

Alice's Arc Annual Report

1 October 2021 – 30 September 2022





Charity number 1164253



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Introduction



A message from our CEO

What a year!

Another record-breaking year for fundraising (close to £700K). 10 new Arcs, joining our first six Arcs, established in different locations across England. A growing portfolio of rhabdomyosarcoma research projects across leading UK research institutions. A pipeline of grant applications reviewed by our expanding international Scientific Advisory Team. A growing community of rhabdomyosarcoma families coming together to support one another, pool our voices and to raise funds. Engagement and endorsement from medical professionals and scientists also passionate about our mission. And, trust in our working model from families in the USA who are determined to bring Alice's Arc to America.

We are delighted with this positive progress. However, each year we are constantly reminded of why we exist. Sadly, the arrival of new Arcs is often driven by the death of a child from rhabdomyosarcoma. This year we pay tribute to Dexter, Ethan, Oliver and Sia who passed away during this period. Our hearts go out to their families who now have to navigate these heavy losses within their lives.

We have also met new families who have received the shocking news that their child has rhabdomyosarcoma. Being propelled into this frightening world is incredibly traumatic and we aim to offer a safe and empathetic space for those who want it. In addition, we celebrate the positive milestones with those families living with the anxiety of being off-treatment and those facing the long-term side-effects of their intensive treatment. Representing every perspective is so important to us. Rhabdomyosarcoma, no matter what the outcome, profoundly changes the life of a family.

We made our largest grant to date with the investment of £1million into a project involving multi-disciplinary teams at the Institute of Cancer Research (as referenced on p21). The research will address the key question of why rhabdomyosarcoma cells change leading to relapse or refractory disease. We hope that the discoveries resulting from this will lead to new therapeutic treatment options that can be used at the point of relapse or to prevent relapse ever happening. This would be a significant research breakthrough given how so few treatment options are available at relapse.



The future looks brighter. We will continue to use our established platform and ever-enhancing brand reputation to provide hope for families whose child or young person may be diagnosed with rhabdomyosarcoma in the future. We are confident to move forward with the global expansion of Alice's Arc. We see this as critical in uncovering research discoveries and bringing these to patients in early phase clinical trials. This will also make our community of families, scientists and oncologists stronger in sharing ideas, creating education & awareness and ensuring the existence of a sustainable portfolio of diverse rhabdomyosarcoma research.

As ever, we are so grateful to all the families, friends and communities who have worked with us this year. Our progress would not be possible without you. Together we are stronger. Please continue to help us pave the way for progress in the fight against rhabdomyosarcoma.

With best wishes,

A handwritten signature in black ink that reads "Sara Wakeling". The signature is written in a cursive, flowing style.

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 21 Arcs across England and Northern Ireland and more in the works. We have also recently applied for a non-profit 501c3 status in order to replicate our model in the USA.

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.

 **ICR** The Institute of Cancer Research

 **UNIVERSITY OF BIRMINGHAM**

 **wellcome sanger institute**

 **UCL**
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

 **UNIVERSITY of York**

 **ESSGO**



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.

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.

Create a global rhabdomyosarcoma research platform

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

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.

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.



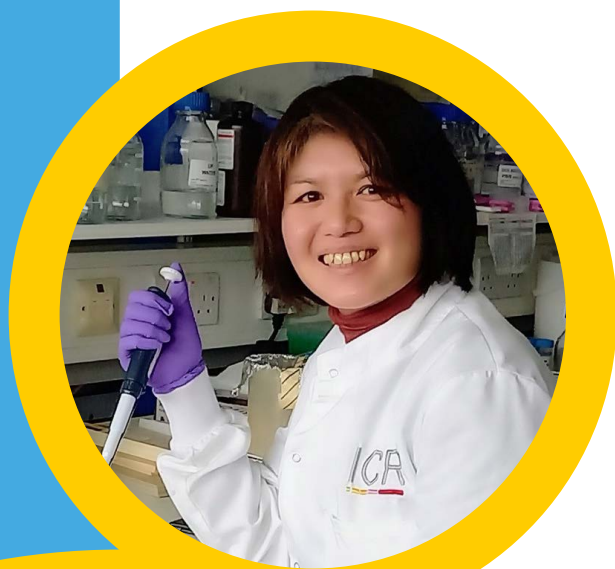
SMPaeds, led by The Royal Marsden's academic partner the ICR, is the first platform of its kind in the UK. It allows children and young people who have relapsed solid tumours to have a biopsy tissue sample taken which is then analysed to identify certain changes in the DNA of the cancer cells which may 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 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 15 countries including Canada, Australia, New Zealand and Israel. The trial will study 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.

"We want to share the success of Amber's journey to give hope, but highlight that there is so much more to do to ensure that every child's journey is as worthwhile as Amber's. I can't return to life before cancer and pretend it didn't happen, and I don't want to. We carry this journey with us and will support the incredible work that Alice's Arc are doing in any way we can."

JEMMA GOOCH-BOAGS, AMBER'S 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.



Newly launched Arcs

During this time, we have launched an additional 10 Arcs, joining our first 6 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 families in the USA have encouraged us to open an operation in the USA (we filed for a 501c3 early in 2023). 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.

Amber's Arc for Amber who was diagnosed in May 2017 and is now six years off treatment. Amber's trusty pet dog is the symbol for her Arc.



Beanie's Arc for Zac who died aged 2 in April 2020, note the beautiful rocket symbol created for his Arc with Beanie and his parents inside.



Dexter's Arc for Dexter who passed away aged 7 in July 2022. Dexter had a love of dragons and his companion through all he endured was Crackle, his toy dragon. His family have chosen Crackle to represent Dexter's Arc.



Ebony's Arc for Ebony who died aged 13 in January 2020. Ebony's Arc is represented by a beautiful butterfly after her Grandad wrote a poem about her being a butterfly after she passed away.



Esther's Arc for Esther who died in June 2016, aged 4. Esther's Arc uses a squirrel image that was used at Esther's nursery school.



Ethan's Arc for Ethan who died in August 2021 aged 9. Ethan already had a symbol and acronym, EA10 that his community developed and it was natural to use this for his Arc.



Leila's Arc for Leila who was diagnosed in October 2021 and is currently stable. Leila choose a cartoon dog image to represent her Arc.



Oliver's Arc for Oliver who died aged 6 in September 2021. Oliver's symbol is his teddy bear who accompanied him throughout treatment.



Sia's Arc for Sia who died in February 2022, aged 4. Sia loved pandas and rainbows hence the colourful array of colours and the fantastic panda representing her Arc.



Will's Arc for Will who died aged 20 in February 2021. Will was a talented artist and drew the beautiful bear image that now represents his Arc.



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 **Dexter, Ethan, Oliver** and **Sia** who lost their lives to rhabdomyosarcoma. Alice's Arc will always remember you and talk about you. You are the inspirations for our work.

Dexter
Constantine-Tatchell

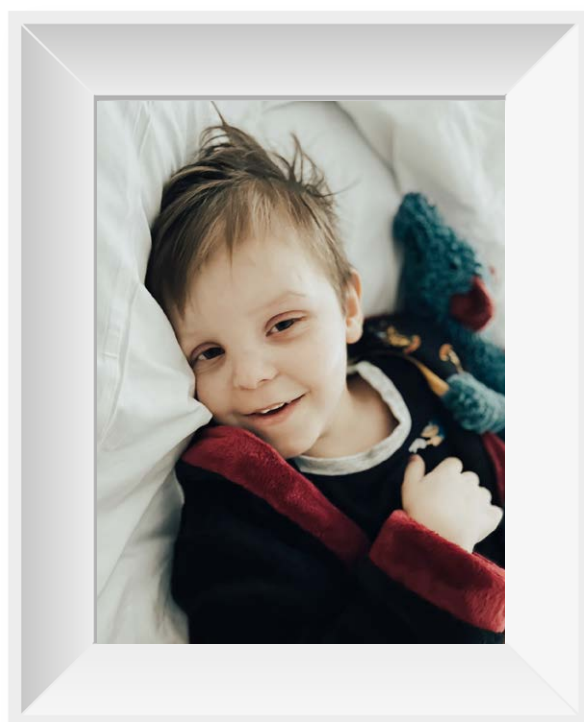
18th August 2014 to 27th July 2022

Snapshot of his story:

Dexter was just five when he was diagnosed with parameningeal embryonal rhabdomyosarcoma, presenting in the nasopharyngeal. It grew aggressively out of his right nostril over a three-day period, after an agonising fight for him to be seen by medics. On December 5th 2019, we were told it was cancer and had to immediately start emergency chemotherapy. Dexter went on to have nine rounds of IVA, 33 days of intense proton radiation therapy, numerous biopsies, lumbar punctures and blood transfusions and finally six months of maintenance chemotherapy which gave our family 15 months of hope that the tumour had been killed off. Dexter's tumour was deemed inoperable in frontline treatment. In March 2022 his three-monthly scans, showed aggressive growth from the original tumour and we were told he had likely a year on chemotherapy but on May 6th, 2022, scans proved that the treatment ineffective. We were given four to six weeks together, Dexter fought on and continued living until he passed away on 27th July 2022. He was seven years old.

"Through Dexter's Arc we will forever support Alice's Arc's drive to change and develop treatments used for this disease."

RACHEL CONSTANTINE, DEXTER'S ARC





Fundraising for Dexter:

£150k

raised by Lush in the UK and Ireland, through sales of their golden Dexter's Dragon Egg bath bomb.

(see fundraising highlight)



£13k

In July 2022, staff from Dexter's school completed the Poole Longfleet Harbour Walk.

(see fundraising highlight)

£3.3k

Dexter's school Longfleet CE ran a Go Gold day.

Dexter's impact



Dexter's family are the co-founders of the handmade cosmetics giant, LUSH. Dexter's story touched the staff part of this global business and they devised a bath bomb known as Dexter's Dragon egg to sell across the UK in-store and online as part of Childhood Cancer Awareness Month in September 2022. They turned this iconic bath bomb gold and 100% of sales (minus VAT) was donated to Dexter's Arc for the purpose of non-animal testing research into rhabdomyosarcoma. This raised an enormous £150K. Being able to take advantage of the Lush platform has enabled Dexter's Arc and Alice's Arc to significantly build our profile. A similar campaign featuring Dexter's golden Dragon Egg was run in February 2023 for International Childhood Cancer Day.



Dexter has brought a huge community of supporters together. Lush, local schools, local businesses, friends and family. Watching a child fight rhabdomyosarcoma can not be forgotten and people are keen to fundraise and raise awareness for Dexter.



Dexter's family want to see bespoke treatment based on individual children and the way they personally respond to chemotherapy and treatments. They also want to see more diverse treatments available at the point of relapse as they literally faced no options.

"Losing Dexter has had a devastating impact on our family. For Alice's Arc to give us the opportunity to unite with other grieving families has been a powerful focus for us, allowing us to raise funds in the wake of Dexter's death. Through Dexter's Arc we will forever support Alice's Arc's drive to change and develop treatments used for this disease. In the hope that rhabdomyosarcoma doesn't needlessly claim the lives of innocent children and destroy lives in years to come."

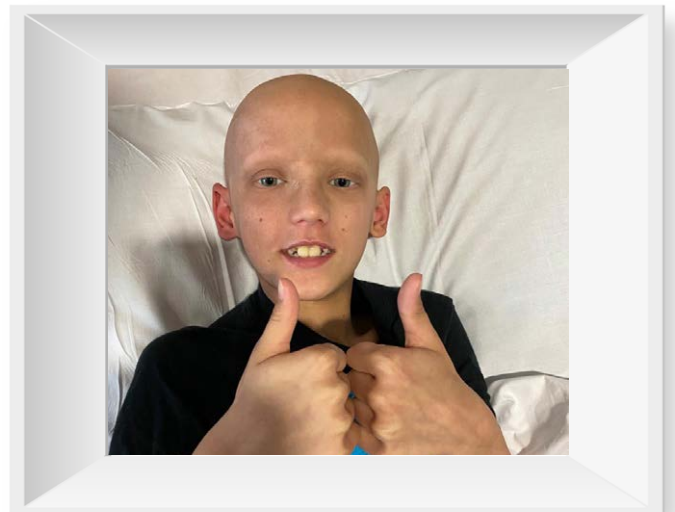
RACHEL CONSTANTINE, DEXTER'S ARC

Ethan Adams

30th July 2012 to 5th August 2021

Snapshot of his story:

Ethan, aged 8, was diagnosed with parameningeal embryonal rhabdomyosarcoma – extending into the anterior cranial fossa area and had also spread to the lungs & bone marrow, in December 2020. Ethan faced cancer, and his subsequent treatment, as he did with everything in life, like an absolute warrior. Sadly, after completing chemotherapy & radiation, scans showed active cancer cells, and no further treatment options were available. Ethan lost his life on 5th August 2021, just a week after his 9th Birthday.



"Children deserve to be invested in, they deserve a future, they don't deserve medication that is over 40 years old, that also brings years of health complications to the ones that do make it through."

MARK ADAMS, ETHAN'S ARC



Ethan's impact:



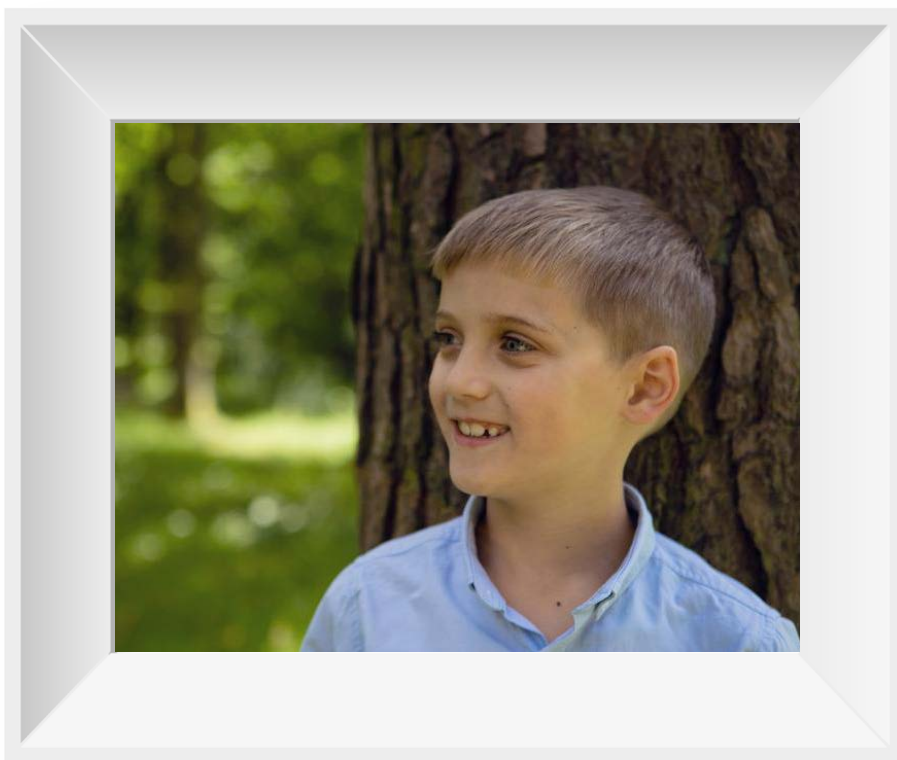
Ethan's family have launched Ethan's Arc in memory of Ethan and recognition to the outpouring of support they received from friend's and their community. Such was the support that Ethan became known by the symbol EA10 which is well-known through out his network.



Ethan's family want to see improvements in general awareness of childhood cancer and it's warning signs. They also found it hard to watch Ethan endure the intensive and harsh treatments and would advocate for kinder treatments to be devised.

"We are absolutely devastated to lose Ethan, and the world has lost such a wonderful character, but Ethan's Arc has given us the inspiration to keep going, it's given us a way of keeping Ethan's name alive and the platform to fight in his honour."

MARK ADAMS, ETHAN'S ARC



"Hopefully the support & hard work of the combined Arcs can lead us to find better and less harsh treatments, possibly even a cure, and we can give children what they deserve, a future."

MARK ADAMS, ETHAN'S ARC

Fundraising for Ethan:

£4k

raised by **6 individuals** walking **Coast to Coast** across Hadrian's Wall, completing 100 miles over 5 days and camping along the way.

£1.8k

was donated by a team of 5 participating in the Great North Run.

£1.4k

raised via **Ethan's Dad's over 40s football team** hosting a fundraising event including a raffle and a band performing.

£365

raised at a Quiz night hosted at a local pub.

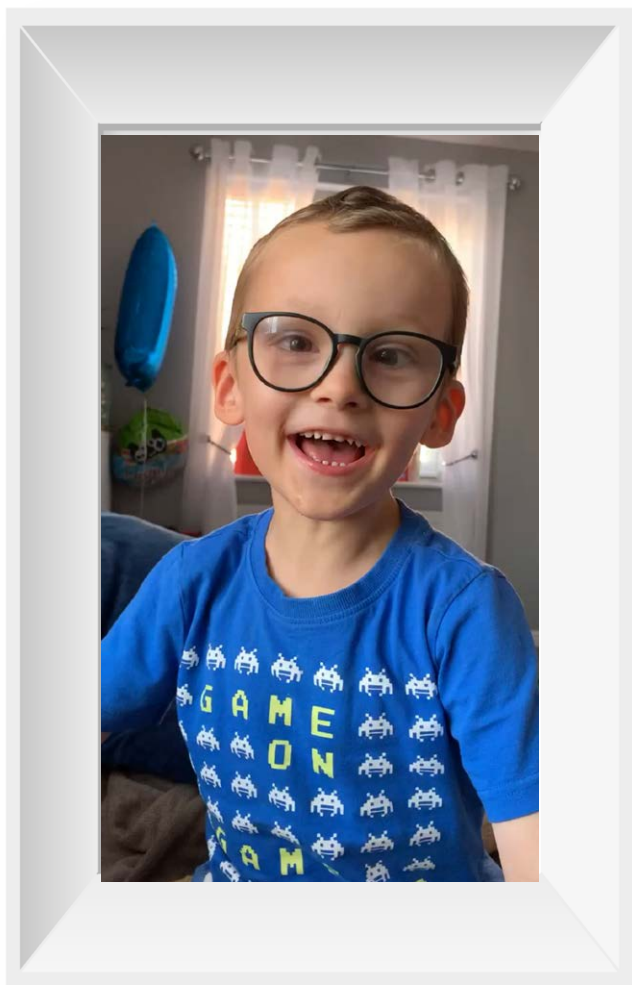
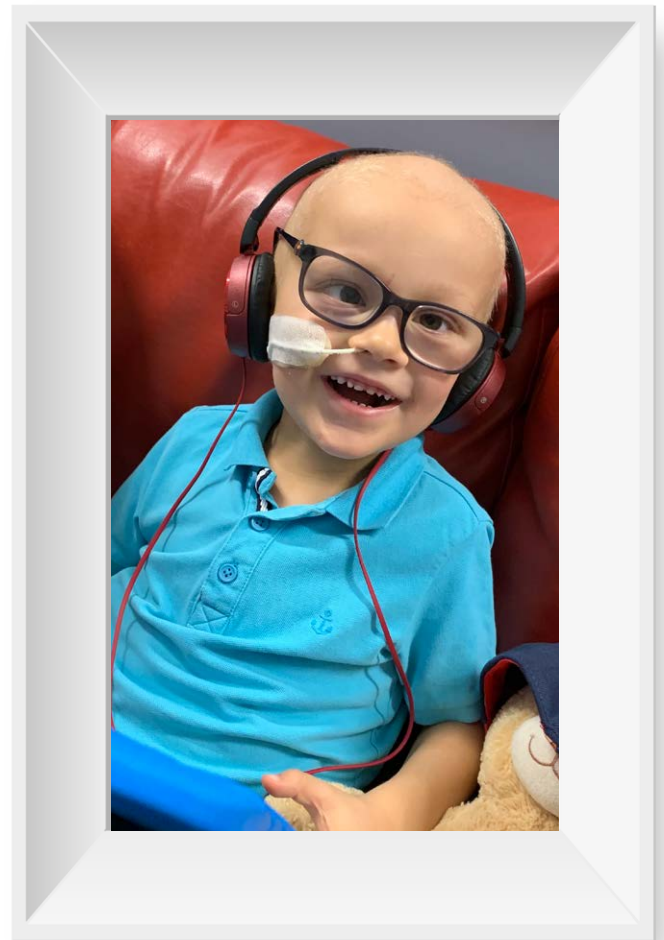


Oliver Hurd

23rd May 2015 to 17th September 2021

Snapshot of his story:

Oliver, aged 4, was diagnosed with pelvic alveolar rhabdomyosarcoma, in August 2019. Two weeks after Oliver finished maintenance chemotherapy, a lump appeared in his neck and Oliver received palliative chemotherapy. However, in July 2021, the disease spread further throughout his body. No treatment options were available. Sadly, Oliver passed away in September 2021, aged 6.





Fundraising for Oliver:

OVER
£7k

raised in memory of Oliver at his celebration of life.

£3.5k

Oliver's **Dad** completed a Coast to Coast (Morcambe to Filey) cycle in a day accompanied by Oliver's trusty **Teddy**.

£2k

Brotherton Bulldogs, local kids Rugby team took part in a cycling challenge.

£1.2k

in daily exercise challenge, Active 365 event for Oliver.

£300

Oliver's best friend, **Leo** walked 101 miles in 30 days.

"Oliver was so full of life, he loved being with his family, playing games and running around, even whilst he was on treatment, he never let it stop him. Losing Oliver to this disease means our lives will forever be broken but by becoming part of the Arcs, we hope we can help save future families from being in the position we are in today."

LISA HURD, OLIVER'S ARC

Oliver's impact:



The launch of Oliver's Arc has led to such fantastic support. Local businesses Henstone Distillery and Orchard Farm Holiday Park have raised awareness of the charity and conducted fundraisers.



Oliver has inspired his young friends to help make a difference for children diagnosed with rhabdomyosarcoma in the future. Friends from Oliver's school and nursery have participated in walking and cycling challenges. It is wonderful to see young children pro-actively wanting to help.



Oliver's family want to see new research to improve treatments available for our children. They want better outcomes in the future and less suffering for children and their families diagnosed with rhabdomyosarcoma in the future.

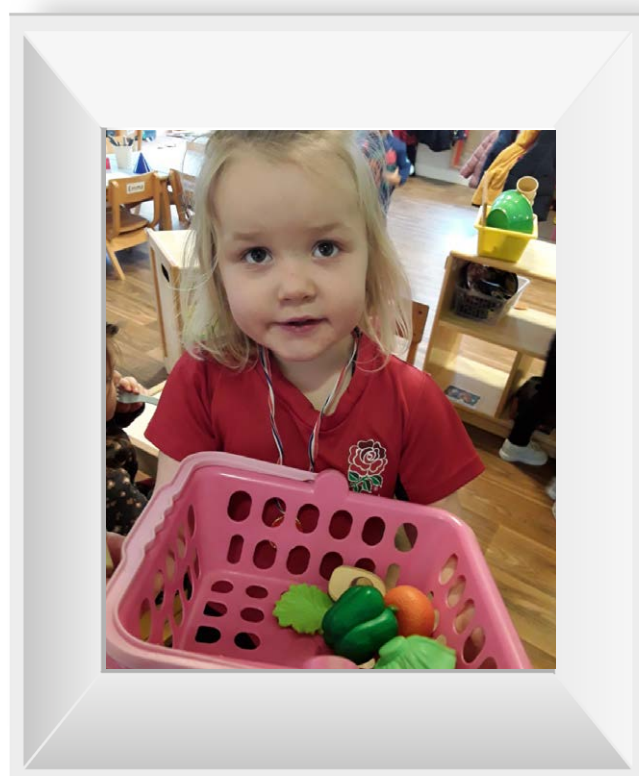
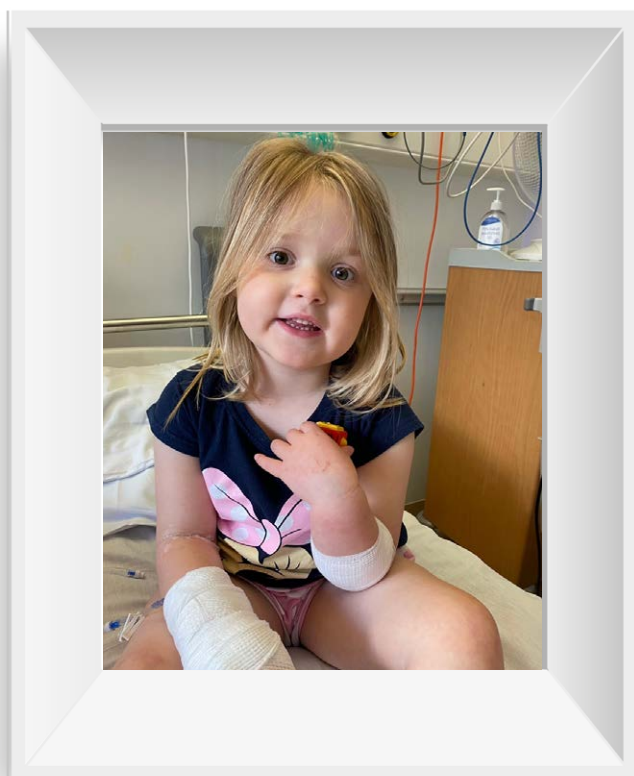
Sia Schoeman

16th February 2017 to 4th February 2022

Snapshot of her story:

Sia was diagnosed with stage 4 metastatic rhabdomyosarcoma in June 2021. The prominent tumour was on her lower left leg, but the disease had already spread to her spine, lungs and bone marrow. At first, Sia responded to first line treatment, but then it stopped working and Sia started second line treatment in December 2021, but by the end of January 2022 the disease had mutated and there were no treatment options left.

Sia went to heaven on 4th of February 2022, only 8 days after we learned that she was terminal and 12 days before her 5th birthday.





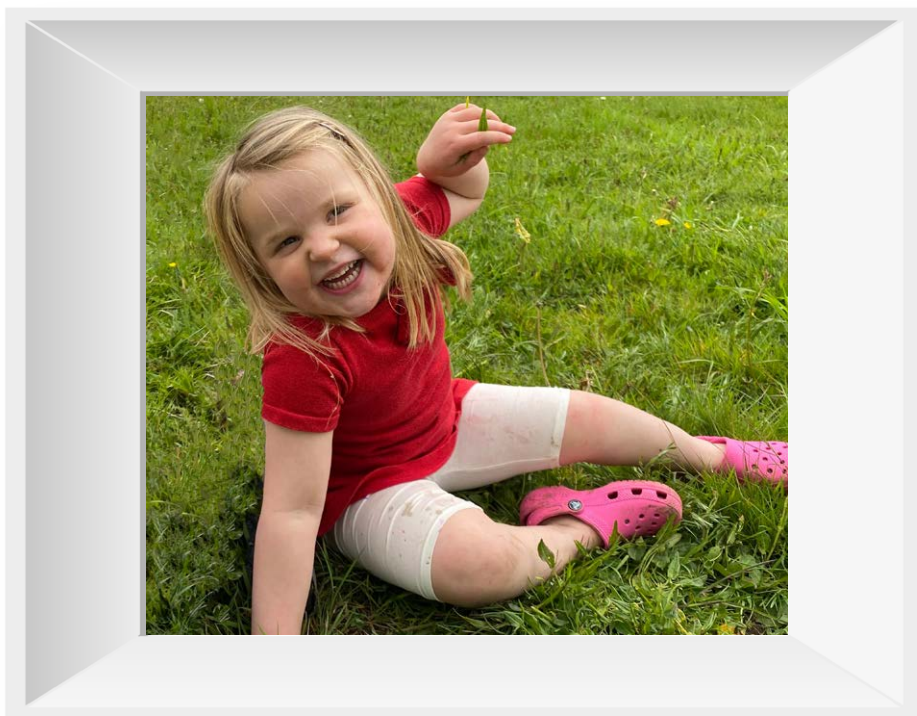
Sia's impact:



Sia has brought together a community of friends, families and supporters and created Sia's Arc. Sia's parents have been raising awareness of rhabdomyosarcoma and how it has impacted their lives. They have honoured Sia on the first anniversary of her passing with an event called 'The 12 Days of Sia'. This involved Sia's school and the John Radcliffe Children's Hospital in Oxford where Sia was treated.



Sia's family want to see a greater awareness of symptoms to look out for, both for parents and GPs. There needs to be a fast-track procedure in the NHS to get to diagnosis quicker. Note though that a quicker diagnosis won't necessarily result in a different outcome, but it would make that initial stage less traumatic for the family. Also, more availability and speed for securing an MRI scan under general anaesthetic, as this also caused a delay in getting the diagnosis.



Fundraising for Sia:

£2k

raised as part of the
12 Days of Sia event.

£1.5k

secured by **Biogen**
colleagues when Sia's Arc
was launched.

£950

raised in memory of
Sia at her celebration
of life.



"We are grateful for the Arcs family – for support and encouragement during the dark days and the opportunity to celebrate small victories together. But most of all, it allows us to keep Sia's legacy alive and active, doing good for those who might find themselves in a similar predicament. We are so much stronger together"

ESTER SCHOEMAN, SIA'S ARC

Research Focus

We donated **£392,842K** towards rhabdomyosarcoma research during this time period.



£217k

to the Institute of Cancer Research

This relates to three projects:



£83K for the 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.



£85K towards year one 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 two on the project exploring the use of liquid biopsies in detecting and predicting disease path in the treatment of children with rhabdomyosarcoma.

£81k

to the University of Birmingham

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

£57k

to 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'.

£33k

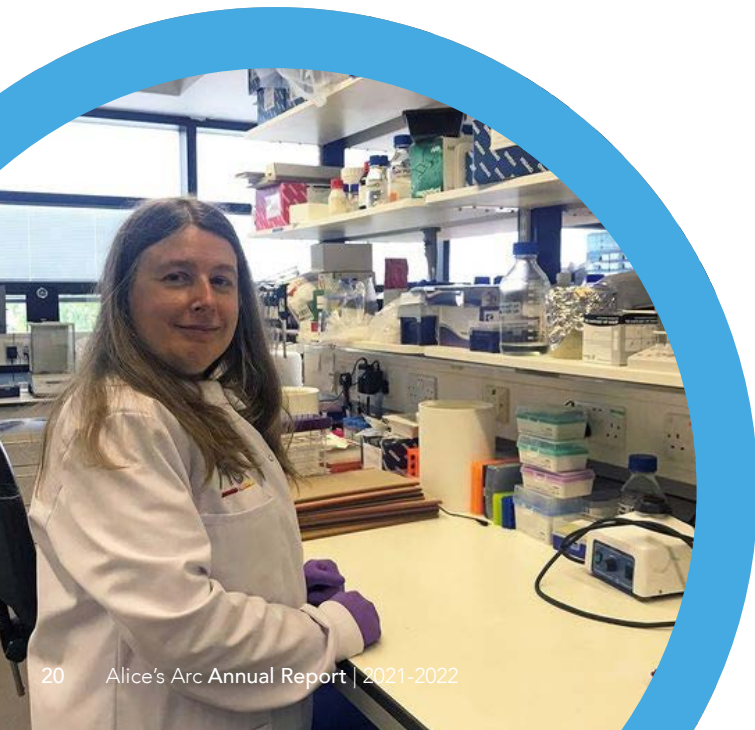
to the European Paediatric Soft tissue sarcoma Study Group (EpSSG)

This money has been used to fund two roles at the EpSSG - **Project Manager & Statistician**. These roles contribute to operational management of the organisation, past and present research analysis, communication & dissemination and education within the paediatric soft tissue sarcoma community.

£3k

to the 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. For example, the development of a pillow case with guidance.



Scientific Advisory Team

We appointed Dr Toby Trahair, Paediatric Haematologist & Oncologist at Sydney Children's Hospital, Australia as a member of the team. This international group comprises adult & paediatric oncologists and medical professionals in other fields. 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 & evaluating research priorities



reviewing & commenting on research progress reports of funded work.



reviewing & assessing grant applications

New Project

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



"£1million grant to unravel the mystery of the causes of cell changes leading to relapsed and refractory rhabdomyosarcoma."

This is pioneering research to find **new therapies that will prevent or treat relapse in rhabdomyosarcoma**. As a reminder, prognosis at the point of relapse is a dismal 8%. This four year project will be co-lead by Professor Janet Shipley (Head of Molecular Pathology) and Dr Alejandra Bruna (Team Leader in Preclinical Modelling of Paediatric Cancer Evolution) at the Institute of Cancer Research. They will also collaborate with Professor Trevor Graham (Director of the Centre for Evolution & Cancer and head of the Genomics and Evolutionary Dynamics team).



Research: laboratory visits

University of Birmingham - 3rd March 2022

Alice's Arc trustees, Natalie Carpenter, David Wakeling and Sara Wakeling visited the University of Birmingham to meet the multi-disciplinary research teams who are conducting two Alice's Arc-funded projects with an emphasis on fusion negative rhabdomyosarcoma and understanding the interactions between the tumour micro environment and the tumour itself. The team provided updates on the research including challenges, promising findings and next steps.

Visit highlights included the tour of the laboratories where we looked through microscopes at normal muscle cells, embryonal rhabdomyosarcoma cells and alveolar rhabdomyosarcoma cells. We were also introduced to a sophisticated microscope that allows the behaviour of rhabdomyosarcoma tumours to be studied in real-time.

It's also such a pleasure to speak to the Phd's and PostDocs who help bring to life what a day in the laboratory is like from their perspective.



Wellcome Sanger Institute - 4th July 2022

The purpose of this visit was to discuss progress on the research 'Identification and evaluation of foetal immune targets in rhabdomyosarcoma.' Project collaborators including Dr Sam Behjati from Sanger, Dr Karin Straathof at UCL Great Ormond Street Institute of Child Health and Professor Janet Shipley at the Institute of Cancer Research were there.

The Sanger team described the analysis they've been doing on the relationship between rhabdomyosarcoma cells and non-cancer cells, the UCL teams updated on their work exploring the feasibility of different targets that can be used to engineer T-cells and the ICR team talked through the living 3D models they representing fusion positive disease and the ability to switch the fusion protein on and off. The ICR are also developing patient-derived models to assess the CAR T-cells.

We were also fortunate to have a tour of the Sanger laboratories and pioneering sequencing technologies that they utilise. This was absolutely fascinating and we came away enthused and hopeful. Bridging the gap between the science and the patient/family community is vital.



Research engagement

Providing tools to engage our community with the research process is important. We want our supporters to understand the complete research cycle. We encourage the researchers we work with to provide short videos describing their research and showing what is happening in the laboratory. For example, the team at **the University of Birmingham** recently produced a video describing the work they are doing for Alice's Arc on fusion negative rhabdomyosarcoma and the tumour micro environment.



In addition, when we introduce new projects, several scientists have provided interviews explaining what a day in the life in the laboratory is like. This has been very well received and we will continue to initiate these kinds of engagement activities.



A PostDoc at the **ICR** also produced a video explainer on the role & impact that a liquid biopsy could have in detected and predicting rhabdomyosarcoma. She also talked about progress on this project that we are funding.

Fundraising highlights

ROYAL PARKS HALF MARATHON 2021

On Sunday 10th October 2021, a team of 100 runners from across the Arcs (Alice's Arc, Beanie's Arc, Freddie's Arc, Gaspard's Arc, Jessica's Arc, Sophie's Arc and Will's Arc) network ran this amazing half through the **Royal Parks of London**. We also had a huge number of spectators supporting and gathering in the Alice's Arc marquee. Final total raised amounted to an enormous £150K demonstrating the power of the Arcs with families and supporters coming together determined to raise much needed funds for research into rhabdomyosarcoma. It was a truly moving event watching the sea of yellow Alice's Arc running vests.



£150k



DEXTER'S LUSH DRAGON EGG BATH BOMB UK SALES

The sale of Dexter's gold dragon egg bath bomb in **UK Lush stores** in September 2022 secured £150K of funds via Dexter's Arc. This money will go towards **non-animal testing research for rhabdomyosarcoma**. Dexter's family are the co-founders of Lush and they were keen to collaborate for Childhood Cancer Awareness Month and to demonstrate their support for Dexter, who passed away in July 2022.



£150k

CROWN'S TOUR DE BROADS CYCLING CHALLENGE FOR AMBER'S ARC

A team of 12 from Crowns decided to cycle the **Tour De Broads** in honour of Amber's story. Amber's mother was one of the team member's participating in the challenge. Four members rode the 100 mile route and eight members rode 50 miles. They raised over £11K in celebration of Amber's milestone of being five years since her diagnosis.

£11k



Crowns Epic Cycle



CHARITY FOOTBALL MATCH FOR LEILA'S ARC

£4k

On the 6th April 2022, a charity **football match** took place in aid of Leila's Arc. Team Leila's Arc XI took on Roberto AC in Nottingham at Radford United's football ground. Leila attended the event despite being on treatment.



'LOVE YOUR SELFIE' FUNDRAISER AT ATRIA WATFORD, SHOPPING CENTRE

£6k

This was an immersive pop-up event hosted at Atria Watford, shopping centre. A 'Love Your Selfie' store was created in support of Jessica's Arc for the month of August 2022. The pop-up comprised nine selfie rooms that were decorated with fun and unusual backgrounds. All proceeds from the ticket sales were donated to the charity in memory of Jessica Macqueen who died in October 2019. The unusual nature of the event attracted press/broadcaster attention and a visit from local MP, Dean Russell.

TEAM OF 15 TAKE ON TOUGH MUDDER FOR GASPARD'S ARC

£11k

A team of 15 people from Gaspard's Arc participated in the **London West 10K Tough Mudder** in May 2022. This is a very tough challenge involving intensive racing, mud, ice buckets, a 15m high platform, electric shock wires and more! They raised an enormous £11K for their amazing efforts undertaking this military-style event. Several companies also provided matched funding increasing the final total.



£3k

ELSA'S ARC HOSTS A RACE NIGHT

This event allowed Elsa McGee's family, friends and community to come together to raise money over an evening of **horse racing**. Attendees sponsored horses and a raffle also took place.



£26k



BEANIE'S ARC

The 22nd April 2022 marked two years since Beanie passed away, aged two. To honour this date, Beanie's Arc donated £26K raised via friends, family and community initiatives.



POOLE LONGLEET HARBOUR WALK FOR DEXTER

Staff from Longfleet CE Primary School completed this charity walk in July 2022. The walk involves following the **Poole Harbour Trail** and team members choose to complete different lengths from 16 miles to 26 miles. They were inspired to do to honour Dexter's journey with rhabdomyosarcoma.

£13k

UNIVERSITY OF SOUTHAMPTON FUNDRAISER FOR WILL'S ARC

Friends of William Rutt, who passed away aged 20 from rhabdomyosarcoma put together a **games and live music event**. They also used the event as an opportunity to educate students about rhabdomyosarcoma and childhood cancer.

£1.5k



£16k

LONDON LANDMARKS HALF MARATHON 2022

Our team of 18 runners from Alice's Arc, Beanie's Arc, Ebony's Arc, Freddie's Arc and Mollie's Arc took on this icon **London half marathon** on 3rd April 2022. As usual, runners included parents, family members and friends through our Arc community and other supporters.



CORPORATE SUPPORT

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

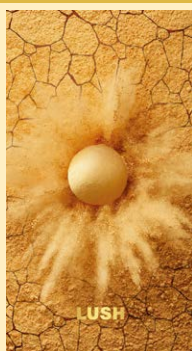
- **Allen & Overy** provided their annual £20K grant and kindly support us by providing legal guidance, design/branding services and project management guidance.
- **Enfuse Group** choose Alice's Arc as their charity of the year and have fundraised and provided their services to support our work.
- **Samsung** supported Freddie's Arc at an awards event.

ALLEN & OVERY

ENFUSE

Childhood cancer awareness month (CCAM) – September 2022

As usual families brought their communities together via school events (Alice's Arc, Dexter's Arc, Elsa's Arc, Freddie's Arc and Mollie's Arc) local businesses, local shops to raise awareness of rhabdomyosarcoma and through the sale of gold goodies. This year we were delighted to have Lush selling Dexter's Gold Dragon Egg bath bombs in the UK. We also ran a social media campaign highlighting the individual stories of 25 families impacted by rhabdomyosarcoma. Sara Wakeling also participated in a video created by the ICR designed for CCAM.



ALICE WAKELING
www.alicesarc.org

DIAGNOSIS: alveolar/fusion positive rhabdomyosarcoma
WHEN: March 2015
LOCATION: submandibular gland/parotid gland involvement and lung met, same location on first relapse and abdomen/pelvis on second relapse
TREATMENT: chemotherapy, proton radiation, surgery and brachytherapy (AMORE)

LEAD HOSPITAL: Great Ormond Street Hospital, London
OUTCOME: Alice died on the 9th October 2019, aged 7
ARC MOTIF: Alice is the founder's daughter and the trigger for the formation of the charity. The handprints represent her bringing a rhabdomyosarcoma community together.

Go Gold for Childhood Cancer Awareness Month

— About 1,900 children (up to the age of 15) are diagnosed in the UK with cancer each year
— Cancer is the number one cause of death by disease for children
— 240 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

Help us make change for the future of children with rhabdomyosarcoma

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

What is Rhabdomyosarcoma

Rhabdomyosarcoma is the most common soft tissue sarcoma occurring in children and young people

accounts for 9% of childhood cancer cases each year. With 2070 children in the UK and 300 in the USA each year

On average, there is an 8.20% chance of survival. This is influenced by the subtype, gene fusion status and location

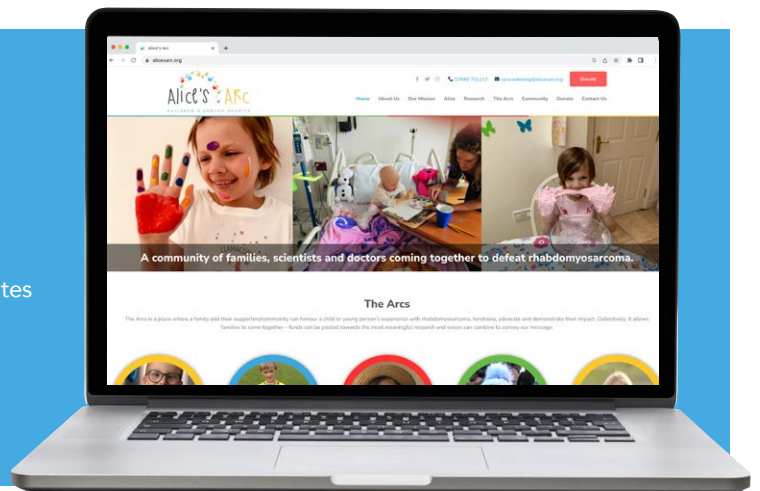
Please support Alice's Arc by making a donation at www.alicesarc.org

Together we are stronger

Other news

Launched a new version of our website

We were delighted to relaunch our modified website to the world. The new website reflects the Arcs model and comprises a webpage for each individual. It also incorporates a new page articulating our research strategy and the portfolio of research being funded. We believe this conveys the growth and strength of our platform.



Attended Childhood Cancer Debate in the House of Commons

On the 29th April 2022, Alice's Arc, along with Gaspard's and Will's mother attended this debate brought to the House of Commons by Dame Caroline Dinenage MP for Gosport following the work of Sophie's Mum (Sophie's Arc) who took the issue to Caroline and the Health Secretary (at the time), Sajid Javid.

Caroline set the scene with her vision for a childhood cancer mission to form part of the new UK 10 year Cancer Plan. She referred to childhood cancer as the 'Cinderella' of cancers and the 'backwater of cancer research.' 22 MP's across parties and geography shared their constituents experiences of childhood cancer.

Many families from the Alice's Arc had been driven to write to their MPs prior to the debate and the stories of Alice, Ebony, Elsa, Jessica, Oliver, Sophie and other children we knew were movingly told. We were very grateful to Sevenoaks & Swanley MP, Laura Trott for highlighting Alice's story and the work of Alice's Arc.

The calls for better investment for researching childhood cancers and particularly solid tumours such as rhabdomyosarcoma consistently arose. Watch this space for next steps!



Trustees reviewed the operational systems of Alice's Arc

This rapid growth led us to spend some time during the course of the year reviewing our operations and efficiency.



Developed Code of Conduct agreement's between each Arc and the charity.



Received our Fundraising Regulator mark.



Devised a formal Complaints policy.



Created an internal operations technology tool to enable the operational efficiency of Alice's Arc.



Co-founder, Sara Wakeling takes on Patient Advocate role for Cancer Grand Challenge, NexTGen

Sara was privileged to be involved in the grant application process and the interview with this incredible and passionate global team of scientists and patient advocates. Sara will now be involved in leading and implementing the patient involvement and engagement plan for the project.

Sara attended the launch summit in Washington DC on June 16th 2022 where the announcement was made that NexTGen had been successful in securing the £20million grant over five years, from **Cancer Grand Challenges**, a global initiative funded by Cancer Research UK and the National Cancer Institute in the USA. Sara was delighted to be part of the launch presentation alongside Co-leads Martin Pule, UCL and Catherine Bollard from Children's National Hospital, Washington DC.

"NexTGen represents crucial and overdue work. It has hope written all over it. NexTGen hopes to transform the way these aggressive solid tumours are treated with less toxic side-effects, giving the children a real chance at growing up and realising their potential. I'm so proud to be part of this exceptional team of scientists, clinicians and advocates who want to change the story for those diagnosed."

SARA WAKELING

NexTGen aims to tackle the challenge of childhood solid tumours by bringing next generation CAR T-cell therapies to children with solid tumours. The vision from Martin Pule is to ensure that these CAR T-cell therapies will be at the frontline within a decade. Central to the work is the launch of three early phase clinical trials – one in the UK and two in the USA. They will initially be focussed on rhabdomyosarcoma, ewings sarcoma and aggressive brain tumours.

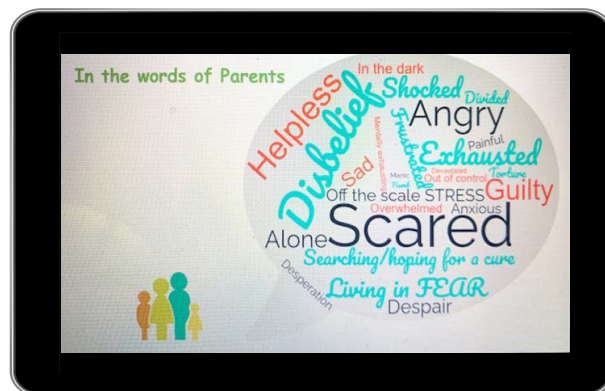


Alice's Arc presents the parent perspective at CCLG RMS education conference

In May 2022, CCLG hosted an in-person **two-day course** on rhabdomyosarcoma and other young onset soft tissue sarcomas. It was aimed at trainees in paediatric oncology, trainees in general paediatrics and other specialties involved in the management of these tumours. It brought together a community of expert rhabdomyosarcoma scientists and oncologists as presenters.

We were honoured to be invited to present on the parental perspective for rhabdomyosarcoma. It is a great pleasure to **represent the multitude of voices of children, young people and their families** impacted by rhabdomyosarcoma. This means articulating the perspective of those newly diagnosed, those on treatment, those who have lost their child, those off treatment and long-term survivors.

It was fantastic to tell the story of the Arcs and all the rhabdomyosarcoma families that we work with and why we have all come together. The oncologists are continuing to refer families to us who may be interested in creating an Arc or who want to be supported by other families with experience of rhabdomyosarcoma.



The course covered pathology, biology, radiology, staging and risk stratification, clinical trials, chemotherapy, palliative care, protons, brachytherapy, the role of the clinical nurse specialist, relapse, targeted treatments, the role of surgery for head/neck, abdominal and limb tumours and late effects and survivorship.

Alice's Arc features in the University of Birmingham's Old Joe magazine

We were delighted to feature in the **Old Joe magazine** alongside the Little Princess Trust and the Azaylia Foundation. The article showcased the rhabdomyosarcoma research we are funding there and our motivations for doing this work.



Sara Wakeling is Appointed Patient Advocate

Sara Wakeling has been appointed as a Patient Advocate on the **Novel Agent's Group** which forms part of the National Cancer Research Institute's (NCRI) Children's Group.





Alice's Arc receives press coverage in the Washington Post, USA

Participated in press interview with a freelance reporter writing a feature entitled '**To save children with cancer, doctors turn to new weapons**'. This was published in the Washington Post in August 2022 and considered the changing face of the landscape for childhood cancer and new initiatives brought about via advocacy such as incentivising pharmaceutical companies to focus on drug development for kids. It also introduced the work of the Cancer Grand Challenge, NexTGen. We were very proud that Alice's Arc was referenced in such a leading American newspaper.

Delivered well-being bags across UK hospitals

We were delighted to supply our family well-being bags to those impacted by rhabdomyosarcoma to **Great Ormond Street Hospital, Leeds Children's Hospital, Birmingham Children's Hospital, Addenbrookes, John Radcliffe, and the Royal Marsden.**

These bags contained items donated via the Arcs and are designed to be useful to the patient, their parents and siblings. This time we had all kinds of beauty items, toys, arts & crafts, sweet cones, branded badges & wristbands and other goodies. We were thrilled that multiple hospitals are now able to provide these to the rhabdomyosarcoma patients.



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 be expanding our platform internationally, starting with the USA.



Focus on embedding and growing the Arcs platform both in the UK & 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 pursue replicating the model internationally, starting with the USA.



Expand our rhabdomyosarcoma research portfolio:

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.



Engage our family community with research:

Continue to produce videos, interviews, education sessions and tools that help communicate findings and enhance understanding of the rhabdomyosarcoma research landscape.



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.



Sustain and expand fundraising initiatives

by maintaining relationships with current supporters and attracting new sponsors.





CHILDREN'S CANCER CHARITY

(A Charitable Incorporated Organisation)

Report and Financial Statements

For the Year Ended 30 September 2022

Charity number 1164253



Alice's Arc

Report of the Trustees for the year ended 30 September 2022

The trustees present its report and financial statements, examined by an independent examiner, for the year ended 30 September 2022.

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 Pettersen, Head of Systems, Risks, Controls and Assurance, 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 the purchase of medicine (as recommended by doctors), equipment, toys, facilities and/or services not provided by national health services or otherwise provided;
- (2) Funding research into rhabdomyosarcoma by working with UK research institutions such as the Institute of Cancer Research, UCL Great Ormond Street, Wellcome Sanger, the University of Birmingham and the University of York.
- (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 2022. 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 children with childhood cancers, in particular Rhabdomyosarcoma, as a class, and their families. The strategies we used to meet these objectives included:

- (a) **Devising & funding a diverse portfolio of rhabdomyosarcoma research projects.** These projects include the development of biological knowledge for fusion negative disease, identifying biomarkers that can be targeted with drugs, devising immunotherapy treatment options via CAR T-cell therapy for rhabdomyosarcoma, using liquid biopsies in the detection & prediction of rhabdomyosarcoma, understanding relapsed & 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.
- (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.
- (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 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 **£2.6 million** to date in incoming resources to meet disbursal and other commitments, over **£700K** of which since 30 September 2022.

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 £670,112 including Gift Aid. This enabled total disbursements of £392,842: £217,667 to the Institute of Cancer Research, £81,135 to the University of Birmingham, £56,773 to the Wellcome Sanger Institute, £33,391 to EpSSG, and £3,875 to the University of Ulster, bringing total disbursements to cancer research organisations to the end of September 2022 to £978,199. After these disbursements, total funds of the charity stood at £859,596 as at 30 September 2022.

Principal Funding Sources

The funding sources for Alice's Arc are from individual and corporate donations. None of the funds of the charity were restricted in the year.

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 £100 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.

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 35.

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 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 Pettersen was appointed as the charity's independent 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 1st January 2019.

Approved by the trustees on **18 June 2023** 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 2022

	Notes	Unrestricted Funds to 30/9/22 (£)	Unrestricted Funds to 30/9/21 (£)
Incoming resources			
Voluntary income: donations	2	661,155	502,359
Gift Aid on donations	7	7,738	3,798
Investment income		1,220	101
Total incoming resources		670,112	506,258
Resources expended			
Costs of generating voluntary income	3	19,863	13,104
Charitable activities		392,842	240,160
Governance costs	3	-	-
Total resources expended		412,706	253,263
Net Income for the year		257,407	252,995
Reconciliation of funds			
Total funds brought forward		602,189	349,194
Total funds carried forward		859,596	602,189

All incoming resources and resources expended derive from continuing activities.

Balance Sheet as at 30 September 2022

	Notes	30/9/22 (£)	30/9/21 (£)
Fixed Assets		-	-
Current Assets		859,596	602,189
Debtors	7	15,475	48,215
Cash at bank and in hand		844,121	553,974
Creditors		-	-
Net Assets		859,596	602,189
General Funds		859,596	602,189
Total Funds		859,596	602,189

Statement of Cash Flows for the year ended 30 September 2022

	30/9/22 (£)	30/9/21 (£)
Net income/(expenditure)	257,407	252,995
Adjustment for: Dividends, interest, rents	(1,220)	(101)
Change in debtors	(32,740)	(40,446)
Cash flow from operating activities	288,927	212,448
Dividends, interest and rents	1,220	101
Cash flow from investing activities	1,220	101
Cash from financing activities	-	-
Beginning of the reporting period	553,974	341,425
End of the reporting period	844,121	553,974
Change in cash and cash equivalents	290,147	212,549

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 1st January 2019

Approved by the trustees on **18 June 2023** and signed on its behalf by:

Mr Nick Wakeling (Treasurer)

Notes forming part of the Financial Statements for the year ended 30 September 2022

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 on 1 January 2019.

(b) Fund accounting

- 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

All donations received are unrestricted. 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. 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

£19,863 costs of generating voluntary income comprises: £11,634 for fundraising events and promotions including marathon places, £4,169 for legal and insurance costs including formalisation of the charity's fundraising code, £3,116 for website and other IT costs, and £944 for postage, design and print, and other miscellaneous items.

£392,842 charitable activities comprise: £217,667 to the Institute of Cancer Research, £81,135 to the University of Birmingham, £56,773 to the Wellcome Sanger Institute, £33,391 to EpSSG, and £3,875 to the University of Ulster.

The independent examiner received no remuneration in scrutinising this report.

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

£15,475 debtors comprise £6,507 donations held with fundraising platforms as at 30 September 2022 and £8,968 Gift Aid on donations received to which the charity is entitled and expects to recover from HMRC within one year. No Gift Aid was claimed/received from HMRC during the year to 30 September 2022 in respect of donations made in this period and in the previous year.

Independent examiner's report to the trustees of Alice's Arc

I report on the accounts of the Trust for the year ended 30 September 2022, which are set out on pages 44-49.

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 Pettersen

Relevant professional qualification or body: ICAEW

Address: 1 Southampton Row London WC1B 5HA

Date: **18 June 2023**





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078 8070 1217



sara.wakeling@alicesarc.org



CHILDREN'S CANCER CHARITY