News from Friends of Rosie

SUMMER 2022

Friends of Rosie
CHILDREN'S CANCER RESEARCH FUND

FRIENDS OF ROSIE HOST MAJOR INTERNATIONAL WORKSHOP ON CHILDHOOD CANCER

Friends of Rosie brought together 40 of the world's top researchers and clinicians from the UK, Europe and North America, to discuss how better to target treatments for children with cancer.

The international workshop was held in Manchester on the 8th and 9th of June 2022. It came less than two months after MPs listened to impassioned pleas in the House of Commons for a concerted effort to bring together the very best in research, training, and treatment, to change the approach to childhood cancer once and for all.

Participants brainstormed how to improve the diagnosis and treatment of children's cancers using state-of-the-art molecular diagnostics. The goal is to better tailor novel drug treatments to individual children according to the genetic markers present in their tumours, something called "precision medicine".

During lively interactive discussions, new technical advances in detecting these genetic markers were presented. These focused particularly on how to use a patient's blood sample rather than often painful attempts to gather pieces of a tumour.


Children's cancer doctors & researchers

Progress in the diagnosis and subsequent treatment of cancer in children depends strongly on international collaboration between the doctors and scientists. Dr Martin McCabe from the Christie Hospital University of Manchester and Professor Bernadette Brennan from The Royal Manchester Children's Hospital agreed that Friends of Rosie had succeeded in helping children's cancer doctors to share novel information advancing diagnosis and treatment. The workshop has developed international collaborations to improve the outcomes for children and young people with cancer.


Dr Martin McCabe

Dr McCabe said, "By bringing together all of the best precision medicine clinical research in childhood cancer in Europe at present, the Friends of Rosie workshop has demonstrated what the different international platforms have taught us, but more importantly, the remaining challenges and the populations of children who are still underserved and poorly understood. We have forged new collaborations both across the spectrum of childhood cancer and within specific diseases that will lead to new knowledge and much-needed progress."

We are very grateful to the pharmaceutical companies, AstraZeneca, Bayer, Novartis and Pfizer, for their generous financial support of the workshop. Another workshop is planned for 2024.

GOODBYES AND HELLOS

We recently bid a fond farewell to our Trustees, Jennie Atherton and Joe Swift. Jennie has given her time, energy, skills, and passion for childhood cancer research for over 30 years and has helped shape the charity and the vital research we fund.

As charity treasurer and accountant, Joe has played a vital role since joining in 1995. He managed the charity's banking, auditing, and annual reporting. We send our warmest thanks for everything that you've both done for Friends of Rosie.

Our founder and Rosie's mum, Lisa Larkin, is also stepping down from her role as a Trustee. In recognition of all that she has done, the Trustees have awarded Lisa with the honorary position of Life President of Friends of Rosie.

Says Lisa, "Of course, I am sad to retire as a Trustee of Friends of Rosie. It has been such a part of my life for a long time, and I am so very proud that, together, we have achieved so much in advancing the cause of research into all areas of childhood cancer. I wish Friends of Rosie continued and greater success under the inspired leadership of Felicity Goodey."


Lisa Larkin

While it's sad to say goodbye, we are delighted to welcome on board three new Trustees – Lesley Dowdall, Mahesh Vara, and Craig Rea.

Lesley has over 20 years of experience in fundraising. She is Director of Development at Withington Girls' School. Mahesh is a solicitor at DWF Law LLP. He was diagnosed with Ewing Sarcoma when he was 8 years old and later at the age of 21. Craig has worked in several industries and was previously Managing Partner at Accenture. Welcome on board!

NEW PARTNERSHIP WITH EXCHANGE CHAMBERS

Friends of Rosie has been selected as the charity partner for Exchange Chambers for the next two years.

Exchange Chambers is an award-winning set of Barristers' Chambers with 200 members and offices in Manchester, Liverpool and Leeds.


Jonathan I'Anson

The CEO at Exchange Chambers, Jonathan I'Anson, said: "Planning is already underway for several fundraising events, including a Charity Ball later this year. The team at Exchange Chambers are determined to raise significant funds to support vital children's cancer research in the Northwest."

The partnership with Friends of Rosie will run through to 2024 with the aim of Exchange Chambers solely funding a new research project, helping find cures, better treatments and improved diagnosis for children with cancer.

Said Friends of Rosie's Chair of Trustees, Felicity Goodey, "We are honoured to be the chosen charity to partner with Exchange Chambers. As a small, volunteer-led charity, support like theirs is what makes all the difference. It allows us to fund more research and kick-start new ideas that could in future change and save children's lives. We're very much looking forward to working together to make a difference."

RESEARCH COLLABORATION WITH NEUROBLASTOMA UK

Friends of Rosie has partnered with Neuroblastoma UK to fund new research to improve treatment for children with advanced neuroblastoma.

Professor Louis Chesler will receive a research grant of £469,093, which includes a donation of £15,000 from Friends of Rosie. The grant will enable the research team to progress their research and develop safer, non-invasive, and more effective treatments for children with the disease. Professor Chesler's research aims to develop blood-based biomarker tests for children with high-risk neuroblastoma to help guide and monitor treatment.

Lisa Larkin, Founder and Trustee of Friends of Rosie (and Rosie's mum) said, "For Friends of Rosie this research has extra resonance as Rosie, our charity's namesake and my daughter, had neuroblastoma. I remember so clearly being given the diagnosis and prognosis that she would die in the same sentence. There seemed to be a lack of priority for childhood cancer research and treatment. That's why we started Friends of Rosie – to pump-prime vital new research to help children like Rosie. 30 years later we are delighted to collaborate with Neuroblastoma UK in this most exciting new project."

About Neuroblastoma
Neuroblastoma is a rare type of childhood cancer. Around 100 children are diagnosed with neuroblastoma every year in the UK.

Friends of Rosie's namesake, Rosie Larkin, died of neuroblastoma at the age of five. It is the second most common solid tumour in children after brain tumours.

Children with aggressive high-risk neuroblastoma are treated with incredibly intensive drugs and invasive procedures that can leave them with lifelong disabilities. And because they have an increased risk of relapse, the long-term outcome of these children desperately needs to be improved.

There's been some progress with developing treatment. But it's slow. Only one new drug has been developed for children receiving front line neuroblastoma therapy since the 1980s.

About the research

Professor Louis Chesler, Professor of Paediatric Cancer Biology at The Institute of Cancer Research said, "To treat a child with neuroblastoma more effectively, we first need to understand how aggressive their cancer is or whether they are at greater risk of relapse. Currently, the only way we can get detailed information about their tumour is from tissue biopsies, which are invasive and potentially dangerous. We do this to analyse tissue samples for molecular changes or 'biomarkers'. These biomarkers help us to diagnose the cancer and guide a child's treatment.

"The medical technology now exists to detect multiple biomarkers in blood quickly and accurately, which could spare children from having to undergo painful tissue biopsies. The research grant from Neuroblastoma UK and Friends of Rosie will enable our team to investigate blood samples and data from different biopsy techniques across three international research centres. Once we've completed our evaluation, we can then propose a less invasive method of diagnostic testing for children with this aggressive cancer."


Prof. Louis Chesler

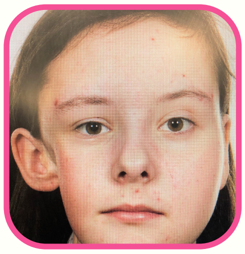
REDUCING THE RISK OF FACIAL ASYMMETRY AFTER RADIOTHERAPY

In 2020, we kickstarted new research looking into ways to decrease the risk of facial asymmetry in children with cancers in the head and neck. We recently caught up with the project team at The University of Manchester to find out how they're getting on with the project.

Radiotherapy is a key part of treatment for many children diagnosed with cancer. Radiation successfully destroys cancer cells but can also damage the surrounding healthy tissue. In the UK, over a quarter of childhood cancers require radiation to the brain, face, head, or neck. As children's bones and healthy tissues are still growing, the radiation dose used to destroy the cancer cells can cause side effects, such as stunted or slowed growth.

Unfortunately, this essential treatment can lead to facial disfigurement and noticeable asymmetry later in life. Such asymmetry may require corrective surgery and is likely to impact a patient's quality of life and emotional well-being.

This pioneering research looks to develop tools to analyse medical imaging data to better understand the causes of facial asymmetry, so better radiation treatments can be delivered in the future.


Emma had rhabdomyosarcoma in her cheek

Dr Abigail Bryce-Atkinson has made great progress on this project and Dr Angela Davey has now joined the team to lead the development of these research methods. Together, they provided an update.

Update from the research team
Abigail: "To be able to use image-based data mining (IBDM), we first need to accurately measure the amount of facial asymmetry from a medical image. To do this, we have produced a descriptive guide for manually measuring facial asymmetry and used this guide to label key anatomical locations in medical images.

"Within our research group, a 'deep-learning' tool (a type of artificial intelligence) was developed so these locations can be identified automatically by a computer, with the same accuracy expected from expert medical professionals.


Dr Marianne Aznar (second left), Dr Abigail Bryce-Atkinson (third left), Dr Angela Davey (second right)

"To measure the amount of asymmetry at these key locations with high efficiency, we are testing computational methods, such as image registration (the process of deforming one image to another) to compare the left and right side of the face numerically.

"This has a big advantage over other methods as it does not rely on subjective measurements or descriptions of the images."

Angela: "With Abigail's guidance, I have taken the lead on the development of image registration methods and will soon be testing these on medical images collected from patients treated at The Christie NHS Foundation Trust. From here, we will be able to update our existing data mining method to relate the radiotherapy dose patients have received in each location to the amount of asymmetry at that location over time. I have also been working closely with Dr Shermaine Pan, a clinical oncologist at The Christie, to gain an understanding of what is required to help clinicians routinely investigate facial asymmetry.

"From these discussions, we aim to develop an "atlas" to help clinicians outline the bones in the face, which will be a valuable tool to aid clinical practice. The atlas will be the first step in defining new radiotherapy dose limits for facial bones, which in combination with this project, aims to reduce the risk of asymmetry in future treatments."

PROTON BEAM THERAPY UPDATE

Friends of Rosie is funding a £70,000 project investigating the biology of protons used in 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.

Sarcomas are cancers that develop in bone and soft tissues anywhere in the body. They require careful, personalised treatment. PBT is an advanced type of radiotherapy using a high-energy beam of protons to precisely target a tumour, minimising damage to surrounding healthy tissue.


Dr Amy Chadwick

Says Amy, “Whenever radiotherapy is used to treat patients, there is an entry and exit dose of radiation. Protons slow down and release most of their energy in a well-defined area within the tumour, meaning that there is no exit dose. With PBT, we can provide a more targeted radiation dose to the tumour. This reduces the risk to critical organs close to the tumour, reducing the chance of long-term side effects of treatment and reducing the likelihood of radiation-induced cancers occurring in later life.

“I've been working with the PBT team since 2015. The group to which I belong designed the dedicated proton research facility at The Christie NHS Foundation Trust. Within the Proton Therapy Centre, there are three gantries for treating patients and the fourth area is dedicated to research. With funding from the Christie Charity, we designed the proton beamline, the control room, and a biology lab to allow us to perform cutting-edge experiments in a hospital setting. Our research beamline has a clinical spot scanning nozzle so we can emulate patient treatment. We also developed a radiobiology end station containing a robotic arm to allow us to irradiate multiple samples to maximise the time we have available using the proton beam. Using this, we can accurately control oxygen levels, mimicking that found in tumour and normal tissues down to 0.1% O2. We think this is the first hypoxia workstation in the world designed for proton research.

“Being able to control the oxygen level is key to our Friends of Rosie work. Low oxygen concentration in tumours is one of the main factors that cause resistance to radiotherapy. When tumours grow, they outstrip their blood supply, so they grow their own supply but this leaves areas of the tumours with low oxygen levels, called hypoxia. Tumour cells exposed to hypoxic conditions are 2-3 times more resistant to radiotherapy, compared to well-oxygenated cells.

"In the PBT research facility, we can mimic this low oxygen environment so we can accurately test different doses of radiation and different drug combinations in what would be the most radio-resistant conditions.”

Adds Emma, “Over the past few months, we've done a lot of the groundwork needed to now start the proton experiments.


Dr Emma Biglin

"Firstly, we need to obtain our benchmark data using the paediatric sarcoma cell lines with conventional radiotherapy to assess how many cells survive after different doses of radiation. The cell lines we've tested represent osteosarcoma, Ewings sarcoma and rhabdomyosarcoma. We recorded data under normoxia conditions (21% oxygen) and hypoxia (0.1% oxygen).

“Secondly, we conducted experiments to quantify DNA damage using radiotherapy, by recording the proteins recruited to repair the DNA damage within the cells. Again, we did this with varying oxygen levels. Now, we're identifying different drug combinations and measuring cell survival after treatment. Once this work is complete, we can start our first experiments with protons.”

Amy continues, “As the PBT centre is being used to treat patients during the day, we can only conduct our experiments in the research facility at night. We've booked our first experiments to start in June and the priority is making best use of the proton beam while we have access to it.
In addition to this research, we're also looking at how we can use 3D cell models to represent a tumour more accurately."

More than half of PBT patients treated at The Christie are children, with sarcomas accounting for approximately 20% of the paediatric caseload for the NHS PBT service. . There is currently no dedicated research into how paediatric sarcoma cells respond to PBT. This project will change that.

Concludes Amy, “So far, PBT has largely been driven by the physics. With this Friends of Rosie funded research, we are driving forward the biology to show that cells respond differently to PBT than conventional radiotherapy. There is great opportunity to exploit those differences and look at how we can make treatments more effective and kinder to patients. For children with cancer, that's even more important to give them a far better quality of life after treatment.”

Project aims

- Determine the response of paediatric sarcoma cells to conventional radiotherapy and PBT
- Quantify the amount of DNA damage caused by each radiation modality and monitor how the cells try to repair this damage.
- Conduct a high throughput drug screen in combination with radiotherapy and PBT
- Validate potential novel drug-radiotherapy combinations to enhance the effect of conventional radiotherapy and PBT.

EWING SARCOMA UPDATE

Friends of Rosie is partnering with The Bradley Lowery Foundation to fund new research into the detection and treatment of a rare type of childhood bone cancer, called Ewing Sarcoma.

The project is 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.

The awarding of the Friends of Rosie funding has facilitated the bringing together of a team of specialised biomarker researchers (Professor Caroline Dive, Dr Dominic Rothwell) with Ewing Sarcoma focused clinician (Dr Martin McCabe) to lead a research team investigating the use of liquid biopsies (blood tests) to monitor patients with Ewing Sarcoma.

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%.

The Friends of Rosie-funded scientist is working alongside a PhD student and clinical research team, as well as commercial partners, ThermoFisher, to develop a clinically useful sensitive blood test.

The first year has focused on establishing the research team and the clinical infrastructure to collect important patient samples that can be processed and analysed. This includes samples from six patients so far. These samples are vitally important to enable the team to test the use of any novel biomarkers developed. In parallel, the research team has been working on establishing optimised protocols for the collection and processing of the clinical samples and downstream assays for detection of disease.

This has resulted in a novel workflow for the collection and analysis of low amounts of RNA and circulating tumour cells in these patients. The team has established molecular techniques that enable the detection of Ewing Sarcoma-specific RNA in the blood samples using a sensitive approach called Real-time PCR (RT-PCR).

They are now testing even more sensitive approaches based on Next Generation Sequencing (NGS) which has the potential to make the assays even more sensitive and applicable to all Ewing Sarcoma patients, rather than needing to design patient-specific assays.

GUARDIAN GIVING SCHEME

Our huge thanks to everyone who has donated and set up a regular direct debit through our Guardian Giving Scheme.

Regular giving by direct debit helps us to better plan how and when we fund vital research projects. By giving a little every month, you can make a huge difference to the pioneering children's cancer research we fund.

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.

30TH BIRTHDAY EVENT

To celebrate our 30th birthday and to thank all our wonderful supporters, we held a virtual event, in the autumn of 2021, during childhood cancer awareness month.

We shared videos from our fantastic Young Ambassadors, Ruth Grace and Daniel, sharing their experiences of childhood cancer, as well as presentations from two of our funded researchers, Professor Caroline Dive CBE and Dr Katherine Finegan, who are both leading cutting-edge research into Ewing Sarcoma and Osteosarcoma respectively.

Our Scientific Advisory Board (SAB) Chair, Professor John Hickman, also shared exactly how we spend your donations to fund vital research. He outlined the rigorous process our SAB goes through when we receive applications for research funding so you can be sure that your hard-earned donation is spent in the best possible way for the benefit of children with cancer.

It was particularly poignant to end the event with insight from Professor Caroline Dive and Professor John Hickman that childhood cancer research is finally beginning to get the attention it deserves. Our role in kickstarting brand-new research ideas is vital in getting new research off the ground. CRUK's revised strategy for paediatric cancer is a positive step forward to keep childhood cancer in the spotlight, as well as more international collaboration on research and clinical trials. You can still watch the recording of the 30th Birthday on our website or YouTube channel.

EASTER EGGSTRAVAGANZA

We were delighted to bring back our Easter egg raffles once again this year and what an Easter of fundraising it was!

Our huge thanks to everyone who hosted a Friends of Rosie Easter egg raffle this year. Together you raised an eggcellent £3,500! Thank you also to our Easter bunny volunteers, Maureen Bennett and Julia and Philip Hyde, who kindly delivered the Easter eggs to the raffle holders and picked up the donation boxes after Easter. We couldn't do this fundraiser without your help. Thank you.

And a special thank you to Dave in the Manufacturing Department at The PJ Livesey Group. Dave re-raffled his winning egg at his daughter's wedding to raise even more money! The giant egg was then broken up for the junior wedding guests to share.

MARATHON SUCCESS

Our wonderful Trustee, Lesley Dowdall, ran the Barcelona marathon in November raising a fantastic £1,440.

Says Lesley, "It was an incredible experience! The atmosphere was amazing and running around such a beautiful city took the pain away (well some of it anyway) from running 26.2 miles!

"I did it in 4 hours 5 mins, which I was very happy with, especially as I struggled in the last few miles. However, knowing how many people had sponsored me, certainly helped to keep me going!"

RAISING THE ROOF AND RAISING FUNDS

The talented Altrincham Concert Orchestra held a Christmas Concert at the Altrincham United Reformed Church with all proceeds from the raffle donated to Friends of Rosie. Our huge thanks go to all members of the Concert Orchestra for choosing to support Friends of Rosie.

CUTTING THE RIBBON AT B&M HULME

Our wonderful Young Ambassador, Ruth Grace, went along to cut the ribbon and officially open the new B&M store in Hulme.

The opening of the new store has seen more than 20 locals hired, and those colleagues were asked to nominate a local charity to act as VIPs on opening day. They chose Friends of Rosie to take centre stage! Our huge thanks to the B&M team for asking Friends of Rosie to be a part of your special day and for your donation of £250 of vouchers.

IN MEMORY

In Loving Memory of
Dorothy Norma Bentley
8th April 1927 - 19th December 2021

We received several donations recently in memory of loved ones lost. Our thoughts and very best wishes go to the family and friends of Lady Monique Lee, Vida Woodward, Dorothy Bentley, and Sheila Gold. Thank you for choosing to support Friends of Rosie with funeral donations in memory of those you love. Your contributions are a wonderful legacy for your loved ones and really do make a difference to children with cancer.

THANK YOU TO ALL DONORS AND SUPPORTERS

There are countless other donations that we simply don't have the room to mention. So, a huge thank you to everyone who has donated and showed your support to Friends of Rosie over the past 12 months. We couldn't do what we do without you.

ASDA COMMUNITY CHAMPIONS

Thank you to the Community Champions and colleagues at Asda in Altrincham for raising £110 for Friends of Rosie in recognition of World Cancer Day in February.

GOING VEGGIE FOR A MONTH

11-year-old, Oscar, took up the challenge of going veggie for the whole of February for Friends of Rosie. Said Oscar, "I decided to go veggie to raise money for children with cancer. Anyone who knows me, knows I love chicken, so this is a real challenge for me!". Oscar raised almost £400 with his challenge and stuck to his promise all month. Well done, Oscar!

JAM TOMORROW

Thank you to Julia Hyde, marmalade extraordinaire, for raising £540 at her recent marmalade sale.

A fantastic amount!