

Alice's Arc Annual Report

1 October 2022 – 30 September 2023






Alice's ARC
CHILDREN'S CANCER CHARITY

Charity number 1164253



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Annual review

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A message from our CEO

Another record-breaker – over £1million raised for research!

It is an absolute pleasure to report on another outstanding year for Alice's Arc. Eight new Arcs joined our existing 16 Arcs in the UK. Two new research projects were added to our portfolio. Two new Clinician/Scientists joined our International Scientific Advisory Team. Continued to support families impacted by rhabdomyosarcoma via our

support groups. Ongoing patient advocacy work and engaging new patient advocates from our community.

Conversely, Ellie, Elliott, Fletcher and Isabella died from rhabdomyosarcoma and we pay tribute to them in this report. As ever, their losses reinforce just how critical our work is and provide continued



inspiration to identify better, kinder treatment options for the future. We met many new families navigating the treatment pathway, coming to the end of treatment and those facing the brutal long-term side effects of current treatments.

Fundraising this year was absolutely phenomenal and so creative! Lush's extraordinary gold bath bombs for Dexter, visiting 92 football league clubs in 92 hours for Oliver, cycling 80 miles around the Wash for Elliott, Mollie's high five run and a go-gold casino night bringing together families, scientists and medical professionals. So much continued support from schools and businesses. And so many more. We are so thankful.

Our ever-growing community allows a collection of powerful family-led voices reinforcing the why behind our work. We exist to bring hope and change. Our video campaign for Childhood Cancer Awareness Month illustrated the role of hope and how by working together we bring the much needed hope for those diagnosed with rhabdomyosarcoma in the future.

I want to express our eternal thanks to all the families and supporters of the charity. To all the Scientists, Clinicians and other Medical Professionals, those starting out and those who have been in it for years, we are so grateful for your hard work and perseverance in this fight against rhabdomyosarcoma. None of us will stop. Together we are stronger.

To my boss, Alice, what do you think of our work?

With best wishes,



Sara Wakeling

About us

Alice's Arc is dedicated to finding a cure and kinder, more targeted treatments for those affected by the childhood cancer, rhabdomyosarcoma. Funding research and contributing to advances in our scientific understanding of rhabdomyosarcoma is crucial to making progress to improve long term survival outcomes and minimise long-term side effects.

The children and families impacted by rhabdomyosarcoma are at the heart of what we do and we work closely together to help achieve our goals. We have created a network of families globally and provide individual Arcs in honour of the children or young people's journeys with rhabdomyosarcoma. These platforms have multiple purposes and are individually tailored to enable families to tell their story, fundraise, advocate and demonstrate the impact they are making. We currently have 29 Arcs across England and Northern Ireland and more in the works. We have also established a non-profit 501c3 in the USA and have commenced work replicating the same work via Alice's Arc, USA. We currently have four Arcs in operation.

In addition, we aim to be a major source of support to our community of families, from diagnosis, treatment, post treatment, relapse, palliative care, loss and survivorship. We deliver this via our family well-being service.

Effective collaboration is critical in achieving change. Through our strong relationships with major research institutions, hospitals, clinicians and families, we present a global rhabdomyosarcoma voice advocating for change and a future where this disease can be cured safely, using new and cutting-edge treatments.





Our goals

A reminder of our research priorities

Examine the causes of rhabdomyosarcoma. This means preclinical, biological research to build understanding about the genetic landscape of the cells comprised in these tumours as well as the interaction with the tumour micro environment.

Help identify new targets and treatments. The identification of new drugs and new treatment techniques to improve prognosis at the point of relapse or for those with metastatic presentation where the likelihood of a cure is slim. For example, T-cell therapy, protein degraders.

Translation into clinical trials. Ensure our research projects and findings link to clinical trials such as FaR-RMS and eSMART. This enables research questions to be tested and assessed in the patient setting. We also have aspirations to devise our own clinical trials in collaboration with the scientists/medical professionals in our community.

Devise kinder treatments. These need to be identified as 95% of survivors will have long-term health issues as a result of treatment. Quality of life is a key consideration in treatment and beyond.

Contribute to enabling research to happen. Often roles need to be created to manage projects, to analyse data and to create innovative technology.

Create a global rhabdomyosarcoma research platform. Breakdown barriers to research and bring together a global team of rhabdomyosarcoma scientists and medical professionals.

Share findings across existing platforms for paediatric solid tumours.

About Rhabdomyosarcoma

Sarcomas are cancers that can resemble bone or soft tissues. Rhabdomyosarcoma is the most common soft tissue sarcoma occurring in children and young people and they tend to look like developing muscle or fibrous tissue.



It is a highly aggressive childhood cancer with 60-70 children diagnosed in the UK every year. It accounts for 5% of childhood cancer cases each year. Outcomes are influenced by the location, staging, fusion gene status and disease subtype.



The two main types are commonly referred to as **embryonal** and alveolar rhabdomyosarcoma. Embryonal is the most common and makes up 60/70% of cases. It commonly presents in the head, neck, bladder, vagina, prostate or testicles and cells look like developing muscle cells of a 6-8 week embryo. **Alveolar** is more common in young adolescents and tends to occur in large muscles like the arms, trunk and legs. The cells look like normal muscle cells in a 10 week old foetus. It grows faster than embryonal and requires more intense treatment.



More recently, biological studies have found that the PAX-FOXO1 gene fusion status of the disease could be important in predicting the outcome and treatment plan offered. This has led to the disease being more frequently described as **fusion negative rhabdomyosarcoma or fusion positive rhabdomyosarcoma**.



On relapse, there is an **8-20% chance of survival**. This is influenced by the subtype, gene fusion status, presence of certain biological markers and location.



Recent international research has uncovered that the presence of certain biological markers in both **fusion negative (MYOD1, TP53)** and **fusion positive (TP53, CDK4, MYCN)** rhabdomyosarcoma can lead to a poorer prognosis. The implications of this research will lead to changes to categorising children to the existing risk categories and may lead to the development of new drugs to treat these specific gene faults.



SMPaeds, led by The Royal Marsden's academic partner the ICR, is the first platform of its kind in the UK. It allows children and young people who have relapsed solid tumours to have a biopsy tissue sample taken which is then analysed to identify certain changes in the DNA of the cancer cells which may be targetable via personalised medicine.



What treatment is available?

Current treatments involve a combination of surgery (if possible), intensive chemotherapy, maintenance chemotherapy and radiation (proton, photon, brachytherapy). Where a known biological marker is discovered via sequencing, tailored drugs may also be available. The first phase one clinical trial to test the safety of CAR T-cell therapy for RMS is expected to open towards the end of 2024.

The clinical trial, FaR-RMS (Frontline and Relapsed RhabdoMyoSarcoma) was launched in September 2020. It will aim to recruit 1250 patients in total. It is now open in 17 countries including Canada, Australia, New Zealand and Israel. It currently has 630 patients registered. The trial studies several aspects of treatment for the disease both for patients newly diagnosed and at the point of relapse. It is open to patients of all ages (children, TYA and adults). It has a multi-arm, multiple-stage design to identify early indications of benefit (or lack of benefit) of new therapies.



The Arcs



Why do we have Arcs?

Throughout Alice's journey with rhabdomyosarcoma we met many other families with children or young people being treated for rhabdomyosarcoma. We connected in person in hospital and through virtual platforms. These brave children and their families are the inspiration for Alice's Arc. The world of rhabdomyosarcoma can be lonely and it is important to find a space where you feel understood, safe and able to share your journey. At the same time, we all have a shared mission - to find new treatments and less harsh treatments to improve the prognosis for children diagnosed in the future. To achieve this families need to come together. By working together we are stronger and can create a long-term, sustainable platform to bring about change.

"Tommy's Arc has provided us with a positive focus, to help raise funds for research development into rhabdomyosarcoma and help support other families facing such a devastating disease."

HARRIET JONES, TOMMYS ARC



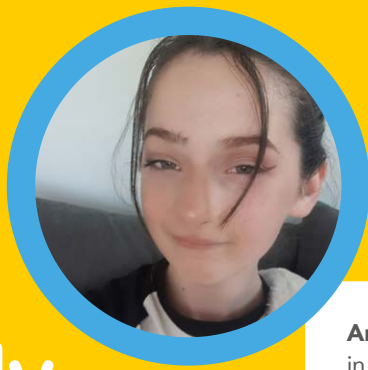
The role of the Arcs:

-  An Arc is a unique place where a family and their supporters/community can honour a child or young person's experience with rhabdomyosarcoma.
-  An Arc can fundraise, advocate and demonstrate impact in their child's name.
-  Ensure that research is parent-led and addresses the needs of families diagnosed in the future.
-  Research is complex and expensive - pooling funds together allows Scientists to formulate more comprehensive research proposals with clinical translation and allows a pipeline of research to evolve from projects.
-  Support families. Our community of rhabdomyosarcoma parents, patients and siblings can offer support to newly diagnosed families, those on treatment, those in remission, those on palliative care, survivors and those suffering the loss of their child.

"The purpose of Maya's Arc is to make that extra little difference, whether it's spreading awareness or raising money to help researching better treatments for children diagnosed with rhabdomyosarcoma in the future."

HOLLIE O'CONNOR, MAYA'S ARC





Newly launched Arcs

During this time, we have launched an additional 8 Arcs, joining our first 16 Arcs. We now have Arcs based in East Anglia, the North West, the North East, The Midlands, the South West, the South East, London and in Northern Ireland.

A unique brand has been developed for each Arc by using an image representing the individual child or young person. In addition, a web page has also been created for each Arc.

Arcs: The future

We have been delighted with the interest shown from families to work together and to create Arcs. As a result of this unique model, funds raised continue to climb at a fantastic rate enabling our scientific board to assess an increased volume of grant applications which has enhanced our rhabdomyosarcoma research portfolio significantly.

The model also continues to attract global interest and we have now launched an operation in the USA which has 4 Arcs so far. It's all about coming together to be stronger, to be more impactful and to ensure that children in the hospital will benefit as soon as possible.

Amy's Arc for Amy, who was diagnosed in December 2019 and is now a teenager living with the side-effects resulting from her experience. Amy and her family picked a cheeky monkey to represent her Arc.



Ellie's Arc for Ellie, who died aged 3.5 years, in December 2022. Ellie was known for wearing her yellow, duck wellies and at her funeral pairs of yellow wellies were filled with red tulips. Therefore, it was fitting to use this beautiful image to represent her Arc.



Elliott's Arc for Elliott, who died aged 5, in December 2022. Elliott's Arc is represented by his favourite toy and love of superheroes like Spiderman.



Fletcher's Arc for Fletcher, who died aged 7, in November 2022. Fletcher's Arc illustrates his favourite toy called Tigey. The spider images represent his love of Spiderman.



Isabella's Arc for Isabella, who passed away aged 2, in October 2022. Her Arc features her favourite doll and her love of sweets and chocolate.



Isabellah's Arc for Isabellah, who finished treatment in September 2022 and is now aged 6. Isabellah chose a beautiful unicorn to represent her Arc.



Maya's Arc for Maya, who was diagnosed, aged 5 in January 2023. Maya's Arc has been created to reflect her love of gymnastics and rainbow colours.



Tommy's Arc for Tommy, who was diagnosed in September 2021 and is currently 8 years old and stable. Tommy has helped design his Arc which is represented by his favourite sheep, known as Balwen and colours of his choice - emerald green and navy blue.



A tribute to...

The death of a child is a life-changing and devastating experience. It impacts all those who knew the child. The loss creates purpose and constructive engagement. No family wants another family to endure this. These children are catalysts for change. They are the reason to raise funds and invest in new research. They will save the lives of those diagnosed in the future.

This year, we want to pay tribute to **Ellie, Elliott, Fletcher** and **Isabella** who lost their lives to rhabdomyosarcoma. Alice's Arc will always remember you and talk about you. You are the inspirations for our work.

Ellie Simms

16th June 2019 to 4th December 2022

Snapshot of her story:

Ellie was diagnosed with high-risk abdominal embryonal rhabdomyosarcoma in May 2021, aged one. Ellie had 16 months of treatment including IVADO chemotherapy and regorafenib on the FaR-RMS trial. However, these treatments had limited results and she sadly passed away on the 4th December 2022, aged three and a half.

"Ellie was such a brave and strong little fighter and despite what she was going through, she still had a smile on her face."

EMMA SIMMS, ELLIE'S ARC





Fundraising for Ellie:

£10k

raised through **Ellie's Dad**, along with friends and family, taking on the National 3 Peaks Challenge and climbing Ben Nevis, Scafell and Snowdon in 24 hours.

£8.5k

donated as a result of Ellie's Winter Ball at Hemswell Court attended by 150 people, who enjoyed welcome drinks, three-course meal, live music, raffle and auction.




£1k

generated via a raffle.

Ongoing donations via local businesses including - Royal Oak, North Leverton and Royal Oak Golf Society.



Ellie's impact:

-  Ellie's Arc has raised over £30k since its inception. Her family, friends and community have rallied together to honour Ellie and contribute to making change in her name. Ellie's Arc have an ongoing programme of fundraisers.
-  Ellie has become well-known for wearing her yellow, duck wellies. They have become a feature at her fundraisers as table centre pieces or a trusty companion on any sporting challenges. Pairs of yellow wellies were filled with red tulips at her celebration of life.
-  Ellie's family want to see changes to the range of treatments offered and less harmful treatments. They want to see targeted treatments designed for specific RMS tumour types. Also on their list is improved training for GPs to enable simple and faster identification of cancer in children and young people.

"Her strength inspired us to create Ellie's Arc and build the awareness and generate donations to support other children with RMS and hopefully lead to better outcomes for them. We've had an outstanding first year with Ellie's Arc thanks to the amazing support around us and we can only hope this continues and makes an immense change to the future of other children"

EMMA SIMMS, ELLIE'S ARC



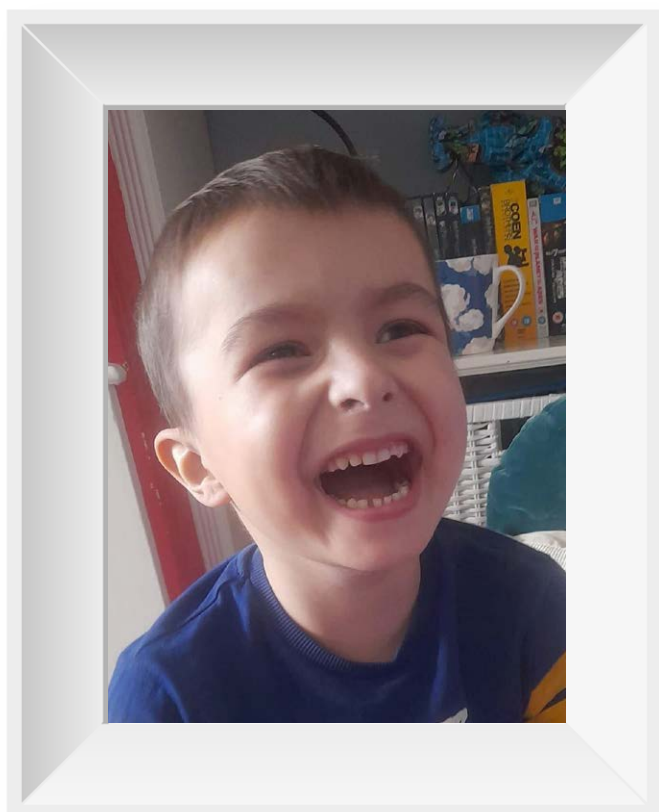


31st January 2017 to 1st December 2022

Snapshot of his story:

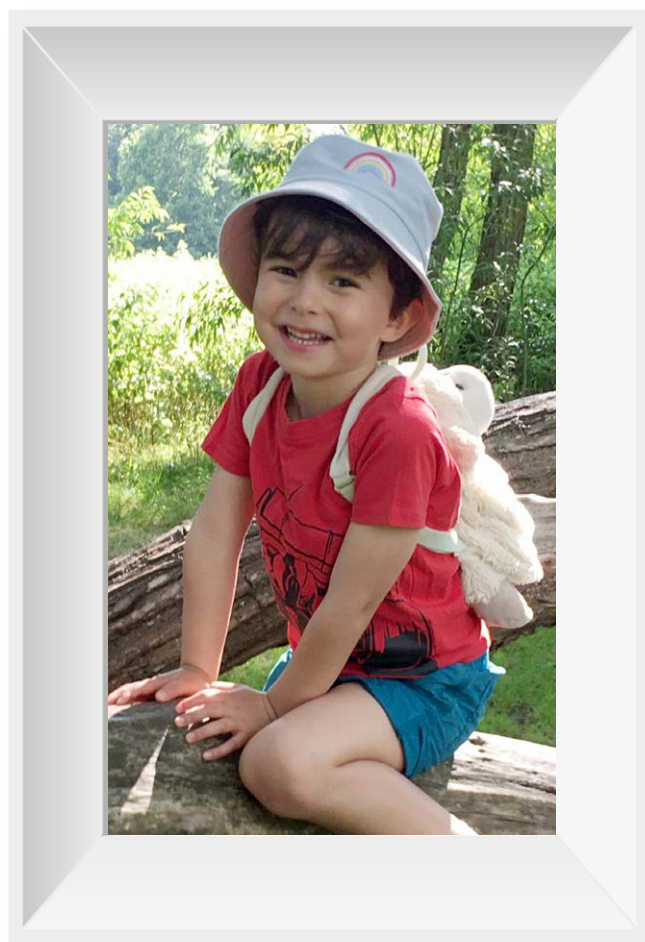
Elliott was aged 4 when he was diagnosed with stage 4 Very High-Risk Metastatic Embryonal Rhabdomyosarcoma in October 2021. The prominent tumour was in his right jaw with intra-cranial extension, and had spread to his lungs, ribs, hips, and left femur.

He responded well to frontline treatment, and was started on maintenance chemotherapy in June 2022, but relapsed in August 2022. After six weeks of second line treatment was unsuccessful and given the pace at which the recurring tumour was growing, there were no effective treatment options left. Elliott began palliative care in November, and went to heaven on 1st December 2022.



“Elliott was bright, funny and kind. He was our world, and when he was diagnosed with rhabdomyosarcoma our world fell apart.”

CHRIS PETO, ELLIOTT'S ARC



“After Elliott died, we were frustrated with both the time it took to get his frontline diagnosis and the lack of treatment options. We sought a community and platform by which to raise awareness and funds for new, better treatments. Alice’s Arc allowed us to create Elliott’s Arc as a way of achieving this.”

CHRIS PETO, ELLIOTT'S ARC



Elliott's impact:



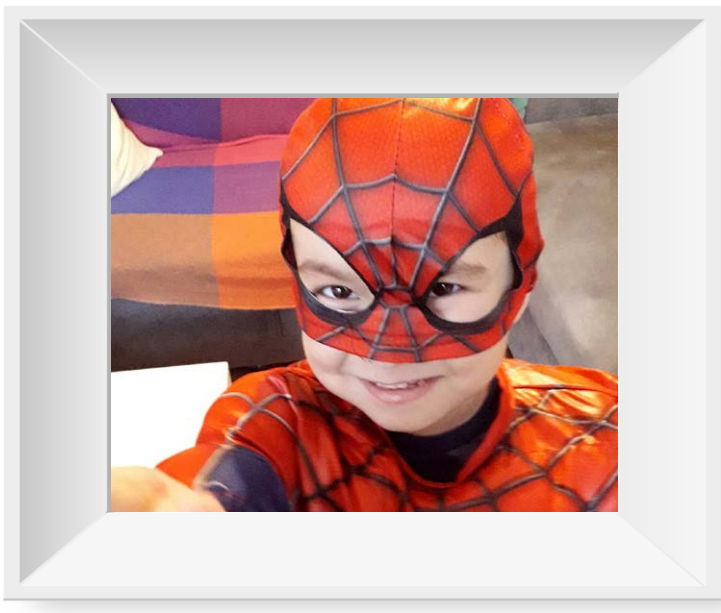
The launch of Elliott's Arc triggered an outpouring of support and recognition in memory of Elliott and his experience with rhabdomyosarcoma. Elliott's school hosted a memorial assembly to celebrate Elliott's life and Elliott's Arc was formally launched with the presentation of a £10k cheque to the charity. These funds were raised as part of Elliott's magical wish-list of things to do whilst on palliative care. The Henley Standard also covered the story and have been ongoing supporters raising the profile of the mission of Elliott's Arc.



Elliott's Arc has raised over £40k since it was founded. With a series of large-scale fundraisers such as SuperPeaks and cycling around the wash in 80 miles. The local community including his school and his parents' workplaces have been tremendous supporters generating funds through regular events in Elliott's honour.



Elliott's family want to see changes made to frontline treatment for rhabdomyosarcoma. They also want to see improvements in the earlier detection of childhood cancer via better training and education at the GP level. They are keen to see more research in order to find kinder and more effective treatments options for the point of relapse. Elliott's family want their funds to help build more understanding about the genetics of the disease and to explore possible new treatments such as immunotherapy.



Fundraising for Elliott:

£10k

was donated upon the launch of Elliott's Arc.

£7.6k

was raised via **Elliott's Dad and Uncle** on a cycling fundraiser called **'Around the Wash in 80 Miles'** complete with Spiderman costumes.

£6.8k

raised for **Elliott's Dad and 9 friends** from his work taking on the 'Superpeaks' challenge.



" Always worried that Elliott might be forgotten, his Arc is a means to keep his story alive, and make finding a cure part of his legacy, however bittersweet that may be."

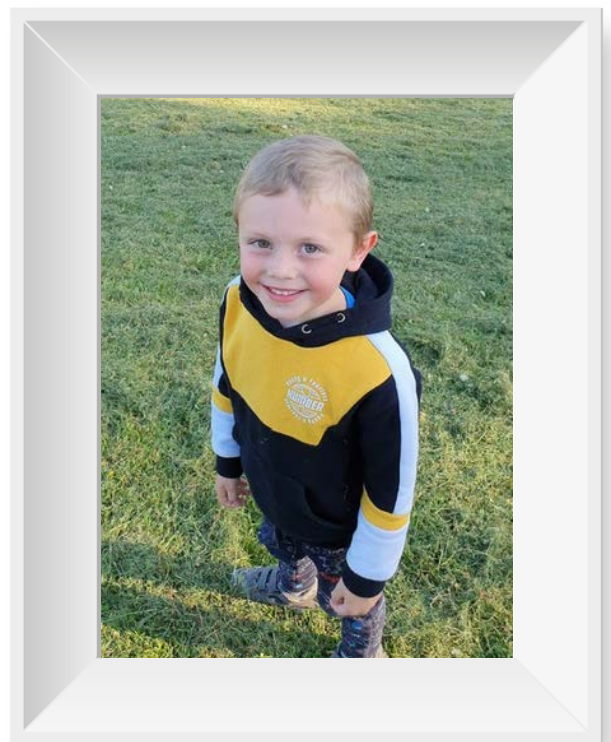
AIMEE PETO, ELLIOTT'S ARC

Fletcher Discombe

17th March 2015 to 16th November 2022

Snapshot of his story:

Fletcher was diagnosed with parameningeal head and neck embryonal rhabdomyosarcoma in the nasopharyngeal region on 9th May 2022 with metastases to the lungs and bone marrow. We were due to emigrate to Australia with flights booked for the 17th May. He was finally diagnosed after multiple trips to our GP and local A&E with a large lump on the side of his neck, each time being turned away and told to keep an eye on it. When he began having double vision they performed an MRI test where the tumour was found. We were quickly transferred to Bristol where Fletch underwent a 15 hour surgery to save his eyesight by debulking the tumour. This was successful and he was started on IVADO chemotherapy. He was to have 9 sessions of chemo followed by 28 sessions of radiotherapy. Fletch had a great response to treatment and had clear scans at the 3 month mark. However following completion of his radiotherapy and 7 rounds of chemo, on our way home he had a massive seizure in the back of the car. He was transferred to PICU in Oxford as Bristol had no beds. Following multiple MRI scans, lumbar punctures and CTs and more seizures we were told the devastating news that Fletcher's cancer had returned to his brain and spine and there were no treatment options. We were transferred to Charlton Farm Children's hospice where Fletch died on the 16th November 2022.



"Fletcher was the most beautiful and brave boy. He was funny, kind and adored his older sister. Losing him has broken us beyond repair. Having the opportunity to have a platform through Alice's Arc has enabled us to feel part of something that can make change. The support of other parents going through the same thing has meant a great deal to us. Launching Fletcher's Arc means we can raise funds and awareness of this terrible disease in the hope that other children and families one day may have a better outcome and kinder treatments."

KAT DISCOMBE, FLETCHER'S MOTHER, FLETCHERS ARC

Fletcher's impact:



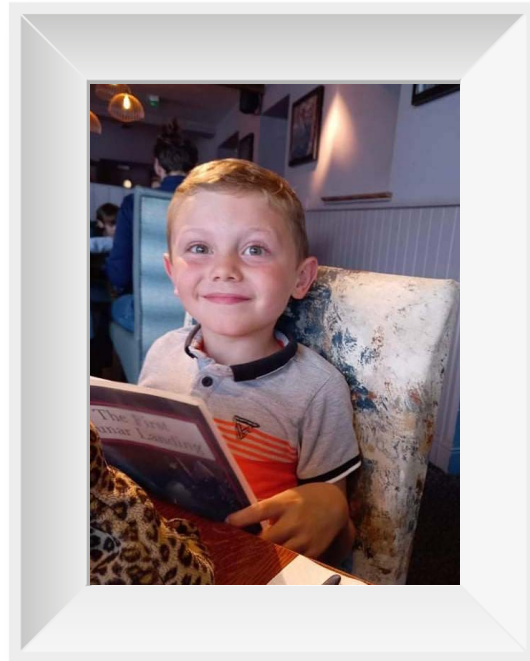
The launch of Fletcher's Arc has led to such fantastic support. With over £8k raised and wide-ranging support from the local community.



Fletcher has inspired the creation of the book 'Piggy Pogwort: Pig at the Gig'. This book is being sold as a part of the Fletch Effect initiative. This involves making and selling handmade gifts in memory of Fletcher. A percentage of sales goes towards Fletcher's Arc.



Fletcher's family want to see faster diagnosis and more awareness of rhabdomyosarcoma by GPs. They want to see increased funding for research into more curative and personalised treatment options. They also feel there has been a lack of support since Fletcher's death.



Fundraising for Fletcher:

£900

raised through Fletcher's Mum's participation in the Royal Parks Half Marathon in London.

£2.5k

via sales of Fletcher-inspired products at charity pop-up stalls across Devon.

£700

generated through sales of Piggy Pogwort Book, a book written in honour of Fletcher.

£425

raised by Fletcher's school, Rydon Primary, going gold for childhood cancer awareness month in September 2023.

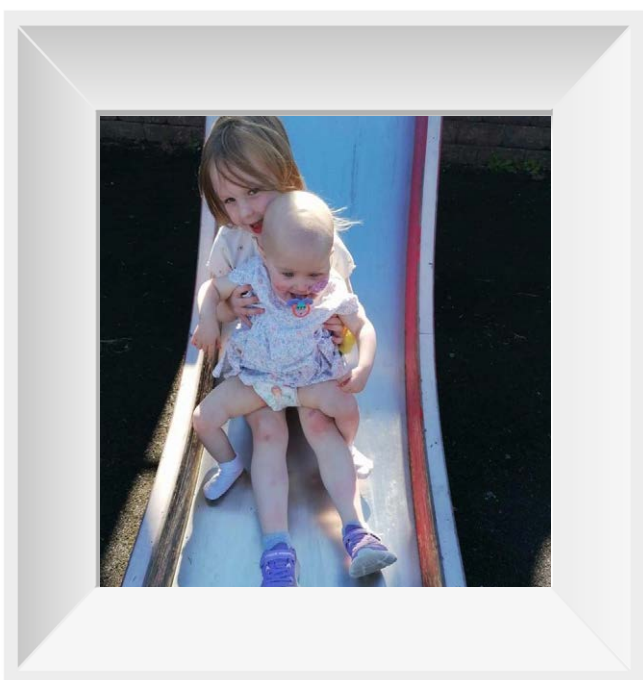
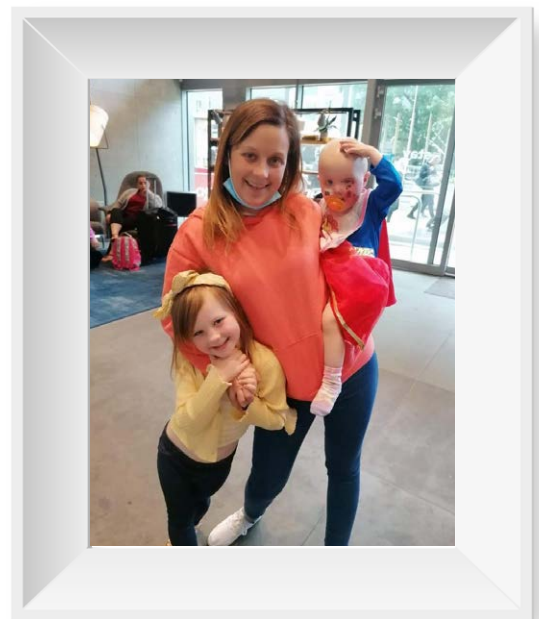
Isabella Steele

12th February 2017 to 4th February 2022

Snapshot of her story:

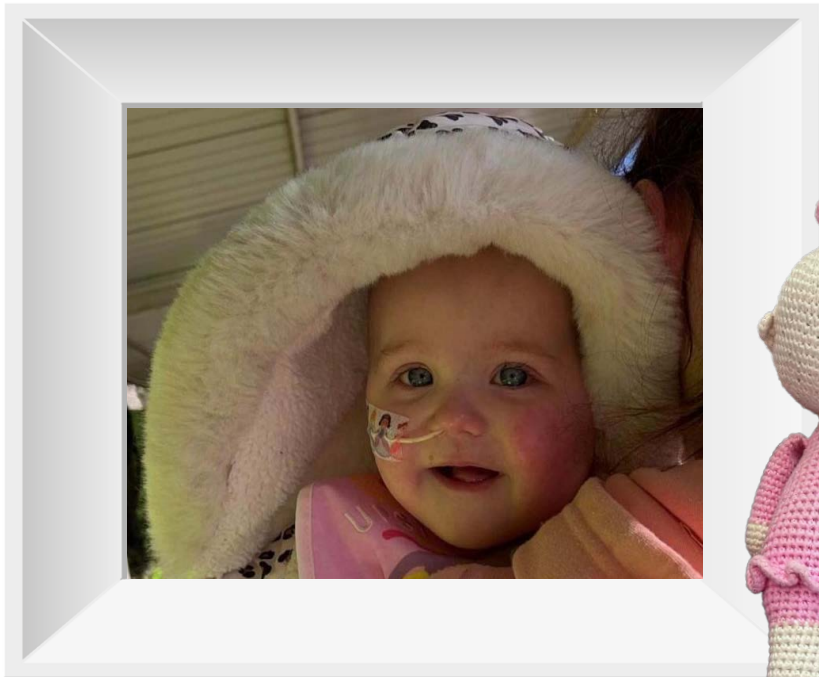
Isabella was diagnosed with stage 4, Embryonal Rhabdomyosarcoma on January 13th, 2022 at the age of 20 months old. Her tumour presented along the jaw and towards the skull. The tumour was deemed inoperable due to its complex location. Isabella received nine rounds of chemotherapy (IVA) and 31 days of intense proton radiation therapy at the Christie, Manchester. This was later reduced to 28 days due to how sensitive her skin was to the radiation. Six months of maintenance chemotherapy was also planned. Her care was led from Children's Hospital, Belfast.

Sadly, a few months after Isabella started maintenance, an MRI scan on the 7th October 2022 showed that Isabella had relapsed with disease now present in the parameningeal region and fluid around the brain and spinal cord. Her primary area of disease remained stable. Isabella passed away 19 days later, aged two years old.



"Isabella was our little hero and is missed so much by her family. Isabella was an inspiration to me. She made me proud every single day. I hope that one day I can make her proud. Being part of the Arc family and working on Isabella's Arc gives me purpose and focus, especially whilst Isabella's big sister, Olivia is at school."

CARLA STEELE, ISABELLA'S ARC



Fundraising for Isabella:

£1k

raised through a spinathon fundraiser hosted by Asda.

£500

raised through a night of mediumship and cards.

£755

raised by **Isabella's Granny** taking part in a triathlon.

£1.4k

donated via sunrise sea dip and morning walk.

£1.5k

raised by **Isabella's Granda** running a marathon.

"I hope that one day children will be able to receive treatment that's a lot less harsh than what Isabella endured. No parent should ever have to sit and watch their child suffer. I hope that one day soon no more children will have to lose their life to this cruel disease and have the chance that my baby didn't."

CARLA STEELE, ISABELLA'S ARC

Isabella's impact:



Isabella's Arc has raised over £5K since it was founded. Isabella's family and community have hosted unique fundraisers to remember Isabella and contribute to making changes in the future.



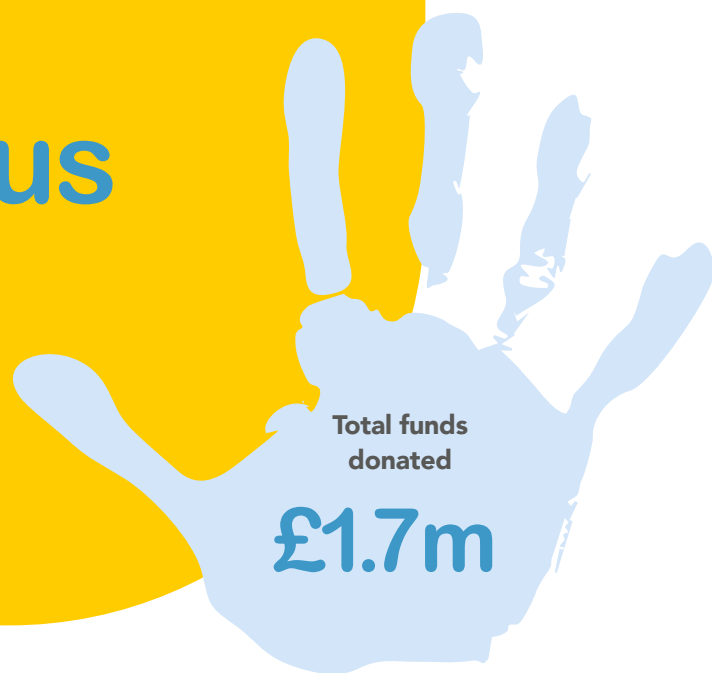
Isabella's family want to see changes to ensure more efficient diagnosis and understanding by GPs of parental concerns. They want to more effective treatment options at the point of relapse and less harmful treatments.

Our year at a glance

Research focus

We donated **£754,540k** towards rhabdomyosarcoma research during this time period.

Total funds donated towards rhabdomyosarcoma research now stand at **£1.7million**.



£47k

The University of Birmingham

This is for year two of a research project designed to investigate fusion negative rhabdomyosarcoma with RAS pathway alterations focusing on DNA repair and replication stress. The overall goal is to find a drug that can target these pathways.

£133k

University College London

These funds are enabling a PostDoc to take the information from Wellcome Sanger's single cell analysis forward to develop a CAR T-cell treatment for rhabdomyosarcoma.

£16k

University of York

This is the payment for year one of Living REFORMS, a project designed to aid families decision-making at the point of relapsed/refractory rhabdomyosarcoma by creating an online 'dynamic' resource containing information for clinicians and parents.





£547k

The Institute of Cancer Research



£339k to kickstart the first year of the project designed to unravel the mystery of the causes of cell changes leading to relapsed and refractory rhabdomyosarcoma. This pioneering research hopes to inform new therapies that will prevent or treat relapsed rhabdomyosarcoma.



£45k for the second year of a work package relating to maturation targets and resistance models that will lead to clinical translation for the project designed to create a CAR T-cell treatment for rhabdomyosarcoma in conjunction with UCL Great Ormond Institute of Child Health and Wellcome Sanger.



£113k towards year two of the project investigating the MYOD1 L122R mutation in fusion negative disease which leads to an extremely poor prognosis. The work aims to understand the impact of this mutation and to screen and validate new treatment options to target it.



£49k for year three on the project exploring the use of liquid biopsies in detecting and predicting disease path in the treatment of children with rhabdomyosarcoma.

£5k

Wellcome Sanger

These funds have been allocated to the work relating to the immune environment scRNAseq which includes re- agents, library making and sequencing for the project entitled 'Identification and evaluation of foetal immune targets in rhabdomyosarcoma'.

£3k

University of Ulster

This project involved two parent focus groups in order to discuss pathways to improve the sleep of children with life limiting conditions. This involves devising engagement and dissemination tools based on the data collated to be utilised as part of Alice's Arc's well-being initiative and hospital bags. Pillow cases have now been produced and distributed at several UK hospital oncology wards summarising key findings.



New Research Projects

We have also been devising new projects in conjunction with scientists and medical professionals. Together with our Scientific Advisory Team we have agreed to fund the following future work:



Accelerating biological studies of RMS to improve patient outcomes

- a) Analyses of retrospective RMS samples from the VIVO biobank including molecular analysis with clinical outcome data (Sanger/GOSH/Sam Behjati)
- b) FaR-RMS prospective co-ordination and management of sample collection and bio banking processes and data generation in order to support current and future biological studies (ICR/Janet Shipley)



Targeting fluorescence guided surgery for RMS using B7H3 as a target to achieve clear surgical margins (GOSH/Stefano Giuliani)

Scientific Advisory Team

We have made two further appointments to our Scientific Advisory Team.



Dr Amy Hont, an Assistant Professor of Paediatrics for cancer immunology and microbial oncology at Children's National Hospital, Washington D.C, USA.



Dr Fariba Navid, a Professor of Clinical Pediatrics and Pediatric Hematologist/Oncologist at Children's Hospital, Los Angeles, USA.

They have joined Dr Melvin Chua (National Cancer Centre, Singapore), Dr Edward Newman (Consultant Neurologist, Scotland, UK) and Dr Toby Trahair (Haematologist and Oncologist at Sydney Children's Hospital, Australia). We are very thankful for their voluntary, expert opinions.

This team help inform, deliver and review our research strategy. The team provides expert guidance on:



identifying, setting and evaluating research priorities

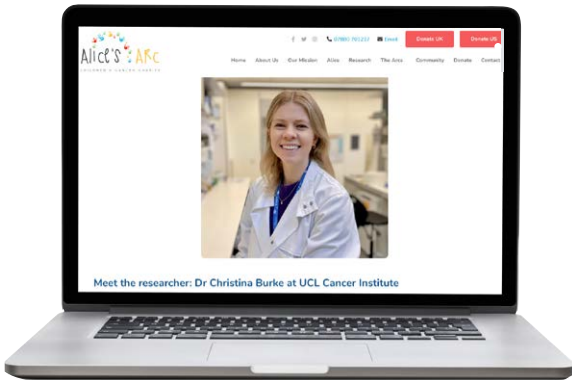


reviewing and assessing grant applications



reviewing and commenting on research progress reports of funded work.

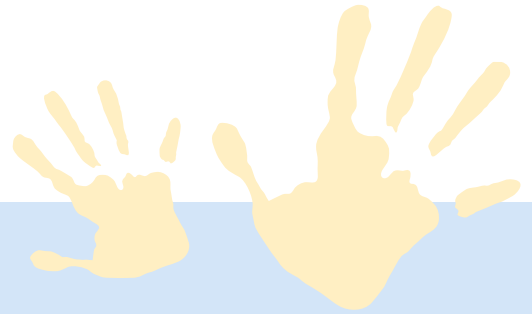




Engagement

PostDoc, Chrissie Burke based at UCL and funded by Alice's Arc provided an interview explainer of what a day in the life at her laboratory is like.

Dr Alejandra Bruna, one of the scientific leads on the molecular plasticity project at the Institute of Cancer Research, took fundraising into her own hands by climbing Mt Montserrat in Spain. She split funds raised between Alice's Arc and the Little Princess Trust.



Article Published



Molecular Characterisation of Circulating Tumour DNA in Pediatric Rhabdomyosarcoma: A Feasibility Study.



Journal of Clinical Oncology.



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Fundraising highlights



£9.5k



GO GOLD CASINO NIGHT HOSTED AT M RESTAURANTS, THREADNEEDLE STREET, LONDON

On Saturday 11th March 2023, we welcomed Arcs, other families, medical professionals and scientists to an event designed to bring this rhabdomyosarcoma community together and to raise funds for our rhabdomyosarcoma research portfolio. Guests enjoyed a glitter bar, a fabulous casino including a roulette raffle, black jack and poker games and a wonderful brass band. We were absolutely thrilled to have our corporate partners, Enfuse there - they sponsored a casino table and donated a ferrari lego set as a prize. Other prizes included UK trips away, dinners in London restaurants, theatre tickets, paintings, spa days, a chocolate hamper and a Scamp and Dude bag. It was so special and inspiring to come together for the cause we are all so passionate about.

DEXTER'S LUSH DRAGON GOES GLOBAL FOR INTERNATIONAL CHILDHOOD CANCER AWARENESS DAY

Dexter's infamous gold dragon egg bath bomb, produced by Lush, was launched for sale globally in February 2023 to coincide with International Childhood Cancer Awareness Day on 15th February 2023. Sales of these secured £500k of funds via Dexter's Arc. The money will go towards non-animal testing research for rhabdomyosarcoma. Dexter's family are the co-founders of Lush and they have been using this powerful platform to raise awareness and funds in honour of Dexter, who passed away in July 2022.

£500k



'AROUND THE WASH', 80 MILE CYCLE RIDE FOR ELLIOTT'S ARC



On Saturday 20th May, 2023, Elliott's Dad and Uncle took on the challenge of an 80 mile cycle ride around the Wash. The event was themed in true Elliott Spiderman style with the cyclists dressed in full Spiderman attire.

Elliott's family, friends and their wider community raised an enormous £7.6k in support of this fundraising event.

£7.6k





JESSICA'S BLACK & PINK CHARITY BALL EVENT

£19k

Jessica's black and pink gala ball brought together 160 people including friends and family wanting to support the cause in memory of Jessica Macqueen. It was held at the hotel, Stoke Place in October 2022 and incorporated a lively auction led by Jessica's Dad.



PLAN.COM TURN PINK FOR JESSICA

£6k

Each year telecommunications company, plan.com turn pink in memory of Jessica. On this date in November, all their offices go pink for the day. Pink was Jessica's favourite colour. This time they raised a massive £6k.



JESSICA'S QUIZ NIGHT

In May 2023, Jessica's quiz night was held in a local village hall in Watford.

Funds were raised via ticket sales, raffle and an auction.

£11.8k



LONDON MARATHON

Andrew Clapton and Brendan O'Driscoll both ran the London Marathon for Jessica's Arc raising a brilliant £8k.

£8k

MOLLIE'S HIGH FIVE FUN RUN

£6k

To mark the 5th anniversary of Mollie's diagnosis with rhabdomyosarcoma, Mollie's Arc held a fun run on Saturday 2nd September 2023. The event offered 3k, 5k and virtual run options and took place at Moira Demesne, Northern Ireland, with the support of Jog Moira running club.

This fantastic event raised over £6k with 300 people attending and local businesses providing refreshments. All runners received a tailor-made Mollie's Arc running buff and wore Alice's Arc running vests from previous sales. These were a great talking point and reminder about why the charity was created.

Mollie's Mum commented: "The five year anniversary was always a mental goal and although we know the risk of relapse does not completely disappear after five years, it still feels like a 'big' milestone worth marking and acknowledging how far Mollie and our family have come."



LONDON LANDMARKS HALF MARATHON 2023

On 2nd April 2023, a team of 6 runners from Alice's Arc, Oliver's Arc, Dexter's Arc and Sophie's Arc took on the challenge of this iconic half marathon that takes in the major landmarks of London. As usual, runners included parents, family members and friends through our Arc community and other supporters.

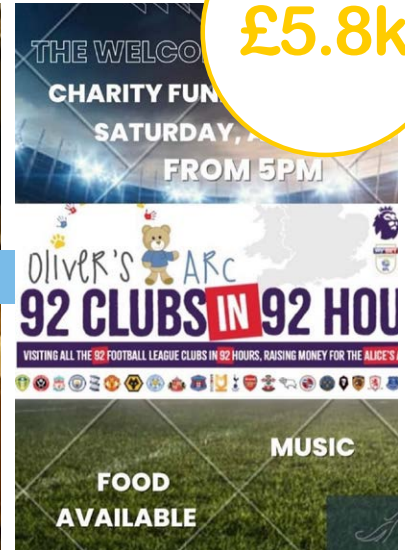
£15k



92 IN 92 CHALLENGE FOR OLIVER'S ARC

A team supporting Oliver's Arc set themselves the unique challenge of visiting 92 football league clubs across the UK in 92 hours, in memory of Oliver Hurd. They started the challenge on 11th April 2023 and completed the challenge at Leeds United in 87 hours 18 minutes, racking up a total of 2516 miles. As part of this, a football action fundraiser was held with lots of interesting football memorabilia and a raffle. A fantastic £5.8k was raised.

£5.8k



LAUNCH OF TOMMY'S ARC

Tommy's Arc was launched in November 2022 when Tommy was on maintenance chemotherapy. Tommy is now off treatment and scans remain stable. Upon the launch of the Arc, Tommy's friends, family and community donated generously. His school, Witham Hall, hosted a Winter Fair and a fun run in honour of Tommy's Arc. It is wonderful to see communities coming together time and time again, touched by an experience with rhabdomyosarcoma and wanting to contribute to making a difference for the future.

£60k



CORPORATE SUPPORT

We are incredibly grateful to the companies that support our work and those that offer matched giving.

- This year we received £20k from **A&O Shearman**. This is an annual grant from the international law firm who have supported Alice's Arc since inception.
- **Samsung** supported Freddie's Arc at an awards event.
- **Enfuse Group** have been our corporate partner, providing a breadth of support and partnership
- **Courtiers** donated £2.5K in honour of Elliott and his Arc.

A&O SHEARMAN

ENFUSE

COURTIERS

PRISON OFFICERS FROM HMYO1 WETHERBY CYCLE 1000 MILES IN 24

On the 13th January 2023, This incredible team of prison officers took on the immense challenge of cycling 1000 miles in 24 hours using exercise bikes outside the main prison gates. They have been inspired by Jack Johnson who is currently receiving treatment for relapsed rhabdomyosarcoma.

£3.5k



CHRISTMAS FAIRS & CHRISTMAS CARDS

We produced our 'Say My Name' Season's Greetings Card. Three designs were created, each incorporating the names of those impacted by rhabdomyosarcoma in our community. Christmas can be a tough time and we wanted to honour these individuals by saying their name. These were sold across the country. Thanks to our corporate supporters, A&O Shearman, these were produced at no cost.

We were grateful for the support of Walthamstow Hall School, Sevenoaks (For Alice) and St Theresa's Catholic School, Leeds (For Elsa) for allowing stalls to be hosted at their respective Christmas Fair and Christmas Market Day. This was a great opportunity to sell the products created through the Arcs as Christmas presents.



SUPPORT FROM SCHOOLS

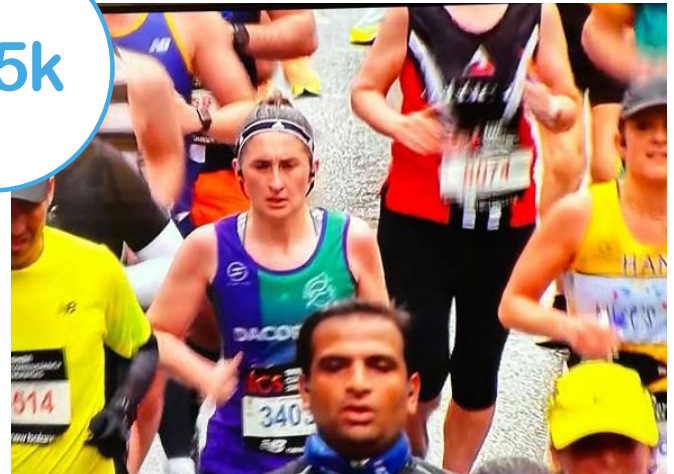
We are always grateful for the great support we receive from schools where a pupil may have been diagnosed with rhabdomyosarcoma or a friend of a child with rhabdomyosarcoma chooses to seek support from their school to run a fundraiser. This year we are thankful for the support of Radnor House, Sevenoaks, Chesham High School, Goldolphin and Latymer, London, Walthamstow Hall School, Sevenoaks, St Theresa's Catholic School, Leeds, Austhorpe Primary School, Leeds, Rydon Primary School, Devon, Longfleet School, Poole, Yorke Mead, St Albans and Poole High School. Every school has provided significant donations via childhood cancer awareness month, being the school's charity of the year and all kinds of fun, fundraising events.



LONDON MARATHON 2023

Our team of runners from Jessica's Arc, Elsa's Arc and Hannah Jarvis, running for her son Ben who is now off treatment took on this 26 mile challenge. Collectively they raised a well-earned £15k. Hannah was even spotted on the television footage.

£15k



SEVEN HOUR WALK FOR MAYA'S ARC

On 23rd September, 2023, a team of Maya's supporters and Maya herself set out on a seven hour walk, starting at Birmingham Children's Hospital and ending at the Oast House in Redditch. This was a wonderful, heart-warming occasion in honour of Maya as she goes through treatment for rhabdomyosarcoma. Donations and other fundraisers linked to the walk raised a fabulous £7.4k.

£7.4k



Other news

Received extensive and high-profile press coverage over the last year

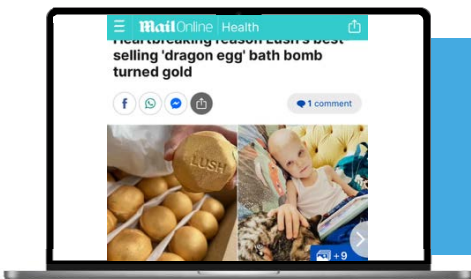
We were delighted with the press interest in Alice's Arc, the Arcs and the rhabdomyosarcoma research being undertaken as a result of funds raised. This was achieved on television, via national broadsheets and local media.

"In memory of Alice: Mother's £2million mission to help cancer-hit families in honour of daughter, 7, who died from a rare form of the disease. Daily Mail, 20th December 2022."



"A Young Girl's Legacy: pioneering blood test can help treat rare childhood cancer. The Sunday Observer, 15th January 2023"

"Parents launch appeal in memory of boy, 5. The Henley Standard, 10th February 2023"



"Lush Bath Bomb Turned Gold to Honour Co-Founder's Grandson, Dexter. Daily Mail, 22nd February 2023"

"Alice's Arc features on BBC Online and BBC South East Lunch and Evening News, 10th May 2023."





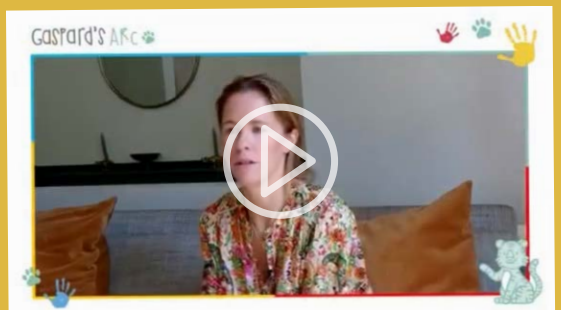
Childhood Cancer Awareness Month (CCAM) – September 2023


Together we bring hope:

This year we produced a series of videos designed to showcase the charity, the Arcs and the role of hope throughout the experience of rhabdomyosarcoma.

We also used it as an opportunity to launch our US organisation through the words of rhabdomyosarcoma survivor, Abbe Pannucci.

We are so grateful to those who told their stories - Abbe's Arc, Dexter's Arc, Ethan's Arc, Freddie's Arc and Gaspard's Arc. We would also like to thank our corporate partners, Enfuse, who produced and designed the videos.













Alice's ARC
CHILDREN'S CANCER CHARITY

Please support Alice's Arc by making a donation at www.alicesarc.org

*Source CRUK 2017-2019 and CRUK 2016-2018


Go Gold for Childhood Cancer Awareness Month

-  Cancer is the **number one** cause of death by disease for children under the age of 14 in the UK.
-  There are **88 different types** of children's cancer.
-  **1,838 new cases** in children each year, on average, in the UK*.
-  **253 children** in the UK die from cancer each year. This is more than 4 children each week*.
-  Only **4 new drugs** have been approved in the last 20 years to treat childhood cancers.
-  **90% of long-term cancer survivors** will develop serious health issues as a result of current treatments.
-  Among children in the UK, **cancer is highest in the under-fives***






Alice's ARC
CHILDREN'S CANCER CHARITY

A community of families, scientists and doctors coming together to defeat Rhabdomyosarcoma



What is Rhabdomyosarcoma

-  Rhabdomyosarcoma is the most common soft tissue sarcoma occurring in children and young people.
-  Accounts for 5% of childhood cancer cases each year. With 60/70 children in the UK and 350 in the USA each year.
-  On relapse, there is an 8-20% chance of survival. This is influenced by the subtype, gene fusion status and location.

Together we are stronger. Help us change the story.

Childhood Cancer Advocacy Work

Working with Early Career Researchers (ECRs)

These young Scientists are the future of cancer research. Patient advocates can help them understand the value of working with patients and care-givers to help inform and enhance the impact of research. They can also influence and inspire their long-term career decisions. Sara Wakeling regularly participates in initiatives working with ECRs. Here are some examples:



In November 2022, Sara Wakeling was honoured to attend the Cancer Grand Challenges, Future Leaders conference in Barcelona. She had the opportunity to participate in a panel and talk to the audience about the role of engaging patients in research and empowering them to pursue a career path in childhood cancer research. It was also an invaluable opportunity to network with ECR's from across the world and different research institutions. We are so grateful to these individuals for pursuing a career in this field.



In May 2023, Sara also participated in a presentation to ECRs at George Washington University, USA promoting how patient advocacy works and how ECRs and can work with patient advocates. She did this alongside fellow advocate, Gavin Lindberg.

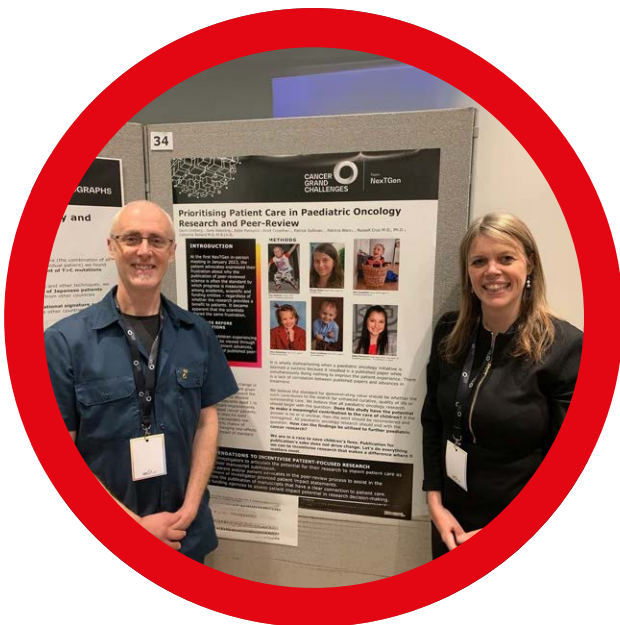




Promoting Patient Involvement In Research

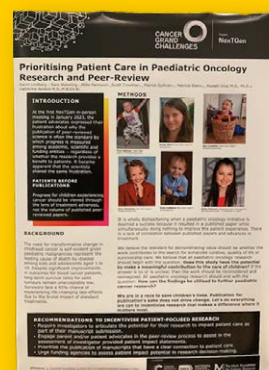
Sara Wakeling is part of the parent group of the EpSSG professional body for paediatric sarcoma. The group are currently shaping how parents can be involved in the important research they are undertaking. This involves participating in regular committee meetings, designing research questions, reviewing patient information as part of clinical trials and ensuring the effective dissemination of research findings. Sara participates in the newly formed rhabdomyosarcoma committee as part of this.

In December 2022, the annual EpSSG conference was held in Rome. Sara gave a presentation on the role of patient advocacy in research with particular emphasis on the way this works within the NextGen, Cancer Grand Challenge where she is the lead advocate.



Prioritising Patient Care in Paediatric Oncology Research and Peer Review - Cancer Grand Challenge, NextGen poster

The NextGen team of patient advocates created a poster, alongside several co-investigators and presented it at the Cancer Grand Challenge Summit in March 2023. The aim of the poster was to shift thinking in the sector and put patients before publications. The idea being that success should be measured through the lens of treatment advances for children with cancer and not the volume of published-peer reviewed papers.



Alice's Arc & the FaR-RMS Clinical Study



FaR-RMS is currently, one of the most clinical significant research studies internationally for rhabdomyosarcoma. It is addressing key research questions such as:



Does the addition of new drugs to standard chemotherapy for patients newly diagnosed improve survival?



For patients whose tumour can be removed surgically after 12 weeks of chemotherapy, is it better to receive radiotherapy before or after surgery?



Does the addition of new drugs to standard chemotherapy for patients with relapsed disease improve survival?



Do higher doses of radiotherapy reduce the risk of the tumour recurring?



Does giving maintenance chemotherapy for longer improve survival?



For those with metastatic disease, does radiotherapy to all sites improve survival?



Sara Wakeling and the Alice's Arc community of families are heavily involved in this study. Sara is a member of the Trial Management Group and attends regular meetings. Families have been involved in PPI groups providing their perspective on information provision and tools to use to communicate better about FaR-RMS. Several of the projects funded by Alice's Arc also connect to this Study.

Engagement with UK Hospitals



Family well-being bags:

We continue to deliver our well-being bags to those impacted by rhabdomyosarcoma to hospitals across the UK. During this period, Sia's Arc delivered bags to the John Radcliffe, Oxford to mark the first anniversary of Sia's death and Elsa's Arc made a delivery to Leeds Children's Hospital in memory of Elsa, who was treated there during her four year experience.




Pillow cases:


As part of the dissemination of our sleep project findings, with the University of Ulster, we produced a pillow case with guidance to improving sleep and a QR code to gather more feedback from families. The pillow case is branded in true Alice's Arc fashion. These are now included in our family well-being bags.




Patients as Co-Author's on Scientific Papers

One part of being embedded as a patient advocate in research involves co-authoring articles with scientists and clinicians to demonstrate partnership in the presentation and assessment of data. From the perspective of the charity, this helps to identify new research questions and pursue opportunities to fund a pipeline of research. The citations below illustrate the articles that Sara Wakeling has been involved in as a co-author.

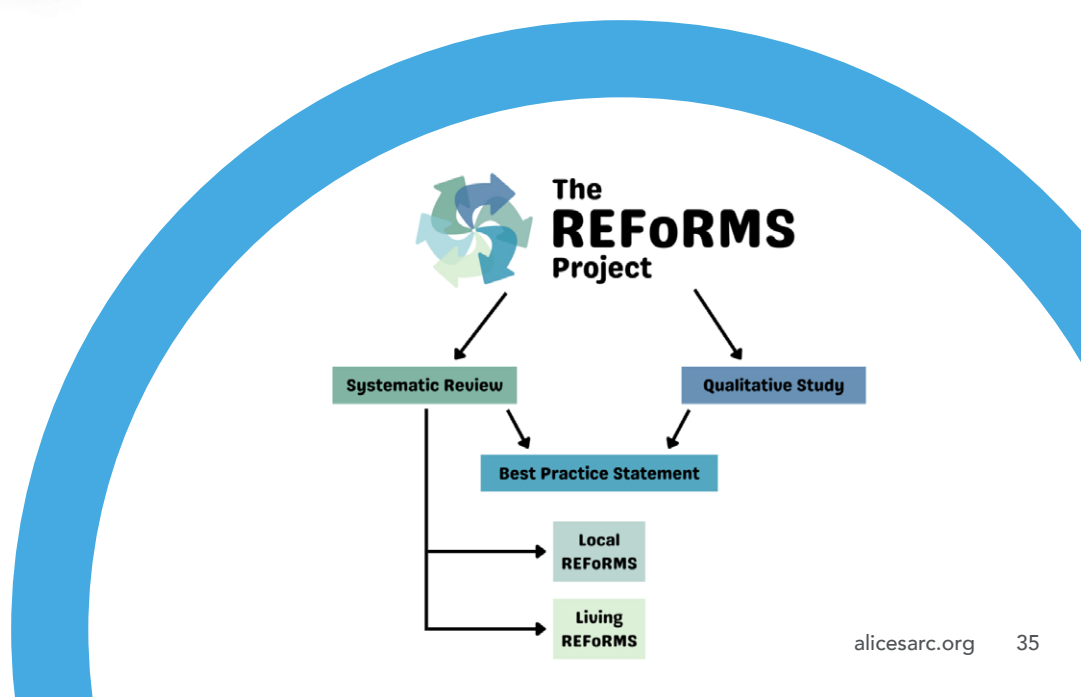
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 Chisholm, J.; Mandeville, H.; Adams, M.; Minard-Collin, V.; Rogers, T.; Kelsey, A.; Shipley, J.; van Rijn, R.R.; de Vries, I.; van Ewijk, R.; et al. **Frontline and Relapsed Rhabdomyosarcoma (FAR-RMS) Clinical Trial: A Report from the European Paediatric Soft Tissue Sarcoma Study Group (EpSSG).** *Cancers* 2024, 16, 998. <https://doi.org/10.3390/cancers16050998>





CHILDREN'S CANCER CHARITY

The future

We have exciting and ambitious plans for the year ahead and will focus on the delivery of our mission to find a cure and better treatments for rhabdomyosarcoma, whilst supporting families going through this journey. We will also focus on growing Alice's Arc USA to help realise our unified mission.



Rigorously review our rhabdomyosarcoma research portfolio and ensure it delivers: Pursue new opportunities for projects in areas such as fusion positive rhabdomyosarcoma where outcomes are dismal. Broaden the portfolio to incorporate clinical translation. Continue to implement robust processes around the management of the research portfolio and securing the most impactful research. Continue to make appointments to our Scientific Advisory Board to help assess and monitor progress.



Focus on embedding and growing the Arcs platform both in the UK and USA: This is central to the strategy of Alice's Arc. Continue to roll out and embed our approach to building family networks via the Arcs. Ensure that funds are directed into research that is meaningful to patients and driven by questions raised through our network. Continue to develop the model internationally.



Engage our family community with advocacy and research: Continue to produce videos, interviews, education sessions and tools that help communicate findings and enhance understanding of the rhabdomyosarcoma research landscape. Encourage families to get involved in PPI/E groups.



Continued implementation of management systems to reflect growth: This involves financial, legal, regulatory and operational management to ensure smooth running.



Family well-being: Continue to work on the roll-out of our Family Well-Being arm and ensure that it is tailored to the needs of families at any stage – diagnosis, treatment, remission, palliative and loss. Develop separate support groups for bereaved families. Ensure our community is well-supported and create platforms to come together face to face.



Sustain and expand fundraising initiatives by maintaining relationships with current supporters and attracting new sponsors. Devise a corporate and partnerships strategy.





CHILDREN'S CANCER CHARITY

(A Charitable Incorporated Organisation)

Report and Financial Statements

For the Year Ended 30 September 2023

Charity number 1164253

Alice's Arc

Report of the Trustees for the year ended 30 September 2023

The trustees present its report and financial statements, audited by an independent auditor, for the year ended 30 September 2023.

Reference and Administrative Information

Charity Name: Alice's Arc
Charity registration number: 1164253
Registered Office and operational address: High Beech
53 Kippington Road
Sevenoaks
TN13 2LL

Trustees

Mrs Sara Alison Louise Wakeling – Chief Executive
Mr David Andrew Wakeling
Mr Nick Richard Wakeling
Dr Melvin Lee Kiang Chua
Mrs Natalie Carpenter

Independent Auditor

Kreston Reeves LLP, Statutory Auditor, Chartered Accountant
37 St Margaret's Street, Canterbury, Kent CT1 2TU

Bankers

Metro Bank, 1 Southampton Row, London WC1B 5HA
CAF Bank, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ
Nationwide, Nationwide House, Pipers Way, Swindon SN38 1NW

Our Aims and objectives

Purposes and Aims

Our charity's purpose as set out in the objects contained in the charity's constitution is: the relief of sickness of people suffering from childhood cancers in particular but not limited to sarcomas in particular but not exclusively by:

- (1) Funding research into such cancers by working with institutions like the Institute of Cancer Research, Great Ormond Street Hospital, University of Birmingham, Wellcome Sanger Institute, UCL Cancer Institute, University of York and the Royal Marsden to fund teams and equipment required to undertake research;
- (2) Funding the purchase of medicine (as recommended by doctors), equipment, toys, facilities and/or services not provided by national health services or otherwise provided;
- (3) Introducing best practices between jurisdictions for treatment and/or easing the suffering of patients and/or their families;
- (4) Raising awareness of such cancers through social and other media, and/or
- (5) Assisting in the knowledge and understanding of such cancers.

Our aims fully reflect the purpose that the charity was set up to further and the public benefit of helping children with childhood cancers, in particular sarcomas, as a class, and their families.

Ensuring our work delivers our aims

We review our aims, objectives and activities each year. This review looks at what we have achieved and the outcomes of our work in the period to 30 September 2023. The review looks at the success of each key activity and the benefits they have brought to those groups of people we are set up to help.

The review also helps us ensure our aims, objectives and activities remained focused on our stated purpose. We have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing our aims and objectives and in planning our future activities. In particular, the trustees consider how planned activities will contribute to the aims and objectives they have set.

The focus of our work

Our main objectives for the year have been focused on helping improve the outcomes and experience on treatment for children with childhood cancers, in particular Rhabdomyosarcoma, as a class, and their families. The strategies we used to meet these objectives included:

- (a) Devising and funding a diverse portfolio of rhabdomyosarcoma research projects. These projects include work to understand fusion negative disease and the biomarkers driving aggressive forms of the disease, identifying drugs to target these biomarkers in an individualised approach, devising immunotherapy treatment options via CAR T-cell therapy for rhabdomyosarcoma, using liquid biopsies in the detection and prediction of rhabdomyosarcoma, understanding relapsed and refractory rhabdomyosarcoma and understanding more about the tumour micro environment and how it influences tumour behaviour. In addition, we are co-funding work to understand the decisions facing parents at the point of relapse and the provision of information on potential treatments at this stage. We hope this will lead to a provision of an IT resource for families and clinicians. Other projects include understanding the molecular changes that lead to relapsed or refractory rhabdomyosarcoma and sequencing retrospective and prospective tissue samples to help accelerate new treatments in the clinic.
- (b) Raising awareness and lobbying for change. We have forged connections with other children's cancer charities and are using our platform of Arcs to create a voice influencing the changes needed to ensure research into rhabdomyosarcoma can happen effectively. We have also joined a coalition of children's cancer charities to help achieve this together.
- (c) We have continued to increase our fundraising activities during this period. This has been largely down to the creation of the Arcs platform and engaging new families who wish to fundraise in honour of their child's journey with rhabdomyosarcoma. Communities come together and funds are pooled.
- (d) Enhancing family well-being. We offer an online community and support group of rhabdomyosarcoma families at any point of the journey. In addition, we also provide well-being bags across multiple UK hospitals and are considering areas to make a difference to the parent experience such as sleep.

The charity has now raised or received commitments for over £3 million to date in incoming resources to meet disbursement and other commitments, over £300 thousand of which since 30 September 2023.

How our activities deliver public benefit

Our main activities and who we try to help are described below. All our charitable activities focus on helping children with childhood cancers, in particular sarcomas, as a class (and their families) and are undertaken to further our charitable purpose for the public benefit.

Who used and benefited from our services?

Over 160,000 children globally are diagnosed with cancer annually. This number is increasing year on year. Childhood cancers are complex; there are over 25 major types and over 100 sub-types. Childhood cancer research is vastly underfunded compared to that of adults. Research and development by pharmaceutical companies cover c60% of funding for adult cancer drugs. It is close to zero for that of children.

Our objects and funding limit the services we provide to children suffering from Rhabdomyosarcoma resident in the UK and the US. However, we are forging international connections with professional bodies such as the EpSSG and families.

All our support is provided free. Equal access to our services among children with childhood sarcomas as a class and their families is an important issue for us. We believe equal access to our support is vital to our success.

Financial Review

Against the size and complexity of children cancer, it is challenging to progress on all of the objectives of Alice's Arc. Nevertheless, the charity, with the aid of sound financial management and the support of its trustees and contacts generated a very positive financial outcome for the period, its seventh year in operation, with income of £1,176,371 (2022: £670,112) including Gift Aid. This enabled total disbursements of £754,540 (2022: £392,842): £547,127 to the Institute of Cancer Research, £133,951 to University College London, £47,928 to the University of Birmingham, £16,543 to the University of York, £5,116 to the Wellcome Sanger Institute and £3,875 to the University of Ulster, bringing total disbursements to cancer research organisations to the end of September 2023 to over £1.7 million. After these disbursements, total funds of the charity stood at £1,231,909 as at 30 September 2023 (2022: £859,596).

Principal Funding Sources

The funding sources for Alice's Arc are from individual and corporate donations. Funds of the charity raised by handmade cosmetics giant Lush, following the death of Dexter, are restricted to animal-free research. £658,681 was raised in the year to 30 September 2023 by Lush.

Alice's Arc is registered with the Fundraising Regulator and with support from lawyers has developed a code of conduct with each Arc to require fundraising to be undertaken for the purpose of the objects of the charity and in compliance with the Fundraising Regulator's Code of Fundraising Practice. Provisions include fundraising involving children, people in vulnerable circumstances, record keeping and advance notice of fundraising events. No fundraising complaints have been received.

Investment Policy

Most of the charity's funds are currently expected to continue to be applied to clinical research in collaboration with cancer research organisations and, pending disbursement, the funds are invested short term with the charity's bankers.

Reserves Policy

The Trustees have examined the charity's requirements for reserves in light of the main risks to the organisation. Given the low day-to-day expenditure by the charity, the target is £20,000 in general funds. The reserves are needed to meet the working capital requirements of the charity and the Chief Executive is confident that at this level they would be able to continue the current activities of the charity. The present level of reserves available to the charity exceeds its target reserve level on this basis.

Plans for Future Periods

The charity plans to continue the activities outlined above in the forthcoming years and continues to explore new projects. In addition to the £1.7 million research grants made in the periods to 30 September 2023, a further £2 million has been committed subject to agreed milestones, primarily consisting of grants of over £1 million each to the Institute of Cancer Research relating to plasticity, and to Wellcome Sanger relating to exploitation of tumour samples. Given current assets, the charity's trajectory and the conditionality and time horizon of these commitments, the trustees are confident they can be met through future fund raising to the extent not already funded.

Structure, Governance and Management

Governing Document

Alice's Arc is a Charitable Incorporated Organisation and was entered onto the Register of Charities on 4 November 2015 with Registered Charity Number 1164253. The charity was established under a Constitution which established the objects and powers of the charity. In the event of the charity being wound up, the trustees have no liability to contribute to its assets and no personal responsibility for settling its debts and liabilities.

Recruitment and Appointment of Trustees

Under the requirements of the constitution there is no limit on the term of trustees. All trustees give their time voluntarily and received no benefits from the charity. No expenses were reclaimed from the charity in the year.

Due to the nature of childhood cancers much of the charity's work inevitably focuses upon young people. The trustees seek to ensure that the needs of this group are appropriately served through the diversity of the trustee body with marketing, legal, financial and medical skills well represented. In the event of particular skills being lost due to retirements, individuals will be approached to offer themselves as trustees.

Some of the trustees have also in their personal capacity provided donations to the charity in the pursuit of its objectives.

Trustee Induction and Training

As co-founders, most trustees are familiar with the practical work of the charity. New trustees will be made familiar of the charity's activities and the context within which it operates by the Chief Executive, including the obligations of trustees, the main documents which set out the operational framework for the charity including its constitution, the current financial position, and the future plans and objectives of the charity.

Risk Management

The trustees review the major risks to which the charity is exposed on at least a yearly basis. These risks are assessed as limited, for example given that the charity employs no staff. Where appropriate, systems or procedures have been established to mitigate the external risks the charity faces, for example through the use of collaboration with established institutions such as the Institute of Cancer Research. Internal control risks are minimised by the implementation of procedures for authorisation of all financial transactions.

Organisational Structure

Alice's Arc has between three and 12 trustees who meet quarterly and are responsible for the strategic direction and policy of the charity. At present the charity has five trustees from a variety of professional backgrounds relevant to the work of the charity. There is no Company Secretary. A scheme of delegation is in place and day to day responsibility for the charity's activities rest with the Chief Executive who is also a trustee.

Related Parties

No trustee or other person related to the charity had any personal interest in any contract or transaction entered into by the charity during the year.

Responsibilities of the Trustees

The trustees are required to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charity as at the balance sheet date and of its incoming resources and application of resources, including income and expenditure, for the financial year. In preparing those financial statements, the trustees should follow best practice and:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent; and
- prepare the financial statements on the going concern basis unless it is not appropriate to assume that the charity will continue on that basis.

The trustees are responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Statement of Recommended Practice: Accounting and Reporting by Charities (FRS 102). The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Trustees

The trustees of Alice's Arc, who are trustees for the purpose of charity law, who served during the year and up to the date of this report are set out on page 38. We certify that, so far as we are aware:

- the accounts present a true and fair view and the accounting policies are adopted as outlined in the notes;
- there have been no changes in accounting policy nor estimates nor material prior year errors (this is the charity's first reporting period);
- there are no material uncertainties related to events or conditions that cast significant doubt on the charity's ability to continue as a going concern;
- there is no relevant audit information of which the charity's independent auditor is unaware; and
- we have taken all the steps that we ought to have taken in order to make ourselves aware of any relevant audit information and to establish that the charity's independent auditor is aware of that information.

Independent Auditor

Kreston Reeves were appointed as the charity's auditor. This report has been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) effective from 1 January 2019.

Approved by the trustees on **26th July 2024** and signed on its behalf by:

Mrs Sara Wakeling (Chief Executive)

Sara Wakeling

Statement of Financial Activities (including Income & Expenditure Account) for the year ended 30 September 2023

	Notes	Unrestricted Funds to 30/9/23 (£)	Restricted Funds to 30/9/2023 £	Total Funds to 30/9/2023 £	Total Funds to 30/9/2022 £
Incoming resources					
Voluntary income: donations	2	496,462	658,681	1,155,143	661,155
Gift Aid on donations	7	6,153	-	6,153	7,738
Investment income		14,276	799	15,075	1,220
Total incoming resources		516,891	659,480	1,176,371	670,112
Resources expended					
Costs of generating voluntary income	3	33,350	-	33,350	19,863
Charitable activities	3	620,889	133,951	754,840	392,842
Governance costs	3	11,938	3,930	15,868	-
Total resources expended		666,177	137,881	804,058	412,706
Net Income for the year		(149,286)	521,599	372,313	257,407
Reconciliation of funds					
Total funds brought forward		859,596	-	859,596	602,189
Total funds carried forward		710,310	521,599	1,231,909	859,596

All incoming resources and resources expended derive from continuing activities.

Balance Sheet as at 30 September 2023

	Notes	30/9/2023 £	30/9/2022 £
Fixed Assets		-	-
Current Assets		1,240,009	859,596
Debtors	7	6,153	15,475
Cash at bank and in hand		1,233,856	844,121
Creditors		(8,100)	-
Net Assets		1,231,909	859,596
General Funds		710,310	859,596
Restricted Funds		521,599	-
Total Funds		1,231,909	859,596

Statement of Cash Flows for the year ended 30 September 2023

	30/9/2023 £	30/9/2022 £
Net income/(expenditure)	372,313	257,407
Adjustment for: Dividends, interest, rents	(15,075)	(1,220)
Change in debtors	9,322	32,740
Change in creditors	8,100	
Cash flow from operating activities	374,660	288,927
Dividends, interest and rents	15,075	1,220
Cash flow from investing activities	15,075	1,220
Cash from financing activities	-	-
Beginning of the reporting period	844,121	553,974
End of the reporting period	1,233,856	844,121
Change in cash and cash equivalents	389,735	290,147

All cash and cash equivalents is held as cash in hand.

These accounts are prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) effective from 1 January 2019.

Approved by the trustees on **26th July 2024** and signed on its behalf by:

Mr Nick Wakeling (Treasurer)



Notes forming part of the Financial Statements for the year ended 30 September 2023

1. Accounting Policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year.

(a) Basis of accounting

The financial statements have been prepared under the historical cost convention, as modified by the inclusion of any fixed asset investments at market value, and in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) effective from 1 January 2019.

(b) Fund accounting

All donations received are unrestricted other than funds raised by Lush.

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Unrestricted funds include any revaluation reserve representing the restatement of investment assets at market values.
- Designated funds are unrestricted funds earmarked by the trustees for particular purposes.
- Restricted funds are subjected to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

(c) Incoming resources

All incoming resources are included in the statement of financial activities when the charity is entitled to, and virtually certain to receive, the income and the amount can be quantified with reasonable accuracy. The following policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes unconditionally entitled to the grant.
- Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by any volunteers has not been included in these accounts.
- Investment income is included when receivable.
- Incoming resources from charitable trading activity are accounted for when earned.
- Incoming resources from grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance.

(d) Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of generating funds comprise the costs associated with attracting voluntary income and the costs of trading for fundraising purposes.
- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.
- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include any audit fees and costs linked to the strategic management of the charity.
- All costs are allocated between the expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource.

(e) Fixed assets

Fixed assets (excluding investments) are stated at cost less accumulated depreciation. The costs of minor additions or those costing below £1,000 are not capitalised. Depreciation is provided at rates calculated to write off the cost of each asset over its expected useful life, which in all cases is estimated at four years. Impairment reviews are carried out as and when evidence comes to light that the recoverable amount of a functional fixed asset is below its net book value due to damage, obsolescence or other relevant factors.

Investments held as fixed assets are revalued at mid-market value at the balance sheet date and the gain or loss taken to the Statement of Financial Activities.

(f) Offsetting

There has been no offsetting of assets and liabilities, or income and expenses other than offsetting of bank interest and associated bank fees, considered immaterial.

2. Donations and Gift Aid

Gift Aid collected by fundraising platforms rather than directly by the charity is included as voluntary income: donations. Gift Aid receivable directly by the charity is included in income when there is a valid declaration from the donor or the amount of donation falls below Gift Aid Small Donation Scheme (GASDS) levels. Any Gift Aid amount recovered on a donation is considered to be part of that gift and is treated as an addition to the same fund as the initial donation unless the donor or the terms of the appeal have specified otherwise.

3. Total Resources Expended

£33,350 costs of generating voluntary income (2022 equivalent: £11,634 excluding £8,229 governance costs) comprises £31,923 costs of fundraising events and promotions, including £15,633 for Royal Parks marathon places, and £1,427 in fundraiser regulatory and platform fees.

£15,868 governance costs (2022 equivalent: £8,229, included in prior year costs of generating voluntary income) comprise: £5,934 for legal costs including in respect of the charity's fundraising code, £8,100 for audit fees including VAT, £269 for insurance, and £1,565 for IT, postage, travel, and other miscellaneous items.

£754,840 charitable activities (2022: £392,842) comprise: £547,127 to the Institute of Cancer Research, £133,951 to University College London, £47,928 to the University of Birmingham, £16,543 to the University of York, £5,116 to the Wellcome Sanger Institute, £3,875 to the University of Ulster and £300 to the Teenage Cancer Trust.

4. Staff Costs and Numbers

There are no employees of the charity

5. Trustee Remuneration & Related Party Transactions

No trustee received any remuneration during the year and no travel costs were reimbursed to them. No trustee or other person related to the charity had any personal interest in any contract or transaction entered into by the charity during the year.

6. Taxation

Alice's Arc obtained tax registration from HMRC on 10 December 2015. As a charity, Alice's Arc is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the charity.

7. Debtors

£6,153 debtors (2022: £15,475) comprise Gift Aid and GASDS on donations received to which the charity is entitled and expects to recover from HMRC. £11,573 Gift Aid and GASDS was claimed/received from HMRC during the year to 30 September 2023 in respect of donations made in previous years, £2,605 higher than had been expected in debtors recognised as at 30 September 2022.

8. Unrestricted and Restricted Funds

Outline summary of fund movements

Fund	Balance brought forward	Income	Expenses	Transfers	Gains and losses	Balance carried forward
Unrestricted	859,596	516,891	(666,177)	-	-	710,310
Restricted	-	659,480	(137,881)	-	-	521,599
Total	859,596	1,176,371	(804,058)	-	-	1,231,909

Analysis of net assets between funds

Fund	Current assets	Current liabilities	Net assets
Unrestricted	714,980	(4,670)	710,310
Restricted	525,029	(3,430)	521,599
Total	1,240,009	(8,100)	1,231,909

Independent Auditor's Report to the Trustees of Alice's Arc

Opinion

We have audited the financial statements of Alice's Arc (the 'charity') for the year ended 30 September 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 September 2023, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the auditor responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the trustees' annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the trustees' report is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement set out on page 45, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditor responsibilities for the audit of the financial statements

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the charity and the sector as a whole, and through discussion with the Trustees and other management (as required by auditing standards), we identified that the principal risks of non-compliance with laws and regulations related to health and safety, anti-bribery and employment law. We considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Charities SORP (FRS 102) Second Edition (released October 2019) and other relevant charity legislation. We communicated identified laws and regulations throughout our team and remained alert to any indications of non-compliance throughout the audit. We evaluated Trustees' and management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined that the principal risks related to posting inappropriate journal entries to increase revenue or reduce expenditure and management bias in accounting estimates. Audit procedures performed by the engagement team included:

- Discussions with management and assessment of known or suspected instances of non-compliance with laws and regulations and fraud, and review of the reports made by management and internal audit; and
- Assessment of identified fraud risk factors; and
- Conducting interviews with appropriate personnel to gain further insight into the control systems implemented, and the risk of irregularity; and
- Identifying key contracts and confirming that all required procurement and tendering procedures have been followed; and
- Performing analytical procedures to identify any unusual or unexpected relationships, including related party transactions, that may indicate risks of material misstatement due to fraud; and
- Confirmation of related parties with management, and review of transactions through-out the period to identify any previously undisclosed transactions with related parties outside the normal course of business; and
- Review of governance arrangements; and
- Review of significant and unusual transactions and evaluation of the underlying financial rationale supporting the transactions

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance.

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation (ie. gives a true and fair view).

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Other matters

The prior year financial statements of the charity for the year ended 30 September 2022 were not audited. Accordingly, the corresponding figures presented as part of the financial statements of the charity for the year ended 30 September 2023 are unaudited.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Samantha Rouse FCCA DChA
for and on behalf of Kreston Reeves LLP
Statutory Auditor
Chartered Accountants

Canterbury

26th July 2024

Kreston Reeves LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.



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CHILDREN'S CANCER CHARITY