Alice's Arc Annual Report

1 October 2023 – 30 September 2024

Contents

Annual review

Alice's Arc
CHILDREN'S CANCER CHARITY

Charity number 1164253

A message from our CEO

A consistent year, with over £980K generated!

It is an honour to continue with the crucial work of Alice's Arc. This year we donated over £600K to our rhabdomyosarcoma research projects. Investing in impactful research is at the heart of our mission to help improve treatments and survival for those diagnosed with rhabdomyosarcoma in the future.

The addition of 7 new Arcs to our existing 24 Arcs in the UK enables us to pool vital funds to ensure we have a long-term pipeline of research projects across research institutions. We are proud to be funding 13 research projects in the UK. It also bolsters our family community leading to strengthened networks for rhabdomyosarcoma families to access unique and authentic support. Additionally, our powerful patient-led approach means our community is increasingly contributing to advocacy work across the childhood cancer sector.

Sadly, we pay tribute to Daisy, Elsie, Maggie, Neive and Olivia who all ran out of treatment options and died from rhabdomyosarcoma. They are yet more reasons behind the existence of Alice's Arc and reinforce our mission. New families received a rhabdomyosarcoma diagnosis during this time period and have connected with us to help navigate the complexity of the situation and offer their help.

As usual this year has seen more creative and effective fundraising. Participation in the Royal Parks Half & The Great North Run. Dexter's crackle bath bombs from Lush. JessFest, Ethan's Shindig and the Dragon's Back Ultra Challenge to name a few. New families or families marking an anniversary providing generous & poignant donations. Continued support from corporate companies and schools. We are so grateful.

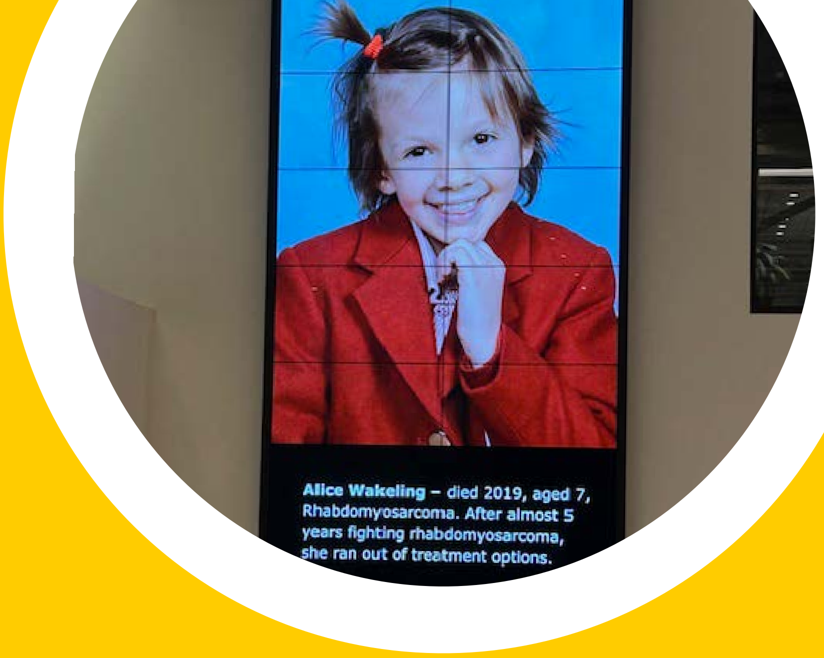
We continue to work closely with Scientists, Clinicians & other Medical professionals. This year we hosted two family research engagement days - one at Wellcome Sanger and one at University of Birmingham. These aim to bridge the gap between our research and the families impacted by rhabdomyosarcoma highlighting the goals and complexities for each stakeholder. We were delighted at the high-attendance from our community and appreciated the time investment from the Scientists.

Finally, we remain eternally gratefully to the Families, Scientists, Clinicians & other Medical Professionals, and supporters of the charity. This is an ongoing and heartbreaking fight against rhabdomyosarcoma. Thanks for always motivating us to persevere. Together we are stronger. For all those who have had the misfortune to hear the word 'rhabdomyosarcoma'.

With best wishes,

Sara Wakeling

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. Alice's Arc has raised £4.5 million and awarded 13 rhabdomyosarcoma UK research grants since it was founded in 2015.

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 31 Arcs across England and Northern Ireland and more in the works. We also have a sister non-profit in the USA and have commenced work replicating the same work via Alice's Arc, US. We have recently awarded our first rhabdomyosarcoma research grant at Children's Hospital of Philadelphia (CHOP).

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, families and other charities, 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.

ICR The Institute of Cancer Research

UNIVERSITY OF BIRMINGHAM

wellcome sanger institute

UCL GREAT ORMOND STREET INSTITUTE OF CHILD HEALTH

UNIVERSITY of York

EpSSG

UCL CANCER INSTITUTE

VIVO biobank

UNIVERSITY OF OXFORD

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 and vaccine development.

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-FOX01 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 in the UK in Q3 2025.

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 19 countries including Canada, Australia, New Zealand and Israel. It currently has 922 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.

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.

"Creating Neive's Arc has given our family a platform to honour Neive's life and experiences with RMS. It has given me a focus and a lot of my energy now goes into Neive's Arc and arranging events... The community and friendships I have made with other parents through the Arc platform has been vital to give me the support and comfort I have needed after losing Neive. I'm so thankful to have been introduced to this wonderful charity whom are striving to change the future for others facing RMS."

SARAH WARWICK, NEIVE'S ARC

"We launched Sophia's Arc in January 2024 as we wanted to help other children diagnosed with Rhabdomyosarcoma after Sophia finished treatment. Unfortunately, our worst nightmare happened in January of this year as Sophia's relapse was confirmed. Now more than ever it's so important we raise money for kinder and more successful treatments. It's helping turn our pain into purpose."

HOLLIE ARROWSMITH, SOPHIA'S ARC

> *"Daisy's Arc represents our relationship with our precious daughter Daisy, our ongoing commitment to advocacy for better treatment and ultimately a cure."*

CHIARA AND ALAN, DAISY'S PARENTS, DAISY'S ARC

Newly launched Arcs

During this time, we have launched an additional 7 Arcs, joining our 24 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 and a fundraising platform.

Daisy's Arc for Daisy, who died aged 13 years old on 27th November 2023. Daisy's Arc is a beautiful reflection of Daisy's love of life with the Warrior Butterfly representing Daisy's metamorphosis and transition.

Elsie's Arc for Elsie, who died aged 4 years, on 3rd January 2024. Elsie's Arc is represented by glowing yellow, sunflowers and rainbows. It demonstrates the sunshine, happiness, joy and hope that Elsie brought to all that met her.

Larayia-Faith's Arc for Larayia-Faith, who was diagnosed in June 2020 and has shown no evidence of disease since her treatment ended. Her Arc is represented by a beautiful white horse and her favourite colours.

Maggie's Arc, for Maggie, who died aged 18, on 20th June 2023. Maggie's Arc encapsulates her love of crystals, the sunrise, mountains, the sea, yellow mangoes from the Philippines and her favourite colour. The flower in the logo was drawn by Maggie.

Neive's Arc for Neive who died aged 6, on 24th October 2023. Neive's Arc illustrates her and her families love of blackberry picking. They picked blackberries in the garden and meadow and would make apple and blackberry crumble together.

Olivia's Arc for Olivia who died aged 8, on 7th January 2024. Olivia's Arc demonstrates her love of horse-riding with the lead horse image representing her horse 'Solo'.

Sophia's Arc for Sophia who was diagnosed in December 2022 and has sadly recently relapsed with disease detected in the original location. Her Arc illustrates her love of the sea and sea life which has influenced the colour scheme. Sophia was born with a visual impairment so bold shades have been used to recognise this.

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.

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 **Elsie, Daisy**, **Maggie**, **Neive** and **Olivia** who lost their lives to rhabdomyosarcoma during this period. Alice's Arc will always remember you and talk about you. You are the inspirations for our work.

Elsie Woolford

15th March 2019 to 3rd January 2024

Snapshot of her story:

Elsie, aged 3, was diagnosed with metastatic Embryonal Rhabdomyosarcoma, right neck primary parameningeal site with pulmonary and vertebral (T2-L5) bone metastases, in September 2022.

Elsie's care was led by Leeds General Children's Hospital where she underwent 9 rounds of intense chemotherapy and 28 sessions of radiotherapy.

Elsie started maintenance chemotherapy in April 2023. Sadly, end of treatment scans in July 2023 showed disease progression to her lungs. Elsie started her relapse chemotherapy straight away which seemed to be going well initially, but in November 2023, we were told that the treatment wasn't working and that no further treatment options were available. Elsie came home on palliative care and fell asleep on January 3rd 2024.

> *"Since losing Elsie, so many people have said ' I don't know how you keep going.' and I reply that with Elsie, she taught me strength and resilience. She faced every challenge with such bravery and with a smile. It's not the 'how', it's the 'why' and Elsie will always be my reason."*

LEANNE, ELSIE'S MUM, ELSIE'S ARC

> *"Elsie's Arc allows us to keep Elsie's memory alive. We've had fantastic support from our community and its been a real team effort. I hope this can continue and we can make a real difference in the future for other children and families faced with rhabdomyosarcoma."*

LEANNE, ELSIE'S MUM, ELSIE'S ARC

Elsie's impact:

- The launch of Elsie's Arc triggered an outpouring of support and recognition in memory of Elsie and her experience with rhabdomyosarcoma.
- Elsie's Arc have raised over £25K since it was founded. Elsie's family and friends continue to participate in fundraisers such as the ones highlighted and more. With continued support from schools and local businesses, Elsie's Arc is bustling with activity.
- Elsie's family want to see kinder treatments for children, more treatment options available at the point of relapse. They also advocate for better shared care for families that live a distance away from the specialist children's oncology hospitals and more knowledge of children's cancer from Consultants in a general hospital setting.

Fundraising for Elsie:

£2.9k

was raised at an 80s/90s Fancy Dress Disco for Elsie at Hunmanby Social Club, with a raffle and music from DJ Adam Jenkinson, who generously donated his time.

£2.4k

was donated when Elsie's Daddy, brothers and family friends took on the challenge of climbing Ben Nevis in conjunction with It's Never You charity. This will be repeated!

£2k

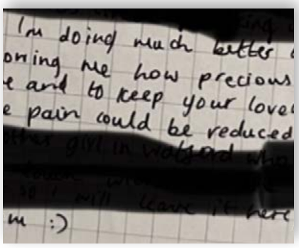
for a Drag Night with Dame Ida at Hunmanby social club.

£1.7k

raised from Elsie's Easter Egg Hunt 2024 at All Saints Church, Hunmanby, with Elsie's brother as the Easter Bunny and a tombola and raffle in Bailey Gardens, where her tree grows.

Daisy Birikorang

11th June 2010 to 27th November 2023



[redacted]
I'm doing much better
oning me how precious
e and to keep your love
e pain could be reduced
[redacted]
m :)

Snapshot of her story:

Daisy was diagnosed with high risk alveolar RMS on the 8th of August 2022, aged 12. She completed 9 rounds of frontline (25 weeks of therapy) VAC chemotherapy and 29 radiotherapy sessions. Daisy was due to start maintenance in March 2023 but two new lumps were found at a routine scan. By the time she had a PET scan the small lumps grew and became one. Daisy started relapse chemotherapy on the FaR-RMS trial VIR (Vincristine, Irinotecan and Regorafenib) at the beginning of May 2023 and managed an additional 8/12 treatments.

In September 2023, Daisy was told that she had "started to lose her battle with cancer". That one line had a detrimental effect on her mental health. She stopped fighting.

She had one more operation to drain fluids from around her heart on 5th of October. Daisy spent 106 days in hospital. She came home on palliative care on the 23rd of October. By this time Daisy had also endured 600 injections of blood thinners twice a day in her legs, 9 operations and numerous scans between MRIs, PET and X-rays.

> *"Daisy's life was bigger than her death. The charity gives our lives a purpose and a meaning. While we won't see Daisy growing up, we hope to witness the lasting impact and results of our efforts working to fund research and increase awareness. Daisy's Arc represents our relationship with our precious daughter Daisy, our ongoing commitment to advocacy for better treatment and ultimately a cure; reflecting our deep connection to her."*
>
> **CHIARA AND ALAN, DAISY'S PARENTS, DAISY'S ARC**

> *"...I am doing much better today, this experience is really showing me how precious life is and to savor the moments you have and to keep your loved ones close in a way I am grateful , but the pain could be reduced because it is so uncomfortable..."*
>
> **DAISY'S DIARY, AUGUST 2022, DAISY'S ARC**

Her inner strength on this journey is only comparable to Superheroes and Warriors you see in the movies.

Her health deteriorated rapidly once she decided to stop the chemotherapy that wasn't working anymore and was just making her sick. A powerful decision she made, taking control back in her own hands at such a young age.

Daisy was free to fly away from the sick body that was trapping her, she earned her wings on the 27th of November 2023. Forever 13, forever young.

> *"We cannot, after all, judge a biography by its length, by the number of pages in it; we must judge by the richness of the contents...Sometimes the 'unfinisheds' are among the most beautiful symphonies.."*
>
> **VIKTOR E. FRANKL, DAISY'S ARC**

Daisy's impact:

- Daisy's Arc has raised over £30k to date. Family, friends, and the community unite to honour Daisy and drive change in her name, raising awareness and involving communities in fundraising for rhabdomyosarcoma.
- Daisy's Arc logo symbolises her courageous transformation, a caterpillar becoming a warrior butterfly. The tattoos on the butterfly's body represent both the scars of her cancer journey and a map to infinite love and hope. The "W" shape on her leg mirrors the Cassiopeia constellation, where a star has been named in her memory. Kneeling, the butterfly reflects on crossing the veil, filled with longing and grace.
- The grief for the loss of Daisy is nothing but love. It is love in her absence here on earth. It inspired the writing of an intimate and personal guide on what not to say to a grieving heart written by her mum Chiara.
- Daisy's love for vanilla frappuccinos and daisy flower pins has become a symbol of remembrance. Many at Rickmansworth School wear the pins in her memory. We hope to make them a feature at fundraisers, sporting events, and bake sales. Her family also encourages planting daisies or forget-me-nots for her birthday.
- Daisy's family advocates for targeted RMS treatments, better relapse options, and less harmful therapies. They also call for improved GP training to speed up childhood cancer diagnoses, and greater awareness of its signs and symptoms.

Fundraising for Daisy:

£17k

raised via the Royal Parks Half Marathon 2023 for Daisy including **Daisy's Dad**, 777 Stores and other friends.

£4.7k

by Barclays Bank from a cake and book sale event.

£1.8k

from Holy Rood Watford Parishioners for Daisy.

£688

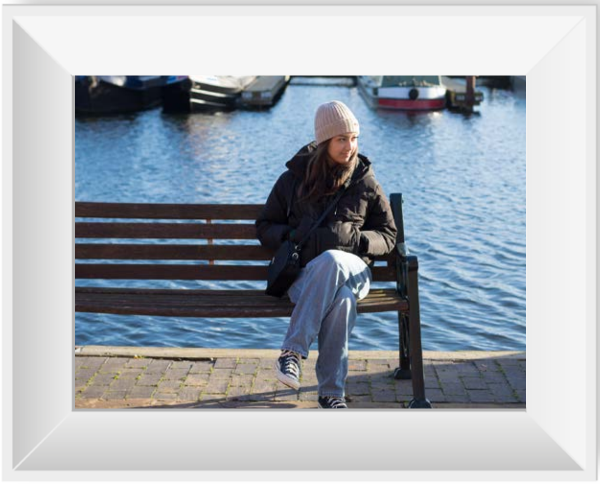
donated from Stagecoach Performing Arts at Watersmeet Theatre, Rickmansworth through their performance of 'Beauty and the Beast'.

Over **£500**

raised on Daisy's birthday with a frappucino & netball fundraiser at her school, Rickmansworth School.

Maggie Adcock

20th May 2005 to 20th June 2023



Snapshot of her story:

On 1st June 2022, Maggie was diagnosed with metastatic fusion-positive Alveolar Rhabdomyosarcoma. Maggie's care was led from Nottingham Children's Hospital where she was enrolled on the FaR-RMS Study and commenced IVADO chemotherapy lasting six months. Following this her scans showed no evidence of disease and she commenced maintenance chemotherapy in December 2022.

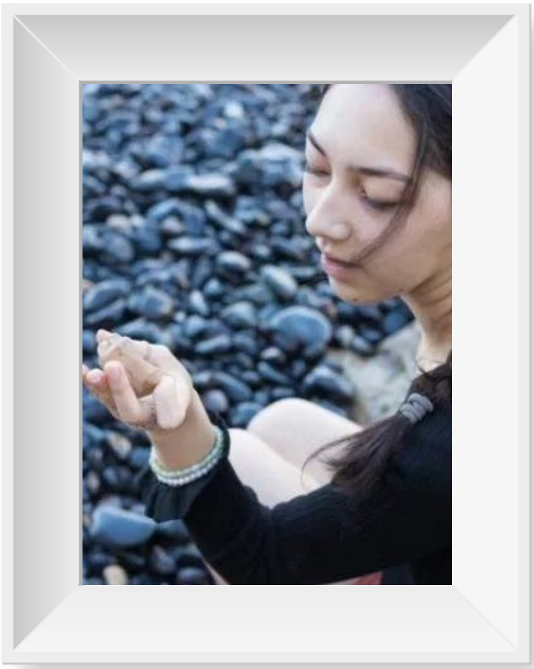
Four weeks later, she started experiencing headaches and a scan revealed the cancer had spread to her brain. Maggie then went on VIT chemotherapy. Due to dizzy spells, Maggie started a new chemotherapy known as Intrathecal Topotecan, at the end of May 2023. However, after further dizzy spells and a seizure, Maggie moved to hospice where she died on 20th June 2023, aged 18.

> *"I'm a big believer in positive outlooks giving positive outcomes."*
>
> **MAGGIE, MAGGIE'S ARC**

> *"If I can't control my cancer, I can control how I feel. That's how I stay smiling."*
>
> **MAGGIE, MAGGIE'S ARC**

Maggie's impact:

Maggie’s Arc has been created as part of the Margaret Adcock Foundation which has three pillars reflecting Maggie’s qualities and wishes - education/ awareness, support and research. Maggie’s Arc has been devised as part of the research pillar to ensure funds are channelled in to rhabdomyosarcoma research grants.



Maggie and her family want to see more targeted treatments for alveolar rhabdomyosarcoma, as well as more personalised approaches to treatment based on tumour genetics. They also advocate for increased funding for research in order to find less invasive treatments with fewer long-term side effects such as immunotherapy. They want to see greater access to clinical trials and experimental treatments providing more treatment options after their experience being unable to access a drug called Elimusertib.

Fundraising for Maggie:

£10k

donated upon the launch of Maggie’s Arc, to meet the goal of the research pillar for the Margaret Adcock Foundation.

THE MARGARET ADCOCK FOUNDATION

Neive Warwick

23rd February 2017 to 24th October 2023

Snapshot of her story:

Neive, aged 5, was diagnosed with embryonal/fusion negative parameningeal rhabdomyosarcoma, in September 2022. Her care was led from Birmingham Children's Hospital and she endured nine rounds of intensive chemotherapy & proton beam therapy. Neive commenced maintenance chemotherapy in April 2023 but sadly her end of treatment scans in September 2023 showed disease progression in the brain and spinal fluid. Neive went home on palliative care to be with her family. She passed away peacefully and gracefully in her own bed on 24th October 2023 at aged 6 years old with her Mum holding hands and surrounded by unconditional love.

"We just keep going, don't we, Mum" and that's exactly what I'll always do, in honour of my special, wonderful little girl."

SARAH WARWICK, NEIVE'S MUM , NEIVE'S ARC

"Neive had a real passion for music and would often sing her beloved Oasis during open mic events. Neive lives on through the music she loved and we will always fundraise through music for Neive's Arc."

SARAH WARWICK, NEIVE'S MUM , NEIVE'S ARC

Neive’s impact:

- The launch of Neive’s Arc has led to such fantastic support from family community and beyond, resulting in £42K and counting being raised to date. Her story has impacted many people’s lives leading to generosity and support for Neive’s Arc.
- Neive’s school created a spiritual garden and there now sits a bench dedicated to her amongst the tranquil gardens within school providing a place of remembrance and calm.
- Neive’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 & personalised treatment options.

> *“Neive enjoyed the outdoors and had a deep rooted love for animals and nature. Her Arc logo is inspired by her love for blackberry picking with her Grandad Tim at the meadow and in our garden.”*
>
> **SARAH WARWICK, NEIVE’S MUM , NEIVE’S ARC**

Fundraising for Neive:

£5.5k

was generated through friends of Neive’s Mum, Lorraine and Aaron climbing Mt Kilimanjaro.

£1.2k

was raised through “A Night for Neive,” marking a year since her passing with local bands she sang with. Music was a big part of her life, now carried on by her sister Molly.

£5k

raised through “90 for Neive” A football match that consisted of family, friends, Neive’s teachers and ex professionals.

£3k

so far through a monthly event hosted by Leamington Spa Parkrun Cafe where homemade treats are baked to generate donations.

£5.5k

was raised by Warwickshire Young Farmers in memory of Neive, with 60 tractors lit up and playing music in their Christmas parade through Leamington Spa.

£1.5k

through several of Neive’s school friends, Mum’s taking on the Jurassic Ultra Coast Challenge.

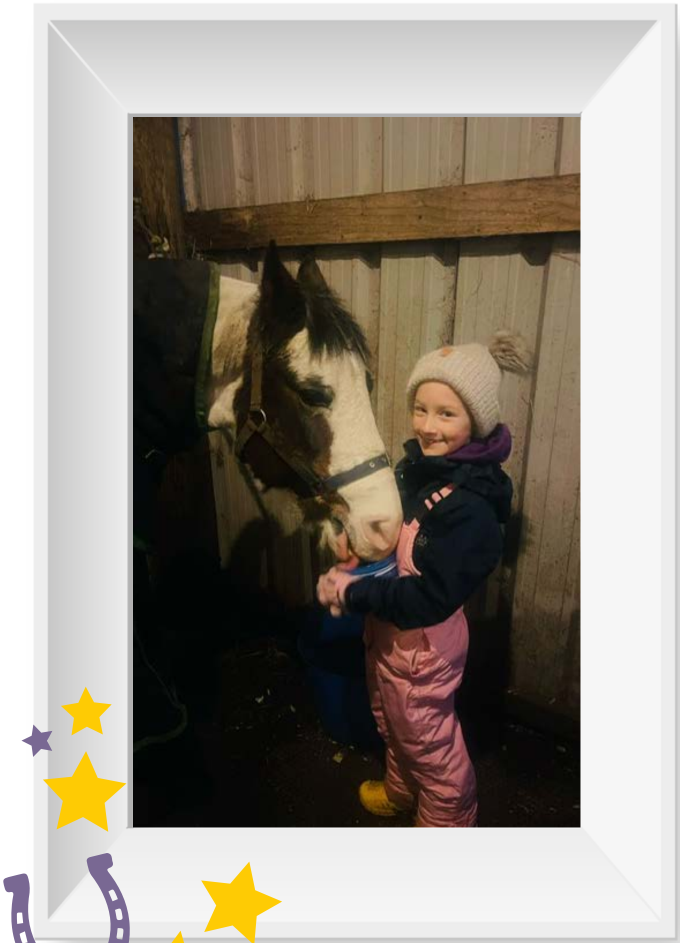
Olivia May Eyre

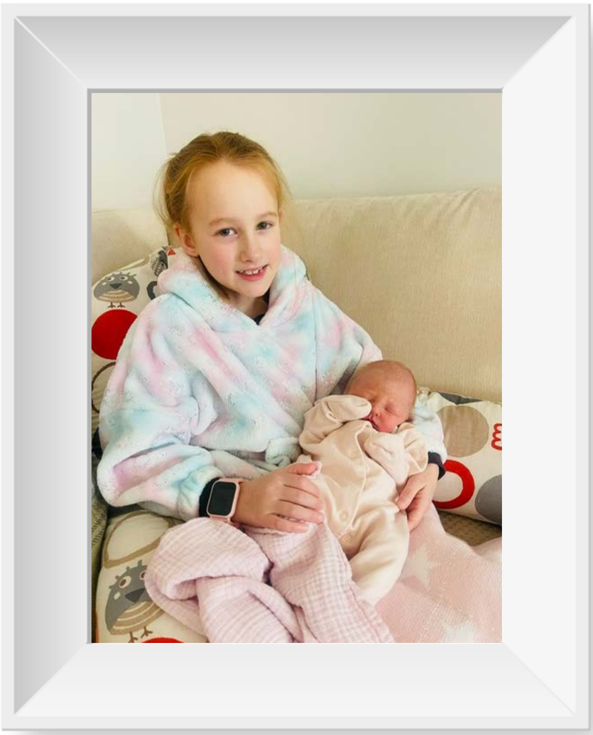
28th July 2015 to 7th January 2024

Snapshot of her story:

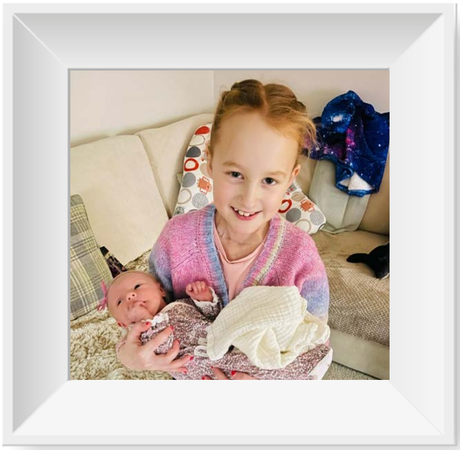
Olivia, aged 4, was diagnosed with forearm alveolar RMS in January 2020. Her care was led by Leeds LGI.

Mainline chemotherapy started 24/01/2020 followed by surgery and radiotherapy which was completed 16/06/2020. 12 months of maintenance followed. Olivia sadly relapsed 2 months after maintenance ended, in her supraclavicular notch. VIT chemotherapy commenced 21/10/2021 and only completed 4 cycles due to chemotherapy not being effective. Surgery then went ahead followed by radiotherapy and maintenance reintroduced on 21/03/2022. She sadly relapsed again in September 2023 following a routine chest X-ray which identified spots in her left lung. Olivia also had lynch syndrome gene which gave hope for an immunotherapy treatment (Nivolumab) but unfortunately this was unsuccessful, and she began end of life care in December 2023 and heartbreakingly passed away peacefully at home on 7th January 2024, aged 8.





> *"Olivia's Arc allows us to not only raise awareness and vital funds but to keep Olivia's memory alive."*
>
> **JEMMA, OLIVIA'S MUM, OLIVIA'S ARC**



Olivia's impact:

Olivia's Arc has raised over £20K since it was started. Olivia's family, friends and community have embraced her Arc and conducted a series of fundraisers.

Olivia's family want to see a dramatic increase in survival rates for those diagnosed with rhabdomyosarcoma. They want to see more research happening in order to improve treatments and outcomes. They want to put an end to the suffering these children experience.

OliVIA'S ARC

Fundraising for Olivia:

£4k

raised through 'Olivia's Bingo' where tickets sold out within a day of going on sale.

£1.7k

generated by 'Olivia's Fair' hosted by the midwife's that helped with the birth of Olivia's sister, Elsie. It was purple themed with fun stalls and a dance show.

£1.5k

for 'Olivia Eyre's Showjumping' fundraiser at the arena that Olivia took part in shows. The event was showcased in Horse & Hound magazine and has became an annual event.

£1.6k

donated through Olivia's Mum's hairdresser's participation in the Benidorm 10K run.

£1K

raised by Olivia's cousin undertaking a bike ride from Scarborough to Whitby.

Our year at a glance

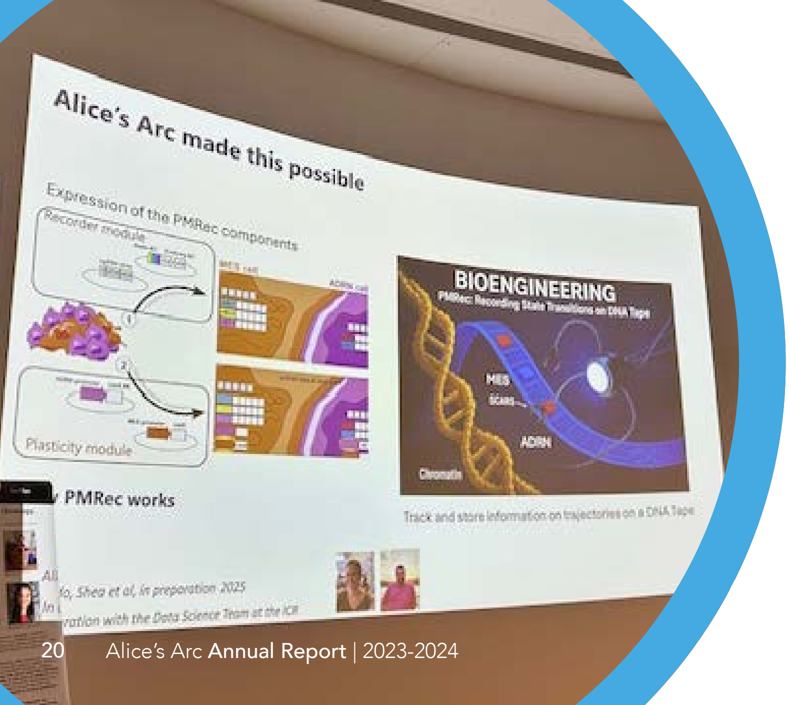
Research Focus

We donated £618K towards rhabdomyosarcoma research during this time period.

Total funds donated towards rhabdomyosarcoma research now stand at **£2.4 million**.

Total funds donated

£2.4m



Alice's Arc made this possible

Expression of the PMRec components

Recorder module

Plasticity module

PMRec works

BIOENGINEERING

PMRec: Recording State Transitions on DNA Tape

Track and store information on trajectories on a DNA Tape

o, Shea et al, in preparation 2025

ation with the Data Science Team at the ICR

£205k

The Institute of Cancer Research

- **£123k** for year one of the research grant entitled "**Accelerating biological studies of RMS to improve patient outcomes**" These funds will be used for the FaR-RMS prospective co-ordination & management of sample collection and bio banking processes and data generation in order to support current and future RMS biological studies.
- **£81k** towards year three 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.

£76k

The University of Birmingham

- For year two of a project aiming to understand more about tumour heterogeneity and the tumour micro-environment for fusion positive and fusion negative rhabdomyosarcoma.

£16k

University of York

This is the payment for year two 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 & parents.

£71k

European paediatric Soft tissue Sarcoma Group (EpSSG)

These funds enable the employment of a Project Manager and Statistician to help ensure the smooth running of this professional body and to facilitate rigorous data analysis from clinical trials.

£250k

Alice's Arc US Inc

Through a collaboration with leading charity, Children with Cancer UK, their kind donation has been utilised by Alice's Arc US Inc to enable the first year of a research project with Children's Hospital of Philadelphia (CHOP) focussed on genomics and immunotherapies for rhabdomyosarcoma.

Family Research Engagement Days

UNIVERSITY OF BIRMINGHAM

Alice's Arc
CHILDREN'S CANCER CHARITY

THE UNIVERSITY OF BIRMINGHAM AND ALICE'S ARC INVITE YOU TO

WORKING TOGETHER: RESEARCHERS AND FAMILIES

29/02/2024

An informal and interactive event will aim to demonstrate the current state of RMS research, to learn more about the projects funded by Alice's Arc and to see the research in action.

TIMES : 1030AM TO 1430PM
LOCATION : UNIVERSITY OF BIRMINGHAM

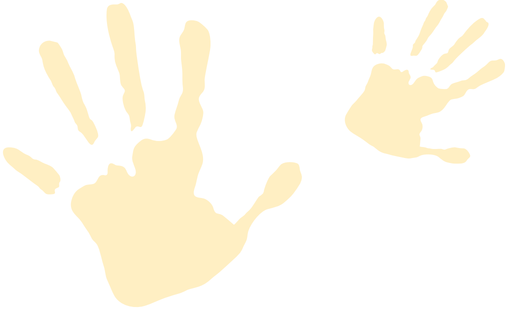
We launched several family research engagement days over the year.
The purpose of these is to bridge the gap between the science and the patients/parents. This helps both parties understand each other's perspectives and to help co-create future directions of research.
By doing this, we can work in true partnership with scientists to improve outcomes for those diagnosed with rhabdomyosarcoma in the future. It also helps us understand where money raised goes and to question progress, challenges and new lines of research.

University of Birmingham, UK

On Rare Disease Day, Thursday 29th February 2024, a collection of Arcs and RMS families visited the University of Birmingham to hear more about the two projects we are funding there, an overview of childhood cancer research, the FaR-RMS trial and a lab tour involving interactive aspects looking at RMS cells through the microscope.

Dr Susanne Gatz led the day alongside PHD student, Neal Sheath and PostDoc, Joseph Wragge whose roles are funded by the charity. They work closely with Professor Jo Morris and Professor Ferenc Mueller. Professor Pamela Kearns also attended to provide her insights on childhood cancer, the role parents can play in research and her personal reasons for doing this work.

The day proved to be informative, emotional and inspiring. Dr Susanne Gatz prepared an image of the family/Arcs and the scientists/clinicians to demonstrate how we are all in this battle together and have the same mission to make steps towards defeating rhabdomyosarcoma in the future. That unity was apparent throughout the day and every voice felt heard. Collectively, we can make progress.



Wellcome Sanger Institute, Cambridge, UK

On the 25th April 2024, we were thrilled at the level of interest from Arc families & other families part of our community who were keen to attend. Rhabdomyosarcoma survivor, Amber, aged 14, who is the inspiration for Amber's Arc was there, curious about the disease that she was diagnosed with when she was 7. Several of the newer Arcs & even those with Arcs pending launch also came along. Some of these families have lost their children very recently and it takes great courage to confront the science of the biological beast that is rhabdomyosarcoma. We also were delighted to have some of the long-standing Arcs there too. Lovely to see Neive's Arc, Sia's Arc, Tommy's Arc, Elliott's Arc & Dexter's Arc. It was also lovely to meet George's parents from Just George. We hope engaging with the science offers some constructive therapy and hope for the future treatments of rhabdomyosarcoma.

We were treated to an overview of the work of Wellcome Sanger by Professor Sam Behjati, updates on work funded by Alice's Arc regarding RMS target identification, RMS sequencing, what RMS cells are and the development of novel engineered CAR T-cell therapy for rhabdomyosarcoma. Dr Karin Straathof (UCL Cancer Institute) presented her work on the projects, as did several PostDocs involved. The day ended with a tour of the sequencing facilities and laboratories.

As ever, there was ia great deal of curiosity leading to interactive discussions and lively debate around sequencing, consent and the development of T-cell therapy.

Research News in the USA

Alice’s Arc, US launched its first grant call in the USA in conjunction with **St Baldricks Foundation Empowering Pediatric Immunotherapies for Childhood Cancer (EPICC) Consortium**. The award will be for a three-year grant of $750K.

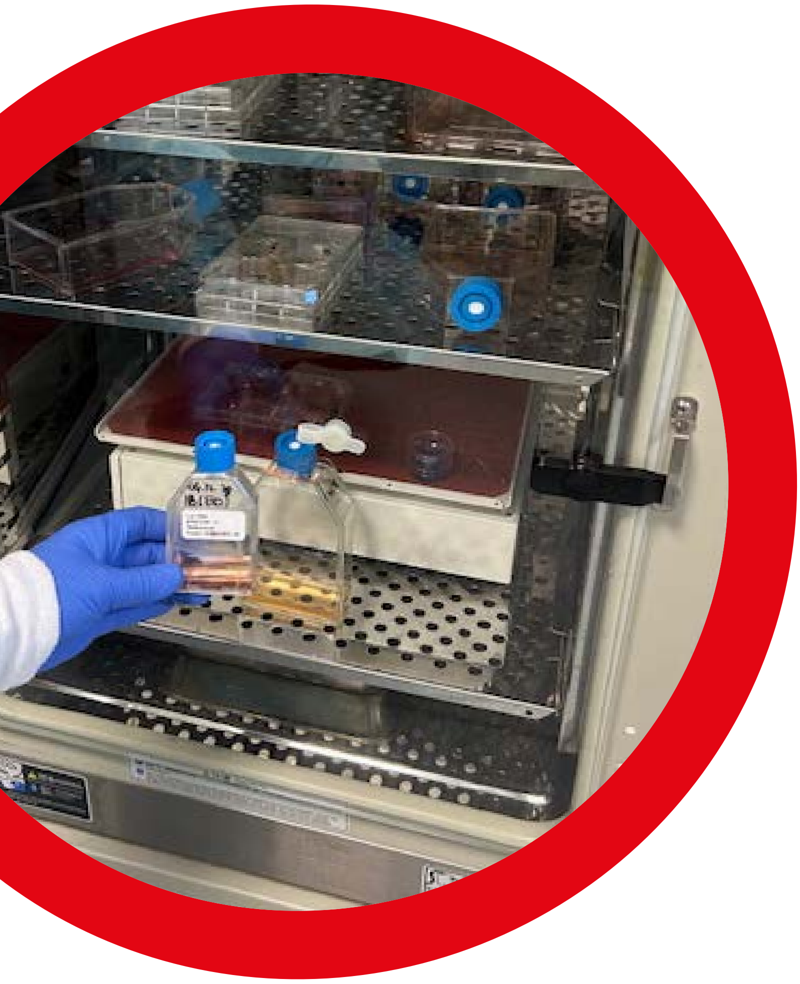
Funding Hope for Kids’ Rhabdomyosarcoma

St. Baldrick’s and Alice’s Arc are partnering to fund a grant for groundbreaking research on new treatments

St. Baldrick's Foundation

EPICC Team

Empowering Pediatric Immunotherapies for Childhood Cancers



The scope for research will focus on rhabdomyosarcoma and address questions around the discovery & development of new IO targets for rhabdomyosarcoma, leveraging the PAX:FOXO1 fusion for novel therapeutics, novel CAR T cell, antibody drug conjugate, monoclonal antibody and/or vaccine approaches to rhabdomyosarcoma therapy and for novel IO combinations such as with protein degradation approaches, epigenetic modifiers, or other therapeutic strategies. The project will complement the work already being funded by Alice’s Arc in the UK in the labs of Dr Karin Straathof (UCL Cancer Institute) and Dr Sam Behjati (Wellcome Sanger Institute) and collaboration will be encouraged.

The consortium has been operating since 2013 and have pushed the first gene therapies over the finish line for FDA approval, treated more than 1370 patients on 45 clinical trials and discovered new immunotherapy targets that can be game-changers.

We look forward to announcing the details!

Articles Published

Clinicopathological Analysis of a European Cohort of MYOD1 Mutant Rhabdomyosarcomas in Children and Young Adults.

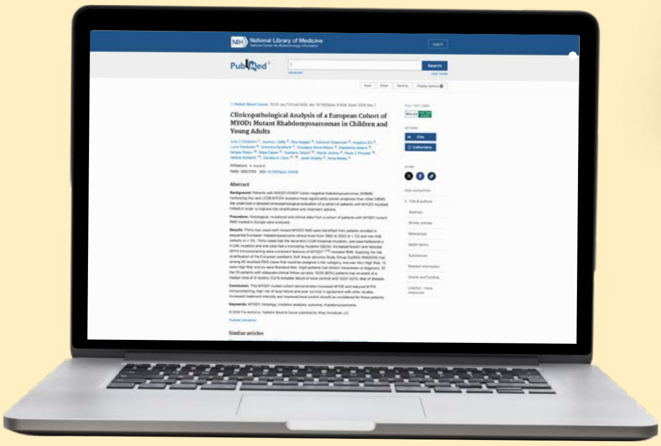
Published: Pediatric Blood Cancer

Authors: Chisholm JC, Selfe JL, Alaggio R, Cheesman E, Zin A, Tombolan L, Parafioriti A, Milano GM, Adams M, Popov S, Česen M, Tafjord S, Jenney M, Proszek PZ, Schlecht H, Carlo DD, Shipley J, Kelsey A.

Frontline and Relapsed Rhabdomyosarcoma (FaR-RMS) Clinical Trial: A Report from the European Paediatric Soft Tissue Sarcoma Study Group (EpSSG)

Published: Cancers

Authors: Chisholm J, Mandeville H, Adams M, Minard-Collin V, Rogers T, Kelsey A, Shipley J, van Rijn RR, de Vries I, van Ewijk R, de Keizer B, Gatz SA, Casanova M, Hjalgrim LL, Firth C, Wheatley K, Kearns P, Liu W, Kirkham A, Rees H, Bisogno G, Wasti A, Wakeling S, Heenen D, Tweddle DA, Merks JHM, Jenney M.



Patient/Parent Involvement & Engagement in Research

SIOP Europe Presentation

May 2024

As part of the role Sara Wakeling plays on the Trial Management Group (TMG) for FaR-RMS, she pre-recorded a video illustrating the role of Parent, Patient Involvement & Engagement throughout the development and implementation of the FaR-RMS trial. This was shown as part of the EpSSG meeting at SIOP Europe in Milan, Italy.

FaR-RMS Annual Grant Review with CRUK

June 2024

Sara Wakeling attended this meeting alongside trial leads to highlight the PPI/E work conducted on FaR-RMS over the review period. In particular, this related to the production of video content to help facilitate understanding and enhance recruitment on the radiotherapy arm of the study.

FaR-RMS
Frontline and Relapse
RhabdoMyoSarcoma study

The Role of Parent/Patient Involvement & Engagement

CANCER RESEARCH UK
BIRMINGHAM CANCER RESEARCH UK CLINICAL TRIALS UNIT
UNIVER
BIRMI

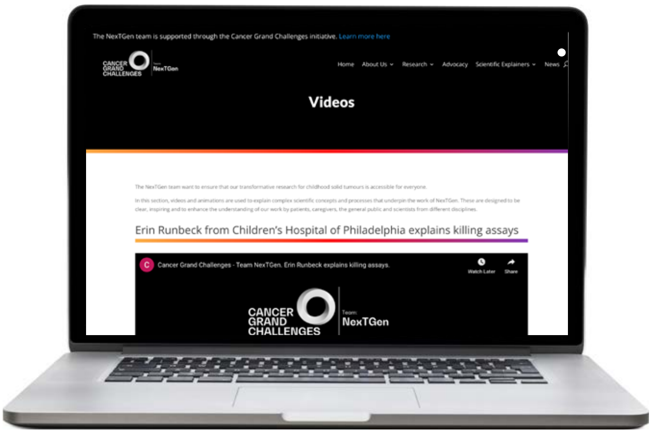
about the role of patient/parent involvement and engagement on the FaR-RMS

FaR-RMS
Frontline and Relapse
RhabdoMyoSarcoma study

NexTGen: Patient Advocacy

Continued involvement in the advocacy team as part of the Cancer Grand Challenges initiative for the NexTGen team. This project is tackling the problem of solid tumours in children and looking to develop next generation T-cell therapies, starting with rhabdomyosarcoma, ewings sarcoma and certain brain tumours. The first clinical trials testing the safety of these T-cells in patients are due to open towards the end of 2025.

Work has included **science communications** e.g. video content, website development, co-lay presentations, **clinical trial involvement** eg, patient information sheets, involvement in Trial Management Groups (TMG), **research work package involvement** eg, attendance at regular meetings and **other initiatives** e.g promoting the work of NexTGen, working with Early Career Researchers, gathering feedback on the role of advocacy and attending regular conferences about the work.



The NexTGen team is supported through the Cancer Grand Challenges initiative. Learn more here

Videos

Erin Runbeck from Children's Hospital of Philadelphia explains killing assays

FaR-RMS: Using Video to Explain Science

FaR-RMS
Frontline and Relapse
RhabdoMyoSarcoma study

A group of parents & care-givers from Alice's Arc helped inform the development of a video to explain the radiotherapy arm on the FaR-RMS clinical trial. A clinician-led workshop was conducted where the group provided feedback on content, key messages, style, tone, theming, use of characters and animation. This information formed the basis for the script, the brief to the video production company and the choices of voiceover and music used. This is another example of how the Alice's Arc community can work to ensure information provided to patients & families is user-friendly and digestible during such complex times.

FaR-RMS Video
for Radiotherapy Arm

Sara Wakeling (PPI), Bridget Shaw (Trial Co-Ordinator) &
Sarah Al-Jilaihawi (Research Fellow)

The Living-REFoRMS Project

Project funded by CCLG and Alice's Arc

Children's Cancer and Leukaemia Group

Alice's Arc
CHILDREN'S CANCER CHARITY

Living Reforms Workshop held in Leeds

January 2024

The Living - REFoRMS project (co-funded with CCLG) brought together a team of researchers and families impacted by rhabdomyosarcoma to discuss the next phase in this important project.

Having systematically reviewed numerous academic studies across the globe on treatments available at the point of relapse or refractory rhabdomyosarcoma, the time had come to start planning how these findings could be converted into an online resource designed for parents/patients and clinicians to utilise in the decision-making process. The workshop aimed to hear the different perspectives on the goals of the product, the information it needs to contain and how it should be presented. We also conducted an assessment of other online resources currently available. Watch this Space as this develops!

This was patient-led research shaping at it's very best with a group of Mum's and Dad's with varying experiences of rhabdomyosarcoma. Having academic researchers and clinicians in the room led to lively discussions and useful insights to the different perspectives each party brings. Patient involvement at every stage of research is absolutely critical and as a parent-led charity with an army of families, we are well-placed to make this happen.

The Living-REFoRMS Project

RHABDOMYOSARCOMA WORKSHOP

We would love your help to design an online resource to support patients, families and professionals to understand treatment options for rhabdomyosarcoma that has relapsed or progressed.

JANUARY
19
10 AM - 3PM

LEEDS CITY CENTRE
Lunch and refreshments provided
Transport costs covered
Accommodation (if required) paid for
Childcare reimbursed

If you want to take part please fill out the form or for more info, contact us on reforms-project@york.ac.uk

Fundraising Highlights

ROYAL PARKS HALF MARATHON 2023

On the 8th October 2023, a team of 105 runners who passionately support our mission to fund research into rhabdomyosarcoma in order to diversify treatment options and improve cure rates for those diagnosed in the future, took on this challenge. The team comprised medical professionals, scientists, families and corporate supporters.

And, together, we raised over £120K for our current portfolio of rhabdomyosarcoma research projects across leading research institutions. Did you know that this £120K can approximately cover the salary of a PostDoc in a laboratory for two years? That's two years learning more about rhabdomyosarcoma and converting this information for use in the clinic.

£120k

'SUPERPEAKS: THREE PEAKS FOR ELLIOTT'S ARC

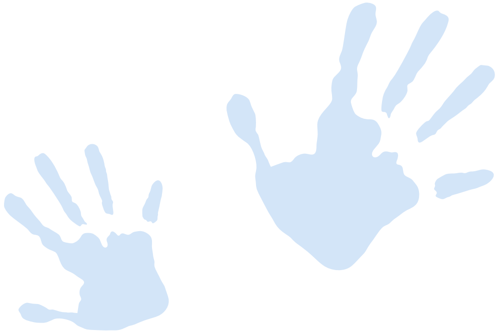
On Saturday 21st October, 2023, Elliott's Dad and seven friends from his work undertook the three peaks challenge within 24 hours. Elliott loved superheroes and as a tribute to him, the team completed the ascent and descent of Ben Nevis, Scafel Pike and Snowdon dressed for the duration as eight of Elliott's favourite superheroes. The team raised an enormous £6.9K in support of this fundraising feat.

£6.9k

GREAT NORTH RUN 2024

On the 8th September 2024, 40 runners supporting the charity, participated in this incredible half marathon for the first time. Runners from Ethan's Arc, Elsa's Arc, Ellie's Arc, Mollie's Arc, Neive's Arc and Alice's Arc raised £20K and thoroughly enjoyed the route and the unique atmosphere. We will be back!

£20k



DRAGON'S BACK ULTRA CHALLENGE FOR ELLIOTT

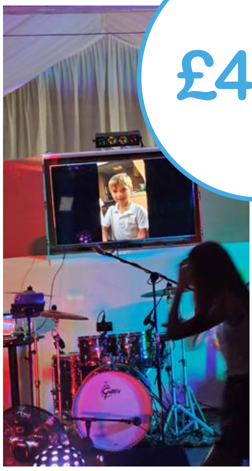
Nathen Smith took on the Dragon's Back Ultra Mountain Marathon from the 2nd September to 6th September 2024 in memory of Elliott Peto. This is a multi-stage race, the distance of 380km is split over six days of running and is considered to be one of the toughest mountain races in the world with participants attempting the whole course covering not only 380km but a 16,400m ascent along the Dragon's Back of Wales. What a challenge and Nathen raised a well-earned £12K for Elliott.

£12k

'SHINDIG' FOR ETHAN'S ARC

On Saturday, 20th September 2024, Ethan's Shindig was hosted in South Shields featuring the band Two Metres Apart, a raffle and lots of family fun. It will be repeated!

£4.1k



LAUNCH OF LATEST DEXTER CRACKLE BATHBOMB BY LUSH

In April, 2024, Lush launched a new edition of Dexter-inspired bath bomb known as Crackle. The bath bomb represents Dexter's Dragon, Crackle and is a sweet, candy-scented bath bomb smelling of hairdo sweets and, of course, it still has the added bonus of popping candy inside.

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.

JESS FEST

On Saturday 14th September, 2024, this incredible music festival was launched in memory of Jessica Macqueen and raising funds for Jessica's Arc. It comprised singers, bands, face painting, glitter tattoos, hair braiding, cake stall, sweet stall, beat the goalie, a bouncy castle and much more! A BBQ and bar was also on offer.

Jessica's family, friends & community raised a tremendous £19K in celebration of Jessica.

£19k

£2.3k

170 MILE BIKE RIDE FOR JESSICA'S ARC

Mark Granville cycled 170 miles over the rolling hills of Leicestershire on Saturday 22nd June 2024.

5 DADS CYCLE FROM LONDON TO BRIGHTON

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.

£6k

£10k

GEORGE BRACEY - TEAM GEORGE

George Bracey was diagnosed with rhabdomyosarcoma on 3rd August 2023. Team George was established comprising supporters of George and his family. George's Dad found Alice's Arc early on in their experience and quickly started participating in fundraisers including the Royal Parks Half and the London Marathon. In July 2024, to mark the end of George's rhabdomyosarcoma treatment, Team George, hosted a gala ball in London and split funds raised between Great Ormond Street, Alice's Arc and Kings Hospital. All these efforts led to over £10K being raised for the charity as well as new corporate partnerships with Tanner Pharma Ltd.

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 choses to seek support from their school to run a fundraiser. This year we are thankful for the support of **Radnor House, Trinity School, Sevenoaks School, Chesham High School, Goldolphin & Latymer, London, Walthamstow Hall School, 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.

PARTNERSHIP WITH LOVE THE GAME UK, KENT

This wonderful football coaching organisation promoted the charity across their networks and created a fundraiser involving 100 kicks per day for Alice's Arc.

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 & partnership.
- **Tanner Pharma.**

Other News

Launched Treats & Treasures Trolley at Great Ormond Street Hospital, London

In December 2023, we launched this family-well being initiative. The trolley contains all kinds of treats and treasures to help parents, siblings and the children diagnosed get through hospital stays and day visits. The trolley is rounded on the wards on a weekly basis.

This was inspired by the Evan Foundation, based in the USA who developed this idea and now have treats and treasures across 30 locations in the USA and Canada. It is a great pleasure for Alice's Arc to partner with them to bring this to the UK. We are also honoured to have had so much support from volunteers and donors enabling this service to be provided at no cost to the charity.

Representatives from across the charity have rounded the charity enabling us to keep in touch with families in the midst of childhood cancer treatment. It has also helped in meeting new families who we can offer support to and set up Arcs.

The EVAN Foundation
EVAN'S VICTORY AGAINST NEUROBLASTOMA

EPSSG BIOLOGY COMMITTEE MEETING IN THE UK

September 2024

The EpSSG Biology Committee convened their first ever EpSSG Biology Committee workshop at Nutfield Priory, with sponsorship from Alice's Arc, The Little Princess Trust and Sarcoma UK.

The group enjoyed a variety of lab talks regarding rhabdomyosarcoma research, including several Alice's Arc funded individuals - Dr Supriti Ghosh (ICR) and Dr Joseph Wragge (University of Birmingham).

The workshop also involved a Consortium discussion to build the foundations for prioritising research and how to work with funders to achieve shared research objectives. This involved presentations from Alice's Arc, Little Princess Trust and Sarcoma UK.

LifeArc Translational Challenge Launch

September 2024

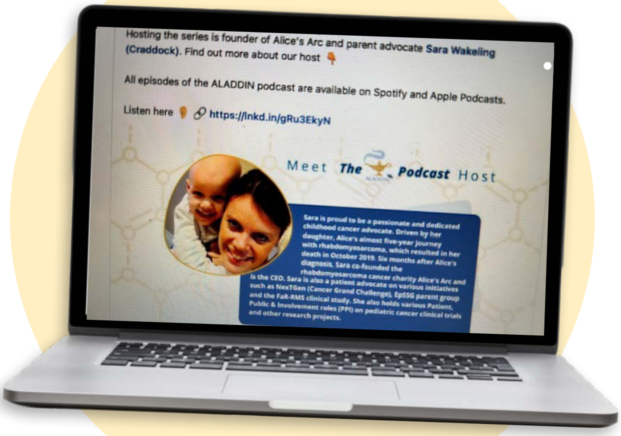
It was an honour for Sara Wakeling to participate in the launch event for the ambitious challenge of improving treatments, trials and decision-making for children with cancer that LifeArc have chosen to confront.

This was conducted in a panel-style discussion involving clinicians, scientists, finance partners and Sara, bringing the patient perspective on where LifeArc can help create change for the future.

Alice's Arc is continuing to partner with LifeArc, in a number of capacities, as they pursue their work.

Aladdin Podcast Host

For over a year, Sara Wakeling has been the host of the ALADDIN podcast. This series of podcasts aims to demystify the world of paediatric drug development via the Education programme, ALADDIN, designed by CCI-Europe. This has involved interviewing a series of global experts from different stakeholder groups across industry, pharma, advocates, clinicians and scientists. Produced in spotify and disseminated across social media ALADDIN.

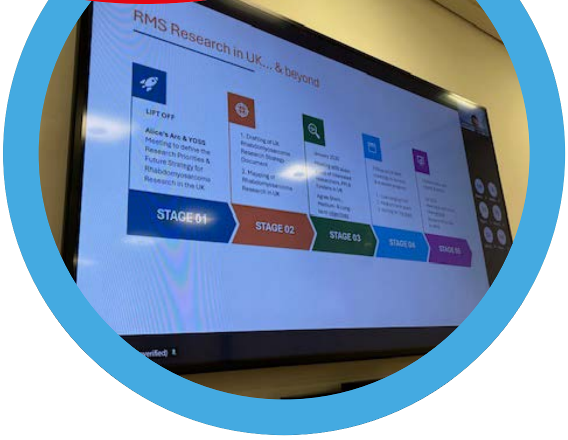

Hosting the series is founder of Alice's Arc and parent advocate Sara Wakeling (Craddock). Find out more about our host 👇

All episodes of the ALADDIN podcast are available on Spotify and Apple Podcasts.

Listen here 👂 🔗 https://lnkd.in/gRu3EkyN

Meet The Podcast Host

Sara is proud to be a passionate and dedicated childhood cancer advocate. Driven by her daughter, Alice's almost five-year journey with rhabdomyosarcoma, which resulted in her death in October 2019. Six months after Alice's diagnosis, Sara co-founded the rhabdomyosarcoma cancer charity Alice's Arc and is the CEO. Sara is also a patient advocate on various initiatives such as NexTGen (Cancer Grand Challenge), EpSSG parent group and the FaR-RMS clinical study. She also holds various Patient, Public & Involvement roles (PPI) on pediatric cancer clinical trials and other research projects.



RMS Research in UK... & beyond

LIFT OFF

Alice's Arc & YOSS Meeting to define the Research Priorities & Future Strategy for Rhabdomyosarcoma Research in the UK

STAGE 01

1. Drafting of UK Rhabdomyosarcoma Research Strategy Document
2. Mapping of Rhabdomyosarcoma Research in UK

STAGE 02

STAGE 03

STAGE 04

STAGE 05

Alice's Arc Hosted UK Rhabdomyosarcoma Research Strategy Day

June 2024

We were delighted to host our starter rhabdomyosarcoma research strategy setting day. The purpose of the day was to commence the process of defining UK RMS research priorities over the next ten years.

This was the culmination of conversations with patient advocates, clinicians, funders & scientists. We all have a collective desire to defeat rhabdomyosarcoma and do the best we can to change the story for those diagnosed in the future. As a rhabdomyosarcoma-focused charity, Alice's Arc has a duty to play our role designing and leading the development of this pipeline of critical research. With an army of families behind us both in the UK and worldwide, we have the ability to fund a pipeline of large-scale projects. However, we want to be transparent and work collaboratively & efficiently with other funders of RMS grants to ensure co-ordination and unnecessary duplication. As a family-led charity, it is essential that this research is co-created with parents & patients based on their experience.

We were delighted to have representation across stakeholders, disease areas, medical disciplines and from various scientific areas in the room. The central component of the day was lively discussion creating SWOT analysis relating to RMS research and the development of short, medium and long term priorities. With thanks to A&O Shearman for hosting.

We want to thank those who attended in-person and online. We appreciate your time & passion to improving outcomes for rhabdomyosarcoma. It was wonderful to hear from patient advocates from our RMS community. As ever, it is their stories that are at the heart of our mission and the triggers of our work.

Alice's Arc strategy session hosted & facilitated by ENFUSE group

September 2024

Alice's Arc UK Trustees were delighted to attend a strategy setting & idea generation workshop today. It was kindly hosted by our corporate partners, digital consultancy, Enfuse Group who have been supporting our work.

The purpose of the session was to define our roadmap for the year ahead. 2025 will mark the 10th anniversary of Alice's diagnosis and the founding of Alice's Arc. We have always been ambitious and we know we have to keep being flexible and challenge ourselves to ensure we are constantly doing our best for children with rhabdomyosarcoma. This was a brilliant opportunity to set goals, generate ideas & explore challenges and how to overcome them.

We are so grateful to the team at Enfuse for such high quality support and their time ensuring that we are truly working in partnership. Collaboration is key.

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.

- **Planning & implementation of 10 Years of Alice's Arc campaig:** 2025 marks the milestone of 10 years since the founding of the charity. Use this opportunity to devise a series of fundraisers & campaigns to showcase the development, research and impact of the charity.
- **Rigorously review our rhabdomyosarcoma research portfolio & 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. Identify meaningful communication mechanisms for reporting research findings.
- **Focus on embedding and growing the Arcs platform both in the UK & US:** 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 & research:** Continue to produce videos, interviews, education sessions and tools that help communicate findings and enhance understanding of the rhabdomyosarcoma research landscape. Create further opportunities for family research engagement days. 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 & partnerships strategy.

Alice's Arc

CHILDREN'S CANCER CHARITY

(A Charitable Incorporated Organisation)

Report and Financial Statements

For the Year Ended 30 September 2024

Charity number 1164253

Alice’s Arc

Report of the Trustees for the year ended 30 September 2024

The trustees present its report and financial statements, examined by an independent examiner, for the year ended 30 September 2024.

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
Dr Natalie Carpenter

Independent Examiner

Alice Hagell, Finance Director, Financial Control, Metro Bank PLC

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, University of York, UCL Cancer Institute, University of Oxford 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 2024. 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 focussed 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 the fusion genes, different subtypes 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 sustain 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 £4 million to date in incoming resources to meet disbursal and other commitments, over £300,000 of which since 30 September 2024.

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 ninth year in operation, with income of £980,714 (2023: £1,176,371) including Gift Aid. This enabled total disbursements of £618,071 (2023: £754,540): £204,694 to the Institute of Cancer Research, £76,049 to the University of Birmingham, £70,784 to The European paediatric Soft Tissue Sarcoma Study Group (EpSSG), £16,543 to the University of York, and £250,000 to Alice's Arc US, bringing total disbursements to cancer research organisations to the end of September 2024 to £2.4 million. After these disbursements, total funds of the charity stood at £1,582,949 as at 30 September 2024 (2023: £1,231,909).

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. £200,832 was raised in the year to 30 September 2024 by Lush (2023: £680,523 including £658,681 received directly from Lush group companies). Restricted funds also include £250,000 received from Children with Cancer UK, with restrictions primarily related to record-keeping.

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 £2.4 million research grants made in the periods to 30 September 2024, a further £2 million has been committed subject to agreed milestones, primarily consisting of grants to the Institute of Cancer Research relating to plasticity, and to Wellcome Sanger & UCL Cancer Institute relating to analysis of tumour samples retrospectively with the VIVO BioBank and prospectively on the FaR-RMS trial. 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 fundraising 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 and their family members 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 material 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

In September 2024, the charity made a payment of £250,000 by way of grant to Alice's Arc US, a 501(c)(3) organisation in the USA. The grant contains the same restrictions as the grant received from Children with Cancer UK and is conditional on the funds being deployed with the objectives of finding a cure and less harsh treatments for Rhabdomyosarcoma in children, as well as providing support to families affected by this condition, including (without limitation) the funding of scientific research. Alice's Arc US is not a member of the same group as the charity, however, it shares two trustees, who do not hold majority voting rights in either charity but have a significant influence. A third trustee of the charity, but not of Alice's Arc US, is also a sibling to one of those trustees. Each of these trustees disclosed any conflict of interest in the making of the grant.

No trustee or other person related to the charity had any other 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 40. 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;
- 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 examiner 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 examiner is aware of that information.

Independent Examiner

Alice Hagell was appointed as the charity's examiner. 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 1st July 2025 and signed on its behalf by:

Mrs Sara Wakeling (Chief Executive)

Statement of Financial Activities (including Income & Expenditure Account) for the year ended 30 September 2024

	Notes	Unrestricted Funds to 30/9/24 (£)	Restricted Funds to 30/9/2024 £	Total Funds to 30/9/2024 £	Total Funds to 30/9/2023 £
Incoming resources					
Voluntary income: donations	2	486,199	450,833	937,032	1,155,143
Gift Aid on donations	7	6,887	-	6,887	6,153
Investment income		34,963	1,832	36,795	15,075
Total incoming resources		**528,049**	**452,665**	**980,714**	**1,176,371**
Resources expended					
Costs of generating voluntary income	3	9,610	-	9,610	33,350
Charitable activities	3	368,071	250,000	618,071	754,840
Governance costs	3	1,086	907	1,993	15,868
Total resources expended		**378,767**	**250,907**	**629,674**	**804,058**
Net Income for the year		**149,282**	**201,758**	**351,040**	**372,313**
Reconciliation of funds					
Total funds brought forward		710,310	521,599	1,231,909	859,596
Total funds carried forward		**837,750**	**745,199**	**1,582,949**	**1,231,909**

All incoming resources and resources expended derive from continuing activities.

Balance Sheet as at 30 September 2024

	Notes	30/9/2024 £	30/9/2023 £
Fixed Assets		**-**	**-**
Current Assets		**1,582,949**	**1,240,009**
Debtors	7	10	6,153
Cash at bank and in hand		1,582,939	1,233,856
Creditors		-	(8,100)
Net Assets		**1,582,949**	**1,231,909**
General Funds	8	837,750	710,310
Restricted Funds	8	745,199	521,599
Total Funds		**1,582,949**	**1,231,909**

Statement of Cash Flows for the year ended 30 September 2024

		30/9/2024 **£**	**30/9/2024** **£**
Net income/(expenditure)		351,040	372,313
Adjustment for:	Dividends, interest, rents	(36,796)	(15,075)
	Change in debtors	6,143	9,322
	Change in creditors	(8,100)	8,100
Cash flow from operating activities		**312,287**	**374,660**
Dividends, interest and rents		36,796	15,075
Cash flow from investing activities		**36,796**	**15,075**
Cash from financing activities		**-**	**-**
Beginning of the reporting period		1,233,856	844,121
End of the reporting period		1,582,939	1,233,856
Change in cash and cash equivalents		**349,083**	**389,735**

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 1st July 2025 and signed on its behalf by:

Mr Nick Wakeling (Treasurer)

Notes forming part of the Financial Statements for the year ended 30 September 2024

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 and received from Children with Cancer UK.

- 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.

(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 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 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

£9,610 costs of generating voluntary income (2023 equivalent: £33,350) comprises costs of fundraising events and promotions, in particular for places on the Great North Run.

£1,993 governance costs (2023 equivalent: £15,868) comprise IT, insurance, postage, travel, and other miscellaneous items.

£618,071 charitable activities (2023: £754,840) comprise: £204,694 to the Institute of Cancer Research, £76,049 to the University of Birmingham, £70,784 to EpSSG, £16,543 to the University of York, and £250,000 to Alice's Arc US.

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

£10 debtors (2023: £6,153) comprise Gift Aid and GASDS on donations received to which the charity is entitled and expects to recover from HMRC. £13,268 Gift Aid and GASDS was claimed/ received from HMRC during the year to 30 September 2024 in respect of donations made in previous years, £239 higher than had been expected in debtors recognised as at 30 September 2023.

8. Unrestricted and Restricted Funds

Outline summary of fund movements

Fund	Balance brought forward	Income	Expenses	Transfers	Gains and losses	Balance carried forward
Unrestricted	710,310	528,049	(378,767)	(21,842)	-	837,750
Restricted	521,599	452,665	(250,907)	21,842	-	745,199
Total	**1,231,909**	**980,714**	**(629,674)**	**0**	**0**	**1,582,949**

Transfers of £21,842 relate to funds raised by Lush (Dexter's Arc) in prior periods which is subject to the same non-animal testing restriction as funds directly provided by Lush group companies (sales of bath bombs).

Analysis of net assets between funds

Fund	Current assets	Current liabilities	Net assets
Unrestricted	837,750	0	837,750
Restricted	745,199	0	745,199
Total	**1,582,949**	**0**	**1,582,949**

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

I report on the accounts of the Trust for the year ended 30 September 2024, which are set out on pages 49 to 55.

Respective responsibilities of trustees and examiner

The charity’s trustees are responsible for the preparation of the accounts. The charity’s trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act
- follow the procedures laid down in the general Directions given by the commission under section 145(5)(b) of the 2011 Act
- state whether particular matters have come to my attention

Basis of independent examiner’s report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a ‘true and fair view’ and the report is limited to those matters set out in the next statement.

Independent examiner’s statement

Since the charity’s gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached

Name: Alice Hagell

Relevant professional qualification or body: ICAEW

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Date: 1st July 2025

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Alice's Arc
CHILDREN'S CANCER CHARITY