



# News from Friends of Rosie

SUMMER 2023



CHILDREN'S CANCER RESEARCH FUND

## COLLABORATION IS THE KEY TO CURE

September is here and that means it's Childhood Cancer Awareness Month – a month to raise awareness of the vital need for more dedicated children's cancer research. To mark this year's Childhood Cancer Awareness Month, we're proud to announce new partnerships and fund-raising opportunities all featured on our relaunched and upgraded website.

Our focus over the past few years has been about building our network and our partnerships with other like-minded charities for the good of children with cancer. As a small charity, we know we'll have far greater impact if we collaborate with others. That collaboration takes many forms. From fundraising together, to jointly funded research projects, to hosting research events and raising awareness of the need for more children's cancer research.



On our new website, you'll see some of the great organisations and charities we've partnered with so far, including The Bradley Lowery Foundation, Neuroblastoma UK, Megan's Rose of Hope and Willberry Wonder Pony.

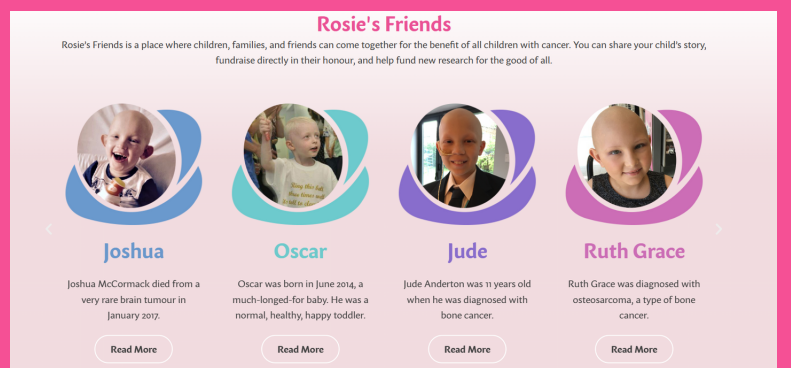
### ROSIE'S FRIENDS

We've also developed a new fundraising channel called Rosie's Friends. Rosie's Friends is a place where children, parents, families, friends, and supporters can come together for the benefit of all children with cancer. They can share their child's story, fundraise directly in their honour, and help fund new research for the good of all.

We're firm believers in the adage that we're stronger together. We know we can make a far greater contribution to the world of research if we work together.

Research has saved the lives of eight out of ten children who now survive their cancer for five years or more. Not all are so lucky. For some types of childhood cancer, cure rates are much lower. In the UK, around 230 children die from cancer each year. Cancer remains the number one cause of death by disease for children and those who survive often endure harsh painful treatments which leave them with life-long consequences. To save lives and reduce the pain and harm from many of the present treatments more pump-priming research is desperately needed.

This Childhood Cancer Awareness Month, you can be the difference by supporting more research. Visit [www.friendsofrosie.co.uk](http://www.friendsofrosie.co.uk) to find out more, donate, or become one of Rosie's Friends.



### FRIENDS OF ROSIE FOUNDER, LISA LARKIN, AWARDED MBE

Earlier this year, we were delighted to announce that Lisa Larkin, the founder of Friends of Rosie, was awarded an MBE for charitable services in His Majesty, The King's Birthday Honours List for 2023.

A Member of the Order of the British Empire (MBE) is awarded for an outstanding achievement or service to the community by an individual.

Lisa has worked tirelessly over the past 32 years to raise funds and awareness for children's cancer research since losing her four-year-old daughter, Rosie, to the disease in 1991.

Lisa's decision to use her daughter's death as a force for transforming the life chances of children with cancer everywhere, has made a major, some might say unique, contribution into vital research to unlock potential treatments and cures for children with cancer.

Along with family and friends in the Northwest of England, Lisa

started Friends of Rosie to fund pioneering research into the causes, diagnosis, and treatment of childhood cancer. Says Lisa, "I feel so honoured to be given this award which enables me to thank all those people who contributed their time, skills, and support over many years. This honour is for them as well as me. Despite advances in the treatment of childhood cancer since our daughter died, there are still many childhood cancers with a poor outlook and today's treatments continue to be harsh, unpleasant, and uncertain.



"I would just like to see a situation where no more parents have to sit in front of a doctor and be told, "We can't cure your child". Dedicated research into childhood cancer is the only thing that will change the outlook for children."

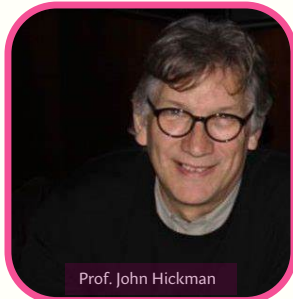
## STRENGTHENING OUR SCIENTIFIC ADVISORY BOARD

Since our last newsletter, we've recruited several new experts to our Scientific Advisory Board (SAB). The quality of our SAB has always been a strength of our charity and we put a lot of work into ensuring we have a good mix of experience, geographical spread and, most importantly, independent advice.

This year, we said goodbye to our SAB Chair, Professor John Hickman. John has been with Friends of Rosie for a number of years and given invaluable advice and guidance to the charity. John was also the brains behind our new series of international research workshops, bringing together experienced clinicians and the best and brightest minds in paediatric oncology research to share research and ideas on how better to target treatments for children with cancer. Even better, he secured funding for the workshop from some of the big pharmaceutical companies, who have been reluctant in the past to support research into childhood cancers.

Our huge thanks go to John for everything he has done for Friends of Rosie over the years, and we wish you a healthy and happy retirement.

With John's departure, we've welcomed our new SAB Chair, Dr Mark Gaze. Mark has been a consultant clinical oncologist at University College London Hospitals and Great Ormond Street Hospital for Children since 1993. His areas of expertise include the management of cancer in children



Prof. John Hickman

and young people with radiotherapy, and the use of radionuclide therapy in adults and children.

Mark hasn't wasted anytime since being appointed and has already rotated new members onto the SAB. As a member of the Associated Medical Research Charities (AMRC), we have to rotate our SAB members every three years.



Dr Mark Gaze

So, this year, we also welcome Dr Kyle Matchett, Dr Gail Horan and Dr Helen Bryant to our SAB. Kyle is a Lecturer in Molecular Immunology and Principal Investigator (PI) at the School of Medicine, Ulster University. Gail is the Radiotherapy Lead for Sarcoma and Paediatrics at Addenbrooke's Hospital in Cambridge. And Helen is Senior Lecturer and Head of The DNA replication and repair group at the University of Sheffield.

They join our current SAB members, Dr Sally George and Dr Juliet Gray, giving us an exceptional SAB ready to advise the Friends of Rosie Trustees on the most promising areas of children's cancer research. Welcome on board.

Our kind thanks go to Dr Sam Behjati, Dr Frank Mussai and Professor Deborah Tweddle who have rotated off the SAB this year. Your guidance as been hugely beneficial in ensuring we only fund the very best research ideas.

## PROTON BEAM THERAPY PROJECT COMPLETES FIRST YEAR

Friends of Rosie has funded a £70,000 project investigating the biology of protons used in Proton Beam Therapy (PBT) to treat sarcomas in children. We recently met with lead researcher, Dr Amy Chadwick, and Research Associate, Dr Emma Biglin, to find out more about this pioneering research.

Radiotherapy (RT) is an essential component of curative paediatric cancer treatment. PBT uses high energy proton beams in place of conventional X-rays. The unique physical properties of protons means that protons stop at a precise depth in tissue, with no radiation dose delivered beyond.

As such, PBT can deliver a highly conformal radiation dose to a tumour, whilst dramatically reducing the volume of normal tissue irradiated, thus reducing the chance of toxicities and second cancers. This is particularly important in the paediatric setting, where developing normal tissues are more sensitive to radiation, which can result in long term complications of treatment, with some studies reporting up to 100% of patients developing radiation-induced late effects.

Explains Dr Chadwick, "Understanding how tumour cells respond to PBT, particularly in regions of the tumour that are most radioresistant, would be a huge step towards being able to therapeutically exploit the understudied biology of protons and could fundamentally impact the use of PBT in the clinic. To date, no studies have reported any pre-clinical data in paediatric sarcoma models with PBT, despite PBT being such an important treatment option for these patients.

"The cellular response to PBT is understudied and this is compounded by limited access to both proton beam infrastructure and proton beam time. Proton beams are almost exclusively located within clinical hospital facilities or physics institutes, often without access to the equipment, facilities or expertise required to perform comprehensive biological experiments. This is why PBT radiobiology has been understudied, historically in non-clinically relevant models in low throughput. This is one reason why expertise from decades of clinical experience and pre-clinical research with conventional RT has simply



Dr Amy Chadwick



Proton Beam Therapy Centre at The Christie Hospital

been translated to PBT treatment by use of a simple weighting factor. We are uniquely positioned in Manchester with our dedicated PBT research facility including bio lab and PBT radiobiology end station with accurate O<sub>2</sub> control. This capability, with automation, is currently not available anywhere else in the world and puts us at a real advantage in carrying out experiments.

"Our project was ambitious, and we are incredibly pleased with the amount of data that we have been able to generate with this funding, both in terms of understanding how paediatric sarcoma cells respond to PBT and by identifying potential therapeutic combinations that overcome treatment resistance. Both areas are critical to harness the full advantage of PBT to enable kinder and more effective treatment for children with cancer, identified as the top priority for children's cancer research.

"We now aim to further our current study to allow us to delve into the mechanisms behind the PBT-inhibitor combinations, such as a detailed understanding of DNA damage and repair and pathway changes in response to the combinations, working with collaborators to take the PBT combinations into more complex clinically relevant 3D models of paediatric sarcomas.

"We also propose to link with children's cancer researchers at other centres across the UK to harness expertise and models for individual disease subtypes, potentially applying for pump-priming or seed funding via Cancer Research UK RadNet."



# PIONEERING RESEARCH FOR CHILDREN WITH HEAD & NECK CANCERS

Over the past 12 months, Friends of Rosie has funded research at The University of Manchester looking at ways to decrease the risk of facial disfiguration in children with cancers in the head and neck.

Dr Marianne Aznar and her team have been looking at how we could enable 'smarter' radiation treatments, leading to a decreased risk of facial disfiguration in the future.



Dr Marianne Aznar

We caught up with Dr Aznar, to find out what the research team have discovered over the past year.

"The aim of this project was to develop new methods of measuring the changes in the face of childhood cancer survivors who might have received radiotherapy to a part of their face. There's two things that we wanted to demonstrate were feasible. One was to use routine images so not have to ask those childhood cancer survivors to come back to the hospital for a specific evaluation but instead use images that were acquired as part of their follow-up. And the second aim was to measure facial asymmetry in such a way that we could link it to the radiation treatment so that, in the future, we can provide better and gentler treatments.

"We know that for children who have received radiotherapy to the face, their bones and their tissues start growing a little bit differently on the side where they receive radiation and obviously that has major impacts on their quality of life and on their self-image. It can also have some functional impacts for example on their teeth if their jaw is not growing correctly. However, we have very little data on exactly what amount of radiation to which part of the bones causes those problems.

"So, what we wanted to do was to find a much more detailed way of looking at the impact of radiotherapy on the bone in the hope that we can in the future either give better information to survivors or their family, or to make or radiotherapy a little bit smarter so that it has less of an impact.

"What we discovered is that by using images that were acquired for the cancer follow-up, we can have a very good idea of what's happening to the rest of the face. At the beginning, we were hoping to show that using those images was as good as having an individual, expert person looking at those bones and saying how much they have changed. What we found is that it's better. It's more reliable, it's more precise and it's more reproducible in different type of images.



Emma Payton has facial asymmetry following her treatment

"That was a great discovery for us, and it enables us to go to potential international partners and see if we can join forces and collect all those images from a large cohort of children so that we can learn enough to improve radiotherapy.

"Now that we've come to the end of our funding award with Friends of Rosie. I just want to give a huge thank you to all the supporters and the fundraisers that have enabled us to carry this research forward. Getting pump-priming money and generating just this initial data is the hardest kind of research funding to get. It would not have been possible without your support."

## COULD A BLOOD TEST DIAGNOSE EWING SARCOMA?

Friends of Rosie joined forces with another like-minded charity, Megan's Rose of Hope, to fund research into the use of a revolutionary new blood test to diagnose Ewing Sarcoma, a rare type of bone cancer. In 1 in 4 children or young people with Ewing Sarcoma there is little chance of survival because the cancer has already spread by the time it is detected with present methods.

We jointly awarded £70,000 for a second year of research looking for a reliable diagnostic blood test. The first year's research was also funded by Friends of Rosie in partnership with another children's cancer charity, The Bradley Lowery Foundation.

The research is taking place at the Manchester Cancer Research Centre and The Christie Hospital in Manchester. The research team includes specialised biomarker researchers, Professor Caroline Dive and Dr Dominic Rothwell, with Ewing Sarcoma focussed clinician, Dr Martin McCabe.

During this second year of research, the team are continuing to collect blood samples from Ewing Sarcoma patients treated at the Christie Hospital for use in the validation of a liquid biopsy assay. They will then further test the assay on Ewing Sarcoma cells and compare RNA and DNA. Please look out on our website for further updates on this project coming soon.

## WELCOME TO OUR NEW TRUSTEES!

We're delighted to welcome on board two new Trustees this year.

Joanne Crosby joined our Board of Trustees as a Parent Trustee. Joanne is mum to our Young Ambassador, Ruth Grace. Her first-hand experiences as a parent of a child who has had cancer are invaluable in helping us to always ensure that children are at the heart of every decision we make at Friends of Rosie. Joanne has settled into her new role very quickly, already organising a Christmas party in December for the oncology wards at The Royal Manchester Children's Hospital.



Joanne Crosby

Katrina London joins our Board in September and brings with her years of experience working in a similarly rare field of cancer. Says Katrina "I have

worked for mesothelioma (asbestos related cancer of the lining of the lung) sufferers for many years and for much of that time there have been limited treatment options. Like childhood cancer, it is a rare cancer and therefore does not appeal to the big pharmaceutical companies.

"Research into childhood cancers faces the same challenges as mesothelioma research and which is why the work done by Friends of Rosie is so important. I am very much looking forward to being part of the team that supports the research projects that may lead to cures and/or treatments with improved outcomes. The loss of a child to cancer has a devastating impact on a family but can also be a huge loss to society as a whole. I feel that being part of a charity that is working to prevent



Katrina London

# CALLING ALL VOLUNTEERS

As a small, volunteer-led charity, we are always looking for the volunteer support of willing and skilled individuals who want to give back.

There are lots of ways to volunteer your time and effort that will make a huge difference to children with cancer. These include:

- Administrative support
- Marketing & PR support
- Graphic design
- Video production and editing
- Business planning / strategy
- Social media support
- Governance advice
- Fundraising

Our aim is simple: To raise as much money as we can to funnel straight back into vital and underfunded children's cancer research. We want the money we receive from donors and supporters to go straight into research and not into running the charity.

To achieve this, we keep our overheads to an absolute minimum with only one part time member of staff and donated office space.

**VOLUNTEERS ARE CRITICAL TO OUR SUCCESS. WE ARE LOOKING FOR PEOPLE FROM ALL WALKS OF LIFE AND A VARIETY OF EXPERIENCE. IF YOU'RE INTERESTED IN VOLUNTEERING, PLEASE JUST GET IN TOUCH TODAY TO FIND OUT MORE - HELEN.GRIFFIN@FRIENDSOFROSIE.CO.UK**

## VOLUNTEER PROFILE

In June, we were delighted to welcome Kym Green as a regular volunteer for Friends of Rosie.

Kym is supporting some of the key administration requirements of the charity, in particular our research requirements and Scientific Advisory Board. She qualified as a chartered accountant in Australia and came to the UK in 1986. After initially working in a property company and in a public company preparing management accounts and ensuring delivery of statutory reporting requirements, she joined the NHS in 1994.

During her NHS career of over 25 years, she held a number of senior finance roles in primary care NHS Commissioning Trusts across Manchester.

At the time of her retirement in 2019, she was Associate Chief Financial Officer for Manchester CCG responsible for the contracting function between commissioning and NHS provider organisations within Manchester.

Says Kym, "I've been aware of Friends of Rosie for some time since my own children were young. I'm keen to use my retirement to give back through volunteering and hope that my experience of engagement with clinicians around service reform, alongside my financial skills, will benefit the charity and support the SAB and Trustees."



Kym Green

## THANKS TO OUR AMAZING CORPORATE SUPPORTERS

We couldn't do what we do without our supporters. Thanks to their kind and generous support, we can fund more pioneering children's cancer research, providing life-changing and life-saving results. Our family supporters do a fantastic job in raising both funds and awareness and we have too many amazing individual supporters to mention them all personally here. But we can acknowledge the fantastic support of our some of our corporate supporters who make a huge difference to the impact we can make. This issue, we'd like to thank Exchange Chambers and the P J Livesey Group.

### EXCHANGE CHAMBERS



Exchange Chambers is aiming to fund a new children's cancer research project after naming Friends of Rosie as its official charity partner.

Exchange's partnership with Friends of Rosie, which will run until 2024, will see the award-winning barristers' Chambers support the charity through a wide range of fundraising initiatives.

In particular, Exchange's fundraising will aim to fund a new research project to help find cures, better treatments, and improved diagnosis for children with cancer.

Jonathan I'Anson, Chief Executive at Exchange Chambers said, "The research ideas Friends of Rosie funds are right at the outset of medical thinking and innovation. Planning is already underway for several fundraising events, including a Charity Ball later this year. We are determined to raise significant funds to support vital children's cancer research."

As well as regular fundraising initiatives throughout the year, Exchange Chambers host an annual charity ball. Last November, the ball raised a huge £17,000 for children's cancer research. The next ball will be held this November, where they're looking to smash last year's total!

### P J LIVESEY GROUP

P J Livesey Group chose Friends of Rosie as their Charity of the Year. The team have been doing a fantastic job fundraising for research. From raffles and cake sales to Christmas jumper days and Coronation celebrations. They also make a monthly corporate donation to Friends of Rosie.

Based in Manchester, for over 40 years the P J Livesey Group has been at the forefront of specialist property development and restoration, taking a determined approach to put quality first every time.

Dorothea Livesey, of P J Livesey, said "We are delighted to support this very worthwhile local charity and help raise awareness for childhood cancer research. My thanks go to everyone who helps in organising events and donating. We are proud to support an independent, volunteer-led charity to help make a difference to children with cancer."



### COFFEE AND MARMALADE RAISES HUNDREDS

Our kind supporters, Philip and Julia Hyde, held a coffee morning and marmalade sale in aid of Friends of Rosie.

Thanks to the huge generosity of everyone who attended the event, an impressive £700 was raised in support of childhood cancer. Events like this really do make all the difference to the projects we support and fund. Our huge thanks go to everyone who attended the coffee morning and kindly donated, and our special thanks to Philip and Julia for being such loyal and dedicated supporters of Friends of Rosie.

### EASTER EGGS RAISE £3,200

Each year, we host Easter egg raffles across Greater Manchester and Cheshire to raise much needed funds.

This year we were delighted to raise a whopping £3,200! Our huge thanks to everyone who ran a raffle and donated including Baldwins Gate CE Primary School, Slater's Country Inn, Premex, the Manchester Cancer Research Centre, P J Liveseys, Stranz hairdressers, Hale Prep School, and Exchange Chambers, among others.



### THREE CHEERS FOR ELIZABETH!

A huge thank you and well done to 11-year-old, Elizabeth Chadwick. Elizabeth raised £140 for children's cancer research by holding a raffle at her school, Our Lady's Bishop Eton Catholic Primary School, in Liverpool.

Elizabeth sadly lost her young friend, Thomas, due to childhood cancer. Now she wants to help other children like Thomas by funding more research for kinder more effective treatments. Elizabeth, you're an inspiration and we're so very grateful.



### SCHOOL SUPPORT

We're delighted that Woldingham School in Surrey has supported Friends of Rosie over the past school year. Huge thanks to Daisy Larkin for nominating Friends of Rosie and to all the students, staff, and parents for your kind support.

### BIG GIVE CHRISTMAS CHALLENGE

Last Christmas, thanks to you, our wonderful supporters, we smashed our Big Give Christmas Challenge target raising £5,399 in just one week! Watch this space for news of this year's Christmas fundraising. Thank you to everyone who donated especially during these tough times.