

News from Friends of Rosie

SPRING 2021



CHILDREN'S CANCER RESEARCH FUND

GUARDIANS OF CHILDREN'S CANCER RESEARCH



Despite all the challenges of Covid, 2021 started on a high for Friends of Rosie and it's all thanks to you, our supporters. For the first time in our 30 years we are delighted to tell you that we are funding more research projects this year than ever before!

We have three projects underway, or about to start, and a fourth project to be announced in the autumn. This is why we exist. To get these vital new research ideas off the ground to help children with cancer. And that's all thanks to you. Last year was a year like no other; all our usual ways of raising money were stopped but you, our supporters, have kept us going and made this pioneering research a reality. We can't thank you enough.

Childhood cancer research remains desperately underfunded and we must continue to make sure children with cancer are not forgotten. That's why we're asking if you can help fight their cause once again; help fund more research and shout out on their behalf.

Knowing that we have a certain amount of regular donations allows us to fund more vital childhood cancer research projects. Ultimately this helps us achieve our goal of giving every child with cancer the chance of a bright, healthy, and happy future.

Which is why we have launched a new regular donation scheme called the Guardian Giving Scheme to help do just that. You give a little every month to make a huge difference to the pioneering children's cancer research we fund.

How to join

It's quick and easy to join. Just visit www.friendsofrosie.co.uk/donate and select 'I'd like to give regularly'. Follow the simple instructions and that's it. All you need is your bank details to hand. If you're not a fan of going online or don't have access, please just get in touch and we can send you a paper Direct Debit form to complete.

Once your donation is set up, you'll become an official Friends of Rosie Guardian. You'll receive a welcome letter, and, at the end of every year, we'll send you a summary of your donations and details of how your gift has helped children with cancer. Give a little each month and be the difference for children with cancer.

THE BIG GIVE



In December, Friends of Rosie took part in The Big Give Christmas Challenge – an online matched giving fundraising campaign. We were just blown away by the generosity of our supporters, raising an astounding £24,160!

We'd set an ambitious target of £15,000 and you helped us to smash it. We can't thank you enough. It was a wonderful way to end an incredibly difficult year for all charities.

Special thanks go to our pledges and The Hospital Saturday Fund as our champion. Both provided the funds to enable us to double all donations during the campaign.

We also couldn't have done this without our fantastic Young Ambassador, Ruth Grace (see page 4) and her family for supporting the charity, along with Pippa, Leila, Winter and Aimee for sharing their experiences of childhood cancer to help raise awareness in a series of videos.

Thanks also to Sally Dynevor (Sally from Corrie) and Ceallach Spellman (from Cold Feet) for supporting Friends of Rosie and encouraging others to do the same. Same time next year!

£24,160 RAISED

30TH BIRTHDAY



This September marks Friends of Rosie's 30th Birthday. We started out in 1991 with the goal of kick-starting pioneering research projects looking for cures and better treatments for childhood cancer. Since then, we've raised over £2.75million and supported 28 research projects.

The research projects that we've helped to get off the ground can lead to critical breakthroughs in our global understanding of childhood cancer and a step change in the way children with cancer are diagnosed and treated.

Research projects that we started have gone on to be funded by Cancer Research UK and the Department for Health and have led to international research partnerships between the UK, Canada, and the US.

It's no mean feat for a small charity to survive and thrive in today's climate. So, we're immensely proud of everything you've helped us to achieve and we're still going strong!

To celebrate this milestone, we'll be hosting some special events and fundraisers this September during Childhood Cancer Awareness month. Keep an eye on our website and social media pages for more details.

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CHILDREN'S CHARITIES UNITE FOR CANCER RESEARCH

Friends of Rosie and The Bradley Lowery Foundation are working together on a promising, new research collaboration for children with cancer. Starting in June 2021, we will be partnering to fund new research into the detection and treatment of a rare type of childhood bone cancer, called Ewing Sarcoma.

The project will be led by Professor Caroline Dive, Director of the Cancer Research UK Manchester Institute at The University of Manchester, and Dr Martin McCabe, Clinical Senior Lecturer, Faculty of Biology, Medicine and Health at The University of Manchester.

Our Chair of Trustees, Felicity Goodey, said "Children's cancer research gets less funding than almost any other type of cancer. Partnerships like this are essential to get more funding focused on childhood cancer research and put it in the spotlight. We're proud to be collaborating with The Bradley Lowery Foundation and using our individual strengths for the shared goal of improving outcomes for children with cancer."

Gemma Lowery, founder of The Bradley Lowery Foundation commented, "Early research is extremely important, but funding is hard to find. We believe working with charities who specialise in different childhood cancers is the best way to get more funds into the research needed."

About Ewing Sarcoma

Ewing Sarcoma is a type of bone cancer that most commonly affects children and teenagers.

It is diagnosed using an X-ray, CT, or MRI scan, and taking a biopsy of the tumour or the bone marrow. In 25% of patients, the cancer will have already spread to other parts of the body before being diagnosed. It also has a high instance of recurrence within two years of diagnosis and survival post-recurrence is dismal at a mere 10-15%.

This project will investigate using a blood sample to discover more about the tumour instead of taking an invasive tissue or tumour biopsy. This would be a far less aggressive procedure for children and could enable the earlier detection of relapse, as well as the improved monitoring of tumour response during treatment.



Sir Alex Ferguson and Mahesh

Mahesh's Story

Mahesh, from Bolton, was first diagnosed with Ewing Sarcoma when he was eight years old, in May 1998. He underwent 12 months of intensive chemotherapy, that also required him to miss nearly 14 months of school.

He then went into remission for almost 14 years. Mahesh was again diagnosed with Ewing Sarcoma at the age of 21. His second round of treatment involved the removal of his left collarbone, eight months of chemotherapy, radiotherapy, and high-dose chemotherapy.

Now, aged 31, Mahesh recalls some of what he went through and his anger at the lack of treatment progress and funding for children's cancer research.

Mahesh says, "I recall little from my illness as a young child. I have probably subconsciously blocked it out. Over time, and during my check-ups, I was told about the long-term side effects of the chemo given to me, such as kidney damage, a weakened heart and infertility. I've had annual scans and appointments every 18 months since I was eight. I'm institutionalised!

"I think what's shocked and angered me the most second time round, is how little progress there has been in the last 14 years. The same treatment options were presented to me as when I was a boy."

"As a patient, I could see little advancement. And yet, I read all the time about the great strides being made in treatments for other cancers, like prostate cancer treatment or lung cancer. Although I'm fortunate enough to be looking ahead now, I have to live with the long-term effects of my treatment. I've seen too many others like me die from this disease – young people with aspiration, talent and lives to live – and that has to change."



Mahesh Vara

SCIENTISTS DISCOVER WAY TO STOP SPREAD OF DEVASTATING BONE CANCER IN CHILDREN



Sophie Taylor, aged 5, was diagnosed with osteosarcoma. She passed away in January 2019

Research, co-funded by Friends of Rosie, could save more lives and lead to kinder treatments for children with bone cancer. Researchers at The University of Manchester and the University of East Anglia have made what may be the most significant step forward for children with one of the most common childhood cancers in 40 years.

Bone cancer in children, also known as osteosarcoma, is currently treated with a gruelling regime of outdated chemotherapy drugs and often limb amputation. But fewer than half the children survive more than five years. This is largely because bone cancer spreads rapidly around the growing body of a child, particularly to their lungs.

New research published in July 2020 identifies a set of key genes that cause bone cancer to spread to the lungs. The research was led by Dr Katherine Finegan from The University of Manchester and Dr Darrell Green, from the University of East Anglia's (UEA) Norwich Medical School.

The work, funded by Friends of Rosie at The University of Manchester, discovered that a protein called, MAPK7, controls the body's immune response to tumours and by removing it researchers can slow the growth of osteosarcomas and prevent their spread to other parts of the body.

Following the discovery, Dr Katherine Finegan and the Manchester team worked with Dr Darrell Green and his group at the University of East Anglia and together found a potential new way to treat osteosarcoma for the first time in 40 years. They are already beginning to develop new drugs against MAPK7 to benefit primary bone cancer patients in the future.

"If these findings are effective in clinical trials it would no doubt save lives and improve quality of life. The treatment should be much kinder, compared to the gruelling chemotherapy and life changing limb amputation that patients receive today."

Dr Finegan and our founder, Lisa Larkin, appeared on BBC North West Tonight to highlight the project and the vital need for more children's cancer research like this. You can watch the clip on our website - <http://www.friendsofrosie.co.uk/donate>

FACIAL DISFIGURATION PROJECT – MEET THE TEAM

Covid won't stop us in our fight for children with cancer! We're delighted that our newest childhood cancer research project is well underway, following some delays due to Covid restrictions. We caught up with the research team at The University of Manchester to find out more about them and their priorities for the first few months of the project.

The project is looking into ways to decrease the risk of facial disfigurement in children with cancers in the head and neck. As children's bones and tissues are still growing, current treatments for facial cancers in children can lead to disfigurement and a future of painful surgeries to correct the effects caused by the treatment. This pioneering new study looks to reduce those side effects to provide children with a better quality of life after treatment.



The research team is made up of Dr Marianne Aznar, Abigail Bryce-Atkinson, and Dr Rebecca Holley.

Can you tell us a bit about your background and what attracted you to childhood cancer research?

Marianne: "Having previously worked as a clinical radiotherapy physicist (healthcare scientist), I worked directly with cancer patients and saw first-hand the devastating effects of the disease on families. I was particularly interested in the late effects of radiotherapy. And so, I worked in that field of research for around 15 years, predominantly with teenagers and young adults. I then brought my late effects experience to childhood cancer research in Manchester."

Abigail: "I've just finished my PHD on paediatric radiotherapy and had a particular interest in the effects of cancer and treatment on children. When children are treated with radiation, it affects their young, growing bodies in different ways than in adult bodies. It's important to me that more research takes place to better understand the effects of treatment on children and to build the case for better and kinder therapies."

Rebecca: "I'm the Project Manager for this project. It's my role to liaise with Marianne, Abigail, Friends of Rosie, and the wider university teams to ensure the project is on track in terms of objectives, budget, and reporting."

"Working with charities, such as Friends of Rosie, we appreciate how important it is to demonstrate that donations and funds are being spent in the best possible way."

What will you be working on over the next three months?

Marianne: "Covid has caused lots of issues with regards to access to the labs and working restrictions for many researchers. However, we're quite fortunate in our team in that our project doesn't need to take place in a lab. We can remotely access the data we need for our research."

"We'll start by looking at images and scans of healthy children to compare to scans of children who have had face or neck cancers. Our focus is on a type of soft tissue tumour called, rhabdomyosarcoma."

"Up to 75% of children treated for head and neck rhabdomyosarcoma will experience some degree of facial underdevelopment as they grow. This can result in significant facial disfigurement, which can dramatically affect their quality of life."

"Our initial focus will be on developing a new method to measure facial disfigurement in children with cancers in the head and neck. We hope to then use this new method to better understand the effects of radiation on the growing skeleton of a child."

"Ultimately, thanks to Friends of Rosie and their supporters, we hope to enable "smarter" radiation treatments, leading to a decreased risk of disfigurement in the future."

Are you collaborating with any other teams on this project?

Marianne: "We will be working closely with Dr Gillian Whitfield, who is Consultant Clinical Oncologist and Clinical Oncology lead for paediatric CNS tumours here at The Christie. Additionally, Dr Eliana Vasquez Osorio, an expert Computer Scientist within our research group, on some of the techniques we will be using in this project."

We are working with Emma Foster-Thomas in the School of Dentistry at The University of Manchester to better understand the effects of radiation on growing teeth. In fact, this is the first ever research project developing specific methodology to look at the interaction between radiation and dentistry.

"We have also met virtually with Dr Indelicato in Florida. Dr Indelicato is an established cancer researcher; whose research focuses on decreasing the acute and late side effects of radiation in children and young adults. We are discussing potential future research collaborations in this area."

We'll be following Marianne, Abigail, and Rebecca over the coming year as their research progresses. We look forward to sharing with you the impact of your vital donations to Friends of Rosie and the difference you are making to children with cancer.

PROTON BEAM THERAPY PROJECT UPDATE

In our last newsletter, we shared news of a newly awarded project to kickstart promising new research into the use of Proton Beam Therapy (PBT) to treat sarcomas in children.

The project is being led by researchers at The University of Manchester, with support from The Christie NHS Foundation Trust. It is investigating the biology of protons used in PBT to treat sarcomas in children.

Covid has unfortunately delayed this project. This is due to the research labs being closed during each lockdown and priority being quite rightly given to the backlog of patients requiring PBT treatment.

However, recruitment is well underway now for a Research Associate for the project with a June start date planned. We'll keep you posted as the research gets underway.



Proton Beam Therapy at The Christie

WELCOME TO OUR NEW AMBASSADORS

Last summer, we were delighted to welcome Ruth Grace Crosby as our first ever Friends of Rosie Young Ambassador. Ruth Grace was diagnosed with osteosarcoma, a type of bone cancer, when she was eight years old in October 2016.

As a Friends of Rosie Young Ambassador, she'll be supporting the charity in promoting the work we do, suggesting new fundraising initiatives, and sharing her experiences to connect with other children who have gone through cancer treatment.

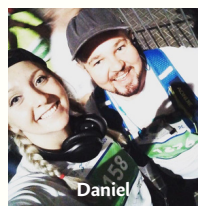
Since joining us, she's already appeared on BBC North West Tonight to promote Friends of Rosie. Her appearance coincided with her return to school after almost four years in treatment. You can watch the footage on our YouTube channel - <https://youtu.be/3eeQvnIoIMs>

Ruth Grace also supported our Christmas Campaign with The Big Give by creating a series of interviews with other children she met on the ward during her cancer treatment (available to view here - <https://www.youtube.com/channel/UCtoIfoutyUnOKExbrA8S2oA>).

She's been relentless in her fundraising activities too, having fundraised online for International Childhood Cancer day in February and sold hair ribbons during lockdown. We're so proud to have you as part of our team, Ruth Grace. You're certainly making a difference.



Ruth Grace



Daniel

Earlier this year, we also welcomed Daniel Richardson as a Friends of Rosie Ambassador. Daniel has supported the charity for several years with running events and challenges. Last year he ran 5k every day for Friends of Rosie (see opposite) and held numerous virtual quiz events during the various lockdowns. Welcome to the team Daniel and a huge thank you for all that you have done for us already.

EASTER EGGSTRAVAGANZA AT HALE PREP



Prisha & Amirah

Hale Prep school proved themselves to be true chocoholics (and eggcellent fundraisers!) this Easter. They raised a cracking £1,000 for Friends of Rosie in their Easter egg raffle.

Our huge thanks go to all the children, families, and staff at Hale Prep school for their continued support of Friends of Rosie. Here are the worthy winners of the Easter egg raffle.

Well done to Artis, Prisha and Amirah. We hope you enjoy all that delicious chocolate.

KIDS FUNDRAISING DURING LOCKDOWN

Although children across the UK were stuck at home for much of 2020, they made the best of the time by completing some wonderful fundraising challenges.

Daisy, aged nine, completed The 2.6 Challenge during the first lockdown. Her challenge included a 2.6k run, 26 skips, 26 star jumps, 26 burpees and 26 toilet roll keep ups. She raised £10 for each completed challenge, reaching a grand total of £50.

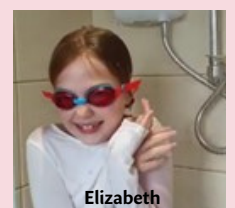
Oscar, aged nine, and George, aged seven, also completed The 2.6 Challenge, culminating in wearing 26 items of their mum's clothes! They raised just over £600.

And a massive well done to nine-year-old, Elizabeth, who raised £350 with her cold shower challenge for children's cancer research.

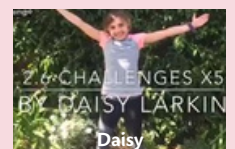
It is wonderful to see so many children raising money to help other children. There are endless benefits to getting children involved in fundraising and supporting charities and we're so grateful for all your worthwhile efforts.



Oscar & George



Elizabeth

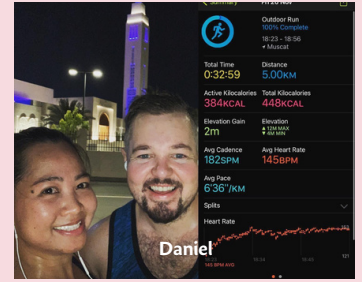


Daisy

A YEAR RUNNING 5K EVERYDAY

A massive thank you and congratulations to our supporter and ambassador, Daniel Richardson. After a whole year of running 5k every, single day, Dan's childhood cancer challenge came to an end in January.

He ran over 1,830km and raised almost £3,500. He celebrated his final two runs via a live event on our Facebook page. He was joined virtually by runners in the UK and Oman (where he now lives) as he marked the end of his inspiring challenge.



Daniel

As a childhood cancer sufferer himself, Dan, now aged 34, is a symbol of hope to many families. To see him living a full and healthy life, after experiencing cancer as a child, is all parents want for their own children.

And to dedicate a whole year, especially during a global pandemic, to running 5k a day and fundraising for other children with cancer, is just awesome. A huge thank you and well done from all of us.

MANCHESTER UTD SUPPORTERS CLUB

Thank you to the Middleton Manchester United Supporters Club for their kind and generous support. We received a much-needed donation of £500 from the club to support children's cancer research projects.

The club chose Friends of Rosie as one of their members lost their grandchild earlier this year to leukaemia at the age of 12. We are incredibly grateful to all the club members for your kind support and to the Manchester United Foundation for coordinating and encouraging local fundraising.

THANK YOU, SIR ALEX FERGUSON

Our huge thanks go to Sir Alex Ferguson, our long-serving Patron, for his recent donation to children's cancer research.

Friends of Rosie received the generous donation from Sir Alex through The Elizabeth Hardie Ferguson Charitable Trust Fund. He set up the Trust in memory of his mother.



Sir Alex Ferguson

HAIRCUT FOR RESEARCH



Joanne

Joanne Crosby, Ruth Grace's mum, celebrated hairdressers being open once again by having her hair cut short to raise funds for Friends of Rosie.

Joanne has had long hair since being a teen but had 12 inches of hair cut off. The hair was donated to The Little Princess Trust who make wigs for children suffering hair loss. Joanne raised just over £200 for children's cancer research and looks fab with her new bob!