

Alice's Arc Annual Report

2020–2021





Charity number 1164253



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Annual review


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A message from our CEO

Rhabdomyosarcoma is relentless. It, or at least our understanding of it, is constantly evolving. BUT, Alice's Arc is a determined and passionate platform. We have experienced unprecedented growth, with the launch of the Arcs. This year we formed six new family Arcs across England and Northern Ireland. This has led to another groundbreaking year of fundraising (£506k) and the consequent expansion of our rhabdomyosarcoma research portfolio.



Cancer is the number 1 killer of children under the age of 14. On average, there are 70 potential years of life lost when a child dies of cancer. Our motivation is the fight for the gift of a child's life. They deserve the opportunity to grow up and live life. Sadly, four families we work with lost their children to rhabdomyosarcoma. Hugh, aged 6. Oliver, aged 6. Sophie, aged 10. Will, aged 20. Each family raised significant funds in memory of their children.

There are families where children continue to do well after treatment. However, 95% of these children will have a significant health-related issue by the time they are 45. We must do more to mitigate the impact of the current gruelling treatment regimes.

We have expanded our research portfolio. We are proud to have rhabdomyosarcoma projects covering fusion negative disease, devising a liquid biopsy, CAR T-cell development and identifying new drugs to target bio-markers. Additionally, we will co-fund a project on decision-making at the point of relapse with the Children's Cancer and Leukaemia Group (CCLG). We have also agreed to fund a Project Manager and Statistician role at the European Paediatric Soft Tissue Study

Group (EpSSG). These are vital to ensure effective analysis of the data from treatment protocols feeds into future clinical trials. We continue to investigate new projects that might unlock preclinical biological information and contribute to the development of new treatments.

The future is promising. We are driven by the hope that children diagnosed with rhabdomyosarcoma will be able to access more diverse, kinder treatment options that offer the chance of a cure. We won't stop. Families continue to engage with our platform. It offers a home and a space to constructively engage when faced with the complexity of rhabdomyosarcoma.

Finally, as ever, we are indebted to all the families, friends and communities who have supported us this year. Our progress would not be possible without you. Together we are stronger. Let's keep going together.



Sara Wakeling



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.

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.

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.

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.

Share findings across existing platforms for paediatric solid tumours.

About Rhabdomyosarcoma

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



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



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



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



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



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



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



What treatment is available?

Current treatments involve a combination of surgery (if possible), intensive chemotherapy, maintenance chemotherapy and radiation (proton, photon, brachytherapy). Where a known biological marker is discovered via sequencing, tailored drugs may also be available.

The 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 11 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.

Launch: The Arcs

Why are we creating the 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 Arcs can:



Ensure that research is parent-led and addresses the needs of families diagnosed in the future.



Research is complex and expensive – pooling funds together allows scientists to formulate more comprehensive research proposals with clinical translation and allows a pipeline of research to evolve from projects.



Support families. Our community of rhabdomyosarcoma parents, patients and siblings can offer support to newly diagnosed families, those on treatment, those in remission, those on palliative care, survivors and those suffering the loss of their child.



"The world of childhood cancer is very lonely. Alice's Arc provides a community of support and a platform to share Mollie's story. I hope this can create hope for newly diagnosed families"

FIONA MULHOLLAND, MOLLIE'S ARC



What is an Arc

And so, we have launched our Arcs platform. The Arcs is a unique concept where a family is offered a space to share their child's journey with rhabdomyosarcoma, a place where a family and their supporters/community can honour a child or young person's experience with rhabdomyosarcoma. They may be newly diagnosed, off treatment, a long-term survivor or they may have passed away. Each Arc can fundraise, advocate and demonstrate their impact in their child's name. Collectively, it allows families to come together – funds can be pooled towards the most meaningful research, voices can combine to convey our message and support can be offered as families navigate this complex path.

We are delighted to have launched with 6 Arcs across England and Northern Ireland. We created a video setting out the rationale for launching the Arcs. We were delighted to have soundbites from a collection of the Scientists we work with and the Arc families to illustrate our mission.

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.



"Elsa's Arc has become an integral part of our grieving process. Fundraising in Elsa's name contributes to keeping her memory alive. By working with Alice's Arc and the Arcs network we hope to make a collective difference to families who will experience rhabdomyosarcoma in the future."

HAYLEY MCGEE, ELSA'S ARC

Elsa's Arc for Elsa who died aged 6 in April 2020, note Elsa's beautiful rainbow symbol drawn by none other than Elsa McGee.



Freddie's Arc for Freddie who passed away aged 5 in October 2018. Freddie is represented by his trusty cuddly bunny, Rufus, who accompanied him wherever he went.



Gaspard's Arc for Gaspard who finished maintenance treatment in January 2021 and is now aged 7. Gaspard's image is of his favourite animal, a tiger.



Mollie's Arc for Mollie who finished treatment in January 2020. Mollie chose to have a picture of her pet guinea pig as her mascot.



Jessica's Arc for Jessica who died in October 2019 aged 9. Jessica had a love of all things horses so her family wanted a beautiful unicorn to represent her Arc.



Sophie's Arc for Sophie who died aged 10 in September 2021. Sophie designed her Arc before she passed away and picked an image of her toy penguin as her motif.



Arcs: The future

We have been delighted with the interest shown from families to work together and to create Arcs. We will be announcing the formation of more new Arcs over the next year. There is also international interest in this model and we will be exploring the feasibility of implementing this. 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. 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 **Sophie** and **Will**, who lost their lives to rhabdomyosarcoma. Alice's Arc will always remember you and talk about you. You are the inspirations for our work.

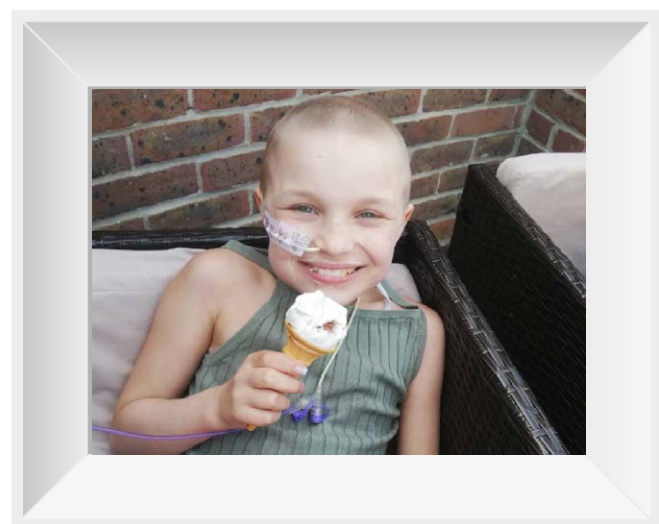
Sophie Fairall

12th August 2011 to 18th September 2021

Snapshot of her story:

Sophie, aged 9, was diagnosed with anaplastic, fusion negative rhabdomyosarcoma in her abdomen, in September 2020.

Having just started maintenance chemotherapy, a new tumour started to grow close to the original site. Sophie, passed away on 18th September, 2021, aged 10.





Fundraising for Sophie:

£84k

Sophie's public campaign received over £84k in donations, in memory of her life.

£8.5k

In June 2021, six members of Sophie's family walked 55kms from Guildford to Fareham

(see fundraising highlight)

£5k

Sophie's family generously donated £5k

£3.8k

Sophie's school Crofton Anne Dale ran a Be Bold. Go Gold day.

Sophie's impact



Sophie's mother wrote a blog entitled 'Sophie's Journey'. It was an honest and brave account of Sophie's experience from diagnosis through to death. It attracted attention across the UK with celebrity, politician and media involvement. Her community became avid supporters of Sophie and so many local businesses conducted fundraising events.



Sophie started a ceramic painting initiative whilst in hospital and this triggered her very own fundraising initiatives.



Sophie was very clear about what she wanted to be changed. She wanted play specialists in hospitals 7 days a week, improvements in hospital food, parents to be fed in hospital, for GPs, nurses and health professionals to be trained in childhood cancer and more funding going towards childhood cancer research. Alongside, Sophie's Arc, Sophie's mother has recently launched a charity called Sophie's Legacy.



Sophie's family want to see new treatment options and enhanced understanding about rhabdomyosarcoma. In particular, they want to see research into anaplastic, fusion negative disease which Sophie had.



William
Ruff

15th January 2001 to 21st February 2021

Snapshot of his story:

William, aged 16, was diagnosed with alveolar rhabdomyosarcoma, in April 2017. He fought valiantly for four years and remained incredibly positive during his battle with this relentless and horrendous disease. Sadly, William passed away on the 21st February 2021 at 2:50am, aged 20, surrounded by his family and fiancée.



Will's impact:



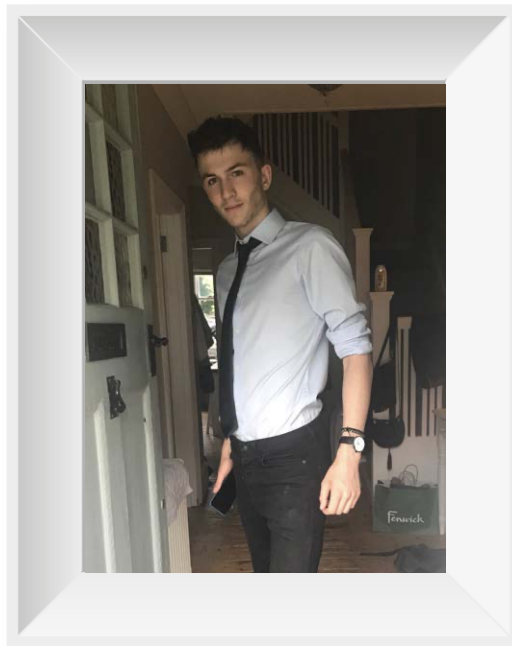
Will's family are launching Will's Arc shortly. Will's story creates a voice for teenagers who are diagnosed with rhabdomyosarcoma. It's important to remember to represent the teen and young people population who experience the disease too.



Will has brought a community together. They want to engage in making constructive change for those impacted by rhabdomyosarcoma. They have been touched by Will's story and want to fundraise and raise awareness in Will's name.



Will's family want to see new treatments designed for treating rhabdomyosarcoma. They are interested in research relating to the development of CAR T-cell therapies for rhabdomyosarcoma and making progress towards understanding metastatic fusion positive disease.



Fundraising for Will:

OVER
£3k

raised as part of Will's funeral service

£15k

in personal donations from Will's family and friends

OVER
£3.2k

Will's friend, **Hollie Riordan** shaved her head and secured over £3.2k

£2k

Will's school, **Aldenham** in Hertfordshire conducted several events

Will's friend, actress, **Georgia Hirst**, became an advocate for Alice's Arc and used her social media platform to raise the profile of the charity and to raise funds.



Our year at a glance



Research Focus

We donated **£240k** towards rhabdomyosarcoma research during this time period.

£124k

to the University of Birmingham

for year one 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.

£49k

to ICR for year one of a research project

exploring the use of liquid biopsies in the treatment of children with rhabdomyosarcoma. The overall goal is to improve outcomes for patients through prediction and early detect of relapse as well as to identify and assess novel treatments in the relapse setting. Alice's Arc has now donated **£394k** towards rhabdomyosarcoma research at the ICR.

£67k

to UCL Great Ormond Street Institute of Child Health

for year one of a research project entitled '**Identification and evaluation of foetal immune targets in rhabdomyosarcoma**'. This work is part of project that has been funded via an innovation grant through Cancer Research UK in conjunction with Children with Cancer UK. Work also involves Wellcome Sanger and the Institute of Cancer Research (ICR). Alice's Arc has also agreed to fund the ICR work package that will look at maturation targets and resistance models that will lead towards clinical translation. The overall goal is to develop a CAR T-cell treatment for rhabdomyosarcoma.



We have 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 projects:



The Investigation of the MYOD1 L122R mutation in fusion negative rhabdomyosarcoma and how it can be targeted. MYOD1 L122R is a particularly aggressive mutation that can be present in fusion negative rhabdomyosarcoma. The work will aim to understand the impact of the mutation on rhabdomyosarcoma cells and to screen and validate new treatment options to target it therapeutically. This will be conducted by Professor Janet Shipley's laboratory at the ICR for a period of three years commencing in March 2022.



Identification and evaluation of foetal immune targets in rhabdomyosarcoma. This was highlighted above and relates to a new work package as part of this project. This work will assess the targets identified in an earlier work package in model systems of rhabdomyosarcoma. This will be led from Professor Janet Shipley's laboratory at the ICR for 18 months starting in February 2022.



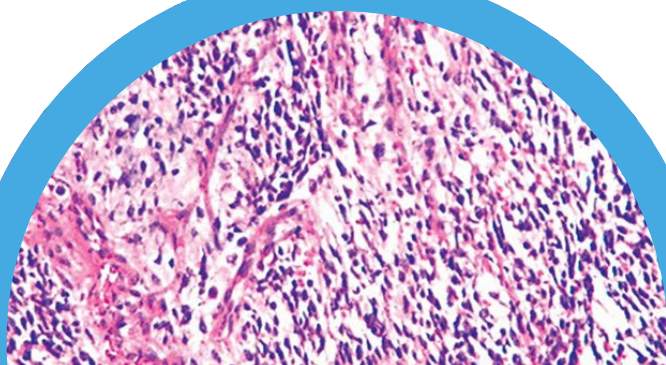
Living REFoRMS – A living systematic review of early phase studies for children and young people with relapse and refractory rhabdomyosarcoma.

This will be co-funded with the Children's Cancer and Leukaemia Group (CCLG). The output of this work will be the development of a high-quality, regularly updated, online resource to share the findings from the review of studies into new treatments. A steering group of families with relapse/refractory rhabdomyosarcoma experience and professionals in this area will meet regularly to offer guidance. The work will be led from the University of York and commence in July 2022 for three years.



Research enabler roles at the European Paediatric Soft tissue sarcoma Study Group (EpSSG) –

We have agreed to fund two roles (Scientific Manager and Statistician) supporting the EpSSG. They aim to promote and manage clinical trials, encourage and facilitate clinical and basic science research, foster optimal standards of care, organise educational meetings for its members and other professionals and advocate for patients. The roles commence on 1st January 2022 and will last for one year initially.



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 PostDoc working on the liquid biopsy work at the ICR produced a video describing this. 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.



Fundraising highlights

London Landmarks Half Marathon 2021

10 runners took on this challenge in support of Alice's Arc and it was so touching to cheer the team on. On Sunday 1st August 2021, a team of ten runners took on the challenge of the **London Landmarks Half Marathon**. This is a truly magical event bringing together such important charities and causes and it was a pleasure to have an Alice's Arc team there for the first time.

The team comprised several fathers running in honour of their children – David Wakeling for Alice, Andy Stewart for Ruby, Declan Mulholland for Mollie and Simon-Peter Edwards for Esther. In addition, several family members ran for Faye. Other runners included Angela Clist, a work colleague of David and two 17 year old girls who attend the school that Alice attended.

£20k



Jessica's Charity Raffle

Jessica's Arc charity raffle attracted enormous support from her friends, family and community, raising an enormous £7k in memory of Jessica Macqueen. They sold 2,400 tickets over three weeks, with the grand draw taking place on 15th July 2021. Prizes included a Dyson Hair Dryer, Nintendo Switch Lite, tickets to the Harry Potter Studio Tour and many more kindly donated.

£7k

£8.5k



55km walk in recognition of Sophie Fairall's fight with Rhabdo

Sophie's aunts, uncles, eldest sister and cousin decided to undertake this challenge to support rhabdo research. On the weekend of 19th to 20th June 2021, six members of Sophie Fairall's family walked over 55km from Guildford to Fareham.



Little Tigers Charity Raffle For Gaspard

Hope With Gaspard/Gaspard's Arc sold 2500 tickets with incredible prizes such as a Louboutin bag, VIP festival tickets and much more. Sales of tickets generated a huge £16k. They managed to secure an enviable prize list including a luxury hamper from a French fashion house, VIP festival tickets and many more including jewellery, concert tickets, wine and champagne. Over 2500 tickets were sold over three weeks and the grand draw took place on the 23rd May 2021.

£16k



Ben's New Forest Rattler

48 people ran, biked and swam to raise money for Alice's Arc, The GOSH charity and Spread a Smile. Ben Jarvis was diagnosed with alveolar rhabdomyosarcoma in July 2020 and is being treated under the care of Great Ormond Street Hospital. He endured nine intensive cycles of chemotherapy, two operations and 23 radiotherapy sessions. He has now finished maintenance chemotherapy.

Ben's family decided to devise a fundraising event to celebrate how far Ben has come. They chose to participate in a variety of events at the New Forest Rattler on the 5th June 2021. Their daughters Daisy and Ellie, along with Ben's grandmother, did a 5k run. Ben's mother ran a half marathon and Ben's father cycled 130k. Many of their family and friends also joined them creating a team of 48 people testing their sporting prowess. They raised an absolutely enormous £60k.

In honour of Ben's journey with rhabdomyosarcoma, they identified three charities to split the funds between. We are so delighted that they choose Alice's Arc as one of their charities, alongside the fantastic Great Ormond Street Charity and Spread a Smile, who so successfully entertain seriously ill children during hospital visits and stays.

£20k

PLAN.COM TURN PINK FOR JESSICA'S ARC

Staff at Plan.com were invited to wear pink on Friday 6th November 2020 in memory of Jessica Macqueen, who passed away from rhabdomyosarcoma in October 2019, aged 9. This is the second annual 'pink' fundraiser and we are delighted for their continued support.

£8k



£4.5k

Virtual London Marathon

On the 4th October 2020, Phil and Vicky Macqueen ran a 26 mile marathon as part of the first ever virtual London Marathon due to Covid-19. They ran in memory of their niece Jessica Macqueen. They completed the mammoth run in 4hrs 40minutes and 3 hours 30minutes respectively, raising £4.5k between them. They received tremendous support along the way with supporters handing out jelly beans and sporting 'for Jess' banners' to spur them on. Special thanks to Dixie Grammar School in Leicestershire who donated £600.



OVER
£23.2k

Corporate Donations

We are incredibly grateful to the companies that have and continue to support us. Also, to all the companies that offer matched giving.

This year we received £20k from **Allen & Overy**. This is an annual grant from the international law firm who have supported Alice's Arc since inception.

£20k

OVER
£3.2k

Through Gaspard's Arc we received £3.25k from **Bullion Vault** and a donation from **ICAP**.



£1.3k

Virtual Gingerbread Making Christmas Fundraiser

People were invited to showcase their gingerbread baking and decorating skills to raise funds for Christmas 2020. We received over 60 entries included Christmas

gingerbread men, Christmas gingerbread biscuits and gingerbread houses.

A shortlist of 5 entries were put to a facebook vote and the winners received prizes from the Biscuiteers and branded Chillies water bottles.



OVER
£4.4k

Head Shave for Jack

Jack's family and friends shaved their heads in honour of Jack, after he was diagnosed with rhabdomyosarcoma in November 2020. We are so grateful to Jack's family, friends and community for raising an enormous £4.4k in recognition of Jack's bravery.



Childhood cancer awareness month (CCAM)



Schools 'Go Gold'

Schools from Alice's Arc, Elsa's Arc, Freddie's Arc, Mollie's Arc and Sophie's Arc had 'Go Gold' school events. Walthamstow Hall School and New Beacon, in Sevenoaks had 'Go Gold' days involving ice cream vans, wear something gold to school, sales of sweet cones and gold merchandise. Crofton Anne Dale School in Stubbington had 'Go Gold' stalls selling a range of 'Alice' bows, Elsa's candles, Mollie's lip balms, customised Arc wristbands, sweet cones and more. Support from schools is so important every September and every school touched by a cancer story wants to help.



'Go Gold' products from the Arcs

Many of the Arcs created a product for the network to sell during the month of September. Gold Alice bows, Elsa's candles, Mollie's lip balms, wristbands, gold awareness ribbons, sweet cones, to name a few.



Sevenoaks, Kent 'Goes Gold'

We are always so grateful for the support of Alice's community. This year local, MP, **Laura Trott** helped us increase awareness throughout Sevenoaks.

She got **Sevenoaks train station** involved and they displayed posters and banners throughout September. They also held a bake sale and enabled a 'gold stall' to pop up several times during September.

A group of local mothers also walked the High Street of Sevenoaks to encourage local shops and businesses to showcase awareness posters about childhood cancer and rhabdomyosarcoma. We were overwhelmed by the support and it was a pleasure to walk through the High Street during the month of September.

UK Landmarks 'Go Gold'

In **Belfast**, **Leeds** and **Portsmouth** landmark buildings turned gold in recognition of children with cancer.



Arcs 'Go Gold' social media campaign

We ran a social media campaign throughout our family network raising awareness of the facts and figures of childhood cancer and rhabdomyosarcoma specifically.



Other news

Devised a video to launch the Arcs family platform

It was such a pleasure to bring together our community of Alice's Arc scientists, medical professionals and new Arcs in a series of interviews that culminated in the production of a five minute video illustrating the work of the charity and the motivations for the development of the Arcs. This was circulated across all our networks.



Logo designed for FaR-RMS trial by a young cancer survivor after input from parents, patients, clinicians and scientists

Alice's Arc worked on this project in conjunction with members of the Royal Marsden NHS Foundation Trust, Youth forum and several rhabdomyosarcoma survivors recruited through Alice's Arc.

This involved four focus groups involving an introduction to the trial, brand development, target audience, idea generation, activity sessions, logo reviews and development. One of the young cancer survivors, Joshua Stedford, is an aspiring graphic designer and he worked with professional graphic designers at international law firm, Allen & Overy on the design of concepts.

Three logos were short listed and various stakeholders were consulted for feedback. These included parents, patients (children and young people), clinicians and scientists.



FaR-RMS
Frontline and Relapse
RhabdoMyoSarcoma study

In the end, opinion was split between two options. The final decision-making factor came down to the fact that the chosen logo was designed by Joshua, the young cancer survivor.

The tree logo represents hope, growth and life. The leaves resemble a central attack or blasting of cells within a tumour converging at a single point. The tree stump represents a wishbone conveying the concept of good luck for a patient embarking on the trial. The blue colour represents the medical community, the yellow/gold expresses the hope and optimism a clinical trial can bring, and the orange is meant to be playful for the younger audience.

The FaR-RMS acronym has been annotated to make it clear what the trial is about.

"We are delighted with the newly designed logo representing the FaR-RMS clinical trial. This project involved impressive collaboration with multiple stakeholders across Europe. It is particularly fitting that the chosen design was by a young aspiring graphic designer who is a young cancer survivor."

PROFESSOR MERIEL JENNEY, CHIEF INVESTIGATOR, FaR-RMS

"The logo is more than just an icon. It represents our group's first hand experience of cancer treatment. Personally, the process allowed me to grow as a designer and benefit from the input of the professional designer."

JOSHUA STEDFORD,
JUNIOR GRAPHIC DESIGNER

Created WhatsApp support groups for our community of rhabdomyosarcoma families



There is nothing like being in the company of families who understand everything there is to know about the complexity of having a child with rhabdomyosarcoma. This is a safe, supportive space where there is mutual understanding and sharing of experiences that help a family feel less alone. Anything can be shared from medical and scientific questions to feelings, frustrations and logistical considerations.

Alice's Arc features in the Institute of Cancer Research's Search magazine (March 2021)

We were delighted to feature in the ICR's Search magazine which is published twice a year. The article showcased the rhabdomyosarcoma research enabled by the funds raised by the charity. It highlighted details of the pledge of £600k that we made in early 2021. This sum has now risen with the addition of future projects that have been agreed (see Research Focus)

Alice's Arc pledges more funds to childhood cancer research

Alice's Arc is a children's cancer charity set up by Sara and David Wakeling following their daughter Alice's diagnosis with stage four rhabdomyosarcoma. Alice was three when she was diagnosed and died two weeks before her 8th birthday in 2019.

The charity is dedicated to funding research to find a cure and better treatments for rhabdomyosarcoma, the most common type of sarcoma found in the soft tissues of children.

We are delighted that Alice's Arc has chosen to support us for a further three years with a pledge of more than £600,000.

“Cancer is a devastating disease for anyone to have to experience, but it seems particularly unfair that children, who ought to be able to grow up happy and carefree, should have to endure such a cruel burden. I am determined to do whatever I can to help alleviate that burden. I am incredibly proud and grateful to have the continued support of Alice's Arc.”

Dr Olivia Ruhen

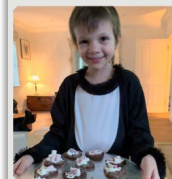
Christmas appeal raises £150,000

We are hugely grateful to all of you who kindly supported our Christmas appeal. So far an incredible £150,000 has been donated to help get Dr Alexandra Drury's research into childhood cancers up and running.

Dr Drury is a new Team Leader, based in our Centre for Cancer Drug Discovery. Her team use cutting edge 'avatars' to replicate a child's cancer in the lab. These avatars, which are at the forefront of personalised cancer medicine, will help them to understand how childhood cancers adapt and become resistant to treatments.

With major fundraising events cancelled and cuts to our research grants as a result of the pandemic, your support is more important than ever to make sure that cancer patients don't get left behind.

There is still time to donate to our childhood cancer appeal. Visit www.icr.ac.uk/hopeforchildren



Alice Wakeling

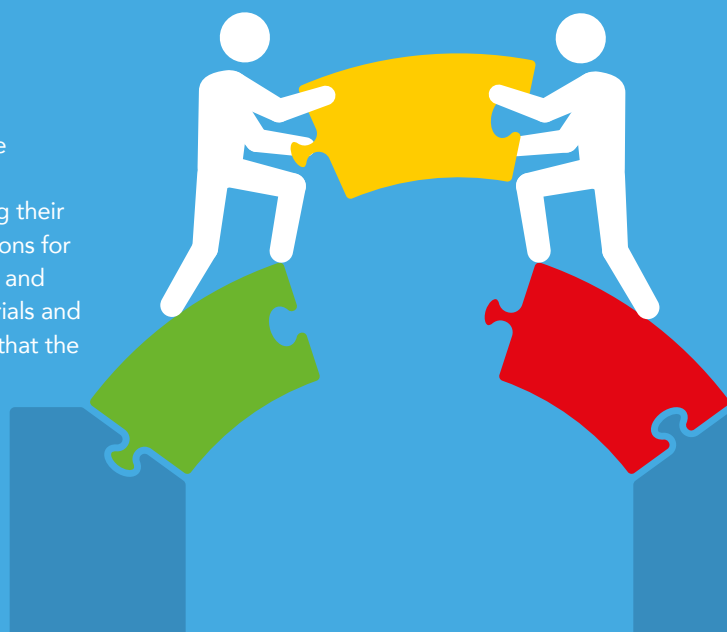


We opened a Paypal account to provide another platform for those donating and fundraising.

CEO, Sara Wakeling takes on several Patient Public Involvement/ Engagement (PPIE) roles

The role that patients/parents can play in scientific research is an evolving, yet highly important one. It's an opportunity to bring the perspective of children, young people and families impacted by childhood cancer and to remind the researchers of the why driving their research. Typical responsibilities may include writing communications for grant applications or for clinical trials in plain language, validating and informing research questions, inputting on the design of clinical trials and ensuring that research findings are shared widely and in a format that the patient, family and public communities can engage with.

Sara joined the parent/patient group of the EpSSG in December 2020. She also joined the REFORMS project. This is being led by researchers at the University of York and is designed to understand the treatment decision-making processes in families where a child has relapsed or refractory rhabdomyosarcoma.



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.



Focus on embedding and growing the Arcs platform:

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. Explore how the Arcs model could work internationally.



Expand our rhabdomyosarcoma research portfolio:

Pursue new opportunities for projects in areas such as fusion positive rhabdomyosarcoma where outcomes are dismal. 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 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.



Sustain and expand fundraising initiatives by maintaining relationships with current supporters and attracting new sponsors.





(A Charitable Incorporated Organisation)

Report and Financial Statements

For the Year Ended 30 September 2021

Charity number 1164253



Alice's Arc

Report of the Trustees for the year ended 30 September 2021

The trustees present its report and financial statements, examined by an independent examiner, for the year ended 30 September 2021.

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, Head of Financial and Regulatory 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

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 such cancers by working with institutions like the Institute of Cancer Research, Great Ormond Street Hospital and the Royal Marsden to fund teams and equipment required to undertake research;
- (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 2021. 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) **A collaboration with the University of Birmingham with disbursements in year amounting to £124,056.** This looks at fusion negative Rhabdomyosarcomas and the role of RAS genes within this patient cohort.
- (b) **A collaboration with the UCL Great Ormond Street Institute of Child Health and the Wellcome Sanger Institute amounting to £66,975.** This looks at an immunotherapy treatment approach applying a new method of treating Rhabdomyosarcoma using a CAR T cell which has already been trialled on other childhood cancers such as Leukaemia and Neuroblastoma.
- (c) **A collaboration with the Institute of Cancer Research with disbursements in year amounting to £49,128.** The money is being used for a project exploring the use of liquid biopsies in the treatment of children with rhabdomyosarcoma. The aim will be to validate new prognostic biomarkers and to monitor the emergence of relapse or resistance in order to adapt therapy accordingly.
- (d) **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.
- (e) **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.

The charity has now raised or received commitments for over **£1.8 million** to date in incoming resources to meet disbursal and other commitments, over **£600K** of which since 30 September 2021.

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 backdrop of limited resources and 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 third year in operation, with income of £506,258 including Gift Aid. This enabled total disbursements of £240,160, £124,056 to the University of Birmingham, £66,975 to UCL, and £49,128 to the Institute of Cancer Research, bringing total disbursements to date to £585,357. After these disbursements, total funds of the charity stood at £602,189 at the end of the year to 30 September 2021.

Principal Funding Sources

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

Investment Policy

Most of the charity's funds are currently expected to be applied to the clinical research in collaboration with the Institute of Cancer Research, The Great Ormond Street Hospital and the Royal Marsden NHS Foundation Trust 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 is exploring 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, The Great Ormond Street Hospital and the Royal Marsden NHS Foundation Trust. 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 27](#).

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 Hagell 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) issued on 1 January 2019.

Approved by the trustees on **18 June 2022** 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 2021

	Notes	Unrestricted Funds to 30/9/21 (£)	Unrestricted Funds to 30/9/20 (£)
Incoming resources			
Voluntary income: donations	2	502,359	335,945
Gift Aid on donations	7	3,798	2,752
Investment income		101	1,445
Total incoming resources		506,258	340,142
Resources expended			
Costs of generating voluntary income	3	13,104	26,446
Charitable activities		240,160	68,784
Governance costs	3	-	-
Total resources expended		253,263	95,229
Net Income for the year		252,995	244,912
Reconciliation of funds			
Total funds brought forward		349,194	104,282
Total funds carried forward		602,189	349,194

All incoming resources and resources expended derive from continuing activities.

Balance Sheet as at 30 September 2021

	Notes	30/9/21 (£)	30/9/20 (£)
Fixed Assets		-	-
Current Assets		602,189	349,194
Debtors	7	48,215	7,769
Cash at bank and in hand		553,974	341,425
Creditors		-	-
Net Assets		602,189	349,194
General Funds		602,189	349,194
Total Funds		602,189	349,194

Statement of Cash Flows for the year ended 30 September 2021

	30/9/21 (£)	30/9/20 (£)
Net income/(expenditure)	252,995	244,912
Adjustment for: Dividends, interest, rents	(101)	(1,445)
Change in debtors	(40,446)	(2,752)
Cash flow from operating activities	212,448	240,716
Dividends, interest and rents	101	1,445
Cash flow from investing activities	101	1,445
Cash from financing activities	-	-
Beginning of the reporting period	341,425	99,264
End of the reporting period	553,974	341,425
Change in cash and cash equivalents	212,549	242,161

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) issued on 1 January 2019.

Approved by the trustees on **18 June 2022** and signed on its behalf by:

Mr Nick Wakeling (Treasurer)

Notes forming part of the Financial Statements for the year ended 30 September 2021

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) issued 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

2. Donations and Gift Aid

All donations received are unrestricted. Gift Aid receivable 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

Costs of generating voluntary income comprises £3,506 for materials (primarily charity-branded facemasks, wristbands and running vests), £3,143 in supplier charges for fundraising events including marathon places, £3,000 for a new website (part-funded by a direct donation), £2,180 for press and video promotion, £662 in fees to Virgin Money, Just Giving and other donation platforms, £138 for postage, £78 for design and print, £397 for other miscellaneous items.

Charitable activities comprise £240,160, relating to the charity's ongoing collaboration with the University of Birmingham £124,056, UCL £66,975, and the Institute of Cancer Research £49,128 on childhood Rhabdomyosarcoma.

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

Debtors comprise £46,985 donations held with fundraising platforms as at 30 September 2021 and £1,230 Gift Aid on donations received to which the charity is entitled and expects to recover from HMRC within one year. £10,337 Gift Aid was claimed from HMRC during the year to 30 September 2021 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 2021, which are set out on pages 34-39.

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

Address: 1 Southampton Row London WC1B 5HA

Date: **18 June 2022**





Please get in touch:



alicesarc.org



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