

## A letter from our Board of Trustees

*"A wife who loses a husband is called a widow. A husband who loses a wife is called a widower. A child who loses his or her parents is called an orphan. There is no word for a parent who loses a child. That's how awful the loss is."*

- from an Orphan's Tale by Jay Neugeboren.

Dear Supporters

This quote was sent to us by the Chairman of our Scientific Advisory Board (SAB), Professor John Hickman. It is the reason why he, and the other distinguished doctors and scientists who are members of our SAB, give huge amounts of their time and expertise to help Friends of Rosie identify promising research, which you, our supporters, make it possible to fund.

Since the COVID-19 pandemic struck, all attention has been focussed on the need to beat it. But up and down the country, many parents are battling, not just this virus, but the fear of losing a child to cancer.

Friends of Rosie's latest call for new research projects attracted a record number of exceptionally high-quality proposals. We fund the ones recommended by our scientific advisors. The details of our newest research programmes can be found on page two.

But there were other projects, equally good, which at present we cannot afford to fund.

Could you help us to raise funds so that more research projects, already identified by our experts, can be funded as well?

Research saves lives. Young lives will be lost, not from COVID-19, but from cancer unless we find the money to pay for the research and save another family from losing a child.

We need you now more than ever to ensure the needs of children with cancer are not forgotten in the coming months as the country recovers from this pandemic and the economic consequences of the 'lock down'. From fundraising, to making a one-off or regular donation, there are lots of ways you can help. Friends of Rosie has only one part-time paid member of staff and no expensive offices. We are volunteer-led meaning that almost all the money you raise goes directly to fund high quality research.

We know that times will be tough for many individuals, businesses, clubs and community groups. Any support, no matter how small, you can offer will make a huge difference in the fight to save children from cancer.

With sincere thanks,  
**The Friends of Rosie Board of Trustees**



## Fundraising ideas – online, virtual and at home



### DONATE YOUR COMMUTE

If you are saving money on your daily commute to work or if you are a season ticket holder and have secured your refund from your rail or bus company – why not donate some of that to Friends of Rosie?  
<https://www.friendsofrosie.co.uk/donate/>



### HOME CHALLENGES

If you're at home with children, set them a challenge and sponsor them for it. It could be cooking, cleaning, or making something. From den building and Lego constructions, to doing chores or taking care of the family pet. Your children can learn, have fun and raise money.



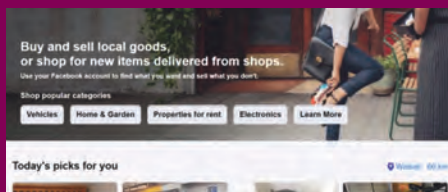
### FITNESS CHALLENGE

Make do with what you have access to and set yourself a fitness challenge. From climbing 100 stairs a day, to running 50 laps of your garden. You choose the challenge, take photos, and ask for sponsorship. You could try a 100 push-ups a day or perfect the most challenging yoga poses. You decide.



### VIRTUAL PUB QUIZ

You don't need a pub to hold a pub quiz! Host a virtual pub quiz and connect with family and friends while raising money. Using Zoom or House Party, get some quiz questions together and ask friends and family to donate to take part. Most of all - have fun!



### HOUSE CLEARANCE

Have a good sort out of your wardrobe, loft or cellar. One man's trash is another man's treasure! Sort out your items, sell them online (try Facebook Marketplace, eBay, Gumtree or Preloved), and donate the money raised.



### AMAZON SMILE / BIRTHDAY DONATIONS

Whenever you shop on Amazon, shop via [smile.amazon.co.uk](https://smile.amazon.co.uk). Select Friends of Rosie as your charity and you'll donate with every purchase. Birthday coming up and can't be with friends and family? Set up a Facebook fundraiser and ask them to make a donation in your name.

Set up your fundraising page at [uk.virginmoneygiving.com](https://uk.virginmoneygiving.com)

# Our research projects

## Research news

In our latest research grant call, we have awarded grants to two very promising research studies. Both are being led by researchers at The University of Manchester.

The first is investigating the biology of protons used in Proton Beam Therapy to treat sarcomas in children. We are very fortunate to have the first Proton Therapy facility in the UK at the Christie Hospital in Manchester, a long-term research partner of Friends of Rosie. The new centre includes a research room so that the proton beam can be used not only to deliver lifesaving treatment, but also to carry out ground-breaking research

The second project is investigating ways to enable smarter radiation treatments to prevent facial asymmetry in children with cancer. Due to the coronavirus, there will be a delay to the start of these projects, as some resources are being used to research COVID-19 vaccination or labs are closed due to social distancing. We'll announce the start dates on our website in due course.



## Project 1: The biology of protons in Proton Beam Therapy to treat paediatric sarcomas

Professor Karen Kirkby and Dr Amy Chadwick at The University of Manchester will lead this project. Their project has three main aims: to better understand the biology of protons in Proton Beam Therapy (PBT); to investigate the use of PBT on radiation-resistant tumours with low oxygen supply; and to better understand the use of drug therapies alongside PBT in children. Dr Chadwick summarises the project below:



"Sarcomas are cancers that can develop in bone and soft tissues anywhere in the body. Due to their rarity, diversity, and treatment complexity, sarcomas in children require careful, individualised treatment.

"Many paediatric patients benefit from radiotherapy as part of their treatment for sarcoma. The most common type of radiotherapy uses X-rays. Although this type of radiation is highly effective, it can cause collateral damage to the healthy tissue that surrounds the tumour, which can result in serious side effects. The developing tissues in children are particularly sensitive.

"To reduce the damage to healthy tissues, whilst still eradicating the tumour, PBT, an advanced type of radiotherapy can be used. A high energy beam of protons is used to precisely target the tumour while minimising damage to surrounding healthy tissue. This makes PBT the preferred radiation treatment for paediatric sarcomas. But there is still a lot to learn about how PBT affects

both tumour cells and those of normal tissues. This funding from Friends of Rosie will allow us to undertake the first and most comprehensive study of PBT in paediatric sarcoma cells using the dedicated research room at The Christie.

Continues Dr Chadwick, "As part of this study we will focus on the oxygen level of tumours. As a tumour grows, it can outstrip its blood supply, leaving some regions of a tumour with significantly lower levels of oxygen. This "tumour hypoxia" causes resistance to radiotherapy, as well as making tumours more aggressive with the potential to metastasise. Our study will mimic the low oxygen environment of tumours during irradiation with PBT so that we can understand how cells in the most resistant parts of a tumour respond to protons. During this study we will perform high throughput drug screening using sarcoma cells to identify potential treatments that may enhance the effectiveness of PBT and overcome the resistance caused by low oxygen levels. The Friends of Rosie funding will allow the first steps in identifying new treatment combinations, which may ultimately make PBT more effective and kinder to children with sarcoma."

## What's next for our osteosarcoma project?

Over the past two years, we have pumped almost £130,000 into a project with Dr Katherine Finegan researching the treatment and detection of osteosarcoma in children. Dr Finegan summarises below the key findings from the project:



"We researched the role of a protein called ERK5, which is believed to advance the spread of osteosarcoma tumours. During the project, we found that ERK5 is needed for the spread of osteosarcoma. Treating osteosarcoma that has spread or metastasised is

very difficult and outcomes for children with metastases have remained virtually the same for 30 years. However, our data looks to change that, by highlighting ERK5 as a new target for the treatment of metastatic osteosarcoma. Thanks to the success of our initial research funded by Friends of Rosie, we have now attracted funding from Cancer Research UK to develop new drugs that block ERK5. These drugs are very effective in our initial testing in osteosarcoma."

The aim of Friends of Rosie is to kickstart or pump-prime new research projects, giving researchers one to two years of initial results and data. This is the hardest funding to attract and only Friends of Rosie specialises in providing it. We measure success if initial research funded by us enables a project team to secure longer term, larger scale funding from bigger charities and medical institutions.

Friends of Rosie funded Dr Finegan's project for two years and we are delighted to confirm that the project has now secured a further three years of investment to begin the development of new drugs to treat osteosarcoma.

The new three-year project will be funded by specialist charity, Hannah's Willberry Wonder Pony. We hope that the research goes on to achieve large-scale funding that will truly help to make a difference to children with osteosarcoma in the future.

## Project 2: Preventing facial disfiguration in childhood cancer survivors



Dr Marianna Aznar and Dr Gillian Whitfield lead our second project investigating facial asymmetry as a result of radiotherapy. As children's bones and tissues are still growing, current treatments for facial cancers in children can lead to disfiguration 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 is led by The University of Manchester and The Christie NHS Foundation Trust, in collaboration with The Royal Manchester Children's Hospital. Dr Aznar summarises the aims of the project below:

"Radiotherapy is an essential treatment component for many cancers. In children, radiotherapy strongly affects bone and tissue growth. For children treated in the head and neck, especially if only one side of the face is treated, this can result in noticeable disfigurement and asymmetry. Rhabdomyosarcoma tumours located in the head or neck will be the key focus of this study. Up to 75% of patients treated for head and neck rhabdomyosarcoma will experience some degree of facial underdevelopment resulting in marked facial asymmetry, which can affect quality of life. Research to understand, reduce, and even prevent side effects is sorely needed.

"In adult head and neck cancer considerable effort has been put into deriving the best doses of radiation to minimise the effects on healthy tissue and to reduce patient side-effects. In contrast, our understanding of the effects of radiation on the growing skeleton of a child is insufficient and current guidelines do not allow for slight variations in clinical decision-making.

"Through this project, we want to develop a new method to measure facial asymmetry in children, using the images routinely acquired during follow-up examinations, for example, MR and CT images. By analysing the measurements from these images, we hope to learn exactly how radiation affects bone growth in the face. At The University of Manchester, we are also collaborating with the Division of Dentistry because often facial asymmetry requires orthodontics treatment.

"Ultimately, we hope to enable "smarter" radiation treatments, leading to a decreased risk of disfigurement in the future."

### Emma's story

Emma Payton, now aged 15, was eight years old when she underwent treatment for alveolar rhabdomyosarcoma, a soft tissue tumour. The tumour was in her masseter muscle in her cheek and wrapped around her right cheekbone. Emma was treated with Proton Beam Therapy, which was successful, but left her with facial disfigurement.

Says Tracey, Emma's mum, "Emma's jaw hasn't grown on the side she was radiated, and she lost a lot of muscle mass on one side of her face when the tumour was operated on. Ahead of her, she has orthodontic surgery to reposition her teeth, jaw realignment surgery, and an operation to remove muscle from her thigh to implant into her face.

"We are truly grateful that Emma's cancer treatment saved her life and she now has the option of cosmetic surgery. She has several painful procedures ahead of her and she wants to go through with them to improve her life as a young woman and hopefully prevent her from being defined by childhood cancer as an adult. Children with cancer go through so much, so any way to minimise these late effects and to give them the chance to truly get on with living after treatment is essential."



## Children and Young People's Cancer Coalition



During 2019, the CEOs of some of the bigger cancer charities set up the Children and Young People's Cancer Coalition. As the remit of the coalition has expanded, so has the membership and Friends of Rosie was invited to join as an associate member in the summer.

The purpose of the coalition is to help reduce duplication between cancer charities, to share best practice and insight, and to amplify policy and campaigning voices.

At Friends of Rosie we measure success by our projects being published in recognised medical research journals and going on to attract larger scale funding from other organisations. Collaborating with the other cancer charities interested in childhood cancers and gaining a better understanding of the research picture across the sector is of great benefit. We can inform the other coalition members of our research projects and connect our researchers, in the early stages, with potential future funders for their projects.

Being part of a coalition also ensures that everyone is looking at the bigger picture and that children with cancer remain at the heart of everyone's objectives.

## AMRC membership

We're very proud to announce that Friends of Rosie is now a fully-fledged member of the Association of Medical Research Charities (AMRC).



The AMRC is the UK's national membership organisation for health and medical research charities. It brings together and supports health and medical charities to produce high-quality research.

AMRC membership gives our supporters further assurance that any money donated to Friends of Rosie will be used to fund only the most promising research projects as recommended by a panel of independent experts and specialists.

Membership status recognises the strength of our governance procedures and policies. We have also published a new research strategy, which can be viewed in the research section of our website, along with a whole host of information about the way we measure and monitor the research we fund.

One of the main criteria for membership is a strong peer review process to assess research applications. We are fortunate that we already have a distinguished and experienced Scientific Advisory Board (SAB) guiding and informing our research decisions. All research applications we receive are peer reviewed in line with AMRC guidance. We have further strengthened our SAB with the addition of Professor Juliet Gray, Associate Professor and consultant in Paediatric Oncology (Southampton) and Dr Sam Behjati, Consultant Paediatric Oncologist (Cambridge). The panel, chaired by Professor John Hickman, also recruits additional specialists where necessary to review particular research applications.

For Friends of Rosie, AMRC membership not only recognises we fund the very best research. It also presents the opportunity to connect and collaborate with other charities and research institutions. Only through collaboration can all charities collectively make a real difference to children with cancer..

## Kilimanjaro challenge raises £15,000



A group of pioneering friends set themselves the challenge of climbing up and cycling down Mount Kilimanjaro. They raised a tremendous £15,000 for childhood cancer research.

In October, the team of twelve completed their Kilimanjaro challenge in just five and a half days. So massive is Kilimanjaro that to climb it is to pass through four seasons in four days, moving from +40c at the foot of the mountain down to -25c at the top.

Our huge thanks go to the whole team and everyone who donated. Special recognition goes to team members, Jon Goodwin and Justin Law, who were integral in reaching such an impressive fundraising total

## Daniel's run 5k everyday challenge

Daniel Richardson, set himself the challenge of running 5k every day during 2020. Daniel was diagnosed with Acute Lymphoblastic Leukaemia when he was just three years old. He was on the same ward, back in 1989, as little Rosie in whose memory our charity was founded.

Today Daniel is a fit and healthy 33 year old, who has already raised just over £650 - <https://uk.virginmoneygiving.com/DanielRichardson8>.

## PJ Livesey go gold for childhood cancer



Throughout September last year, Trafford-based property developers, P J Livesey, turned gold in support of Childhood Cancer Awareness Month. Their fundraising efforts raised a whopping £2,180.

Dorothea Livesey, of P J Livesey, commented: "We are delighted to support this very worthwhile local charity and help raise awareness for childhood cancer research."

## Square wheels club support

The members of the Square Wheels Lodge based in Coventry have chosen Friends of Rosie as their charity for 2020.

They have organised a whole host of events in support of Friends of Rosie. Our thanks go to Peter Hughes, Doug Squires, and all lodge members for their kind support.

## MAXIMUS Foundation support



Thanks to an employee nomination scheme, Friends of Rosie was the beneficiary of a £2,500 grant from the MAXIMUS Foundation UK.

Our thanks go to MAXIMUS Foundation Trustee, Kristina Moore, and to Sarah Taylor who nominated us. They presented the cheque donation to us at the Manchester Cancer Research Centre.

## Christmas giving

A big thank you to everyone who supported Friends of Rosie by ordering your Christmas cards via [charitycards.co.uk](http://charitycards.co.uk).

Thanks also to those who displayed our Christmas message posters, particularly Hardwicke House Group Practice in Sudbury, who displayed the posters across their five surgeries. And a huge thank you to the team at RMS in Altrincham for supporting us at their #RMSQuizmas raising £300. We also received several kind donations from supporters giving in lieu of sending Christmas gifts and cards

## Deans Court Chambers run for Rosie



A team of members and staff from leading Manchester-based barristers', Deans Court Chambers, ran the 2019 Manchester 10k raising £2,000 for Friends of Rosie.

## One month, run every day = five marathons!

Our own communications manager, Helen Griffin, set herself the challenge to run every day during September totalling 211km – the equivalent of five marathons!

She also did a Sober September and managed to raise just over £1,000 in the process. Our huge thanks go to everyone who donated and a special thank you from the Trustees who are in awe of Helen's incredible energy and passion for our charity.

## Gatley Memory Walk

In recognition of Childhood Cancer Awareness Month, the End of Treatment Bells and the local community in Gatley village held a Memory Walk to remember loved ones.

The walk raised over £1,000, with £500 being donated to Friends of Rosie to support new childhood cancer research projects. Our huge thanks go to Tracey Payton, founder of the End of Treatment Bells, and everyone who attended, helped to organise, and supported the Memory Walk.

## Easy ways you can help

If our newsletter inspires you to become a friend of Rosie, here are some simple ways to help:

- ✓ **FUNDRAISE** via the Virgin Money Giving website
- ✓ **NOMINATE** Friends of Rosie as your charity of choice at work or at your child's school, nursery or college
- ✓ **DONATE** via bank transfer, by cheque or via PayPal
- ✓ **GIVE** your time to support our charity events
- ✓ **SHARE** your experience of childhood cancer

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