahl's *Fantastic Mr Fox* is family fun at its finest. The Nuffield Theatre in Southampton is playing host to the world premiere of this flagship production from November to January. We are the theatre's nominated charity partner for the Christmas season with twenty-five percent of all fundraised income being donated to us from 30th September. Tickets are selling out fast, so book now to avoid disappointment. Visit: www.nuffieldtheatre.co.uk



Dress Up all Dahlicious for Roald Dahl Day

Celebrate Roald Dahl Day with a fun-filled Dahlicious Dress Up Day. It's a great way to get children's imaginations whizzing and inspire them to read. They can dress up as their favourite Roald Dahl character or even in yummy yellow, Roald Dahl's favourite colour. All you need to do is ask your child's teacher to register for their party pack and we'll do the rest! We have lots of dressing up tips so you have everything you need to prepare your child. Find out more at: www.roalddahl.com/dahlicious