

Alice's Arc Annual Report

2019-2020





Charity number 1164253



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A message from our CEO

The world of rhabdomyosarcoma is never easy. It brings great complexity and loss. However, this energises us, and we have experienced unprecedented growth and renewed hope during this period.

Personally, the year has been very difficult. Alice passed away on the 8th October 2019, almost five years after her fight began. Her second relapse was found in August 2019 appearing in her abdomen and pelvis, an area where cancer had not been detected before. She was given weeks to live. To watch our little girl deteriorate, knowing that there were no existing feasible, curative treatment options available to her, will haunt me for the rest of my life. Her loss runs deep and motivates us to achieve breakthroughs for the families and children unlucky enough to experience a rhabdomyosarcoma diagnosis.

Other families have also experienced the devastating losses of their children. Jessica MacQueen, aged 9 and Elsa McGee, aged 6. We work very closely

with both these families and they have made significant contributions to our fundraising pool. Elsa's Trust has entrusted £30k to Alice's Arc and Jessica's community raised £20k after her death, in addition to other fundraising activities.

We formed a relationship with HopeWithGaspard, who are fundraising exclusively for Alice's Arc in honour of their son, Gaspard's experience with rhabdomyosarcoma. Gaspard is doing well and almost one year off treatment.

We broadened our connections with rhabdomyosarcoma families across the UK, Ireland, Europe, the US, Canada and Asia. They may be newly diagnosed, relapsed, survivors, stable or bereaved. Every family has a voice in this fight.



This year, the backdrop of Covid-19 created uncertainty. Yet, through all the loss and added challenges, we managed to have a record-breaking year of fundraising, with £340,142 raised, doubling our total from last year.

We hosted several events prior to the first lockdown in March 2020. These included 'Go gold' casino night and 'Active for Alice'. We sold Alice's Arc face masks, running vests and wristbands to sustain fundraising. Additionally, there were multiple 'virtual' sporting fundraising initiatives. Childhood cancer awareness month (September 2020) was also a great success raising awareness and generating £30K.

Research is vital to achieving our mission. We have continued to provide the Institute of Cancer Research with funds. We have revisited our research priorities and broadened our relationships across UK research institutions. In addition, we have pledged £1.2 million for five

rhabdomyosarcoma research projects commencing in 2021 and spanning three years.

The future is exciting. We are driven by the hope that children diagnosed with rhabdomyosarcoma will be able to access more diverse, kinder treatment options that offer a cure. We won't stop. We have ambitious plans to engage other families experiencing rhabdomyosarcoma.

Together we are stronger.

Finally, as ever, we would like to thank all those who have supported us this year. It wouldn't be possible without you. Let's keep going together.



Sara Wakeling

Sara Wakeling




Our goals

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.

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

Through our work, in collaboration with major research institutions, clinicians and families, we present a global rhabdomyosarcoma voice advocating for change and a future where this disease can be cured safely.

 ICR The Institute of Cancer Research


 UNIVERSITY OF BIRMINGHAM


 wellcome sanger institute


 UCL
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

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. Outcomes are influenced by the location, staging, fusion gene status and disease subtype.

 **The two main types are known 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.



What treatment is available?

Current treatments involve a combination of surgery (if possible), intensive chemotherapy, maintenance chemotherapy and radiation (proton, photon, brachytherapy).

The new clinical trial, FaR-RMS, (Frontline and Relapse RhabdoMyoSarcoma) was launched in September 2020, across the UK and Europe, with plans to open in Israel and Australia. The trial will study several aspects of treatment for the disease both for patients newly diagnosed and also at the time of relapse. It is open to patients of all ages (children, TYA and adults) across Europe. It has a multi-arm, multiple-stage design to identify early indications of benefit (or lack of benefit) of new therapies.



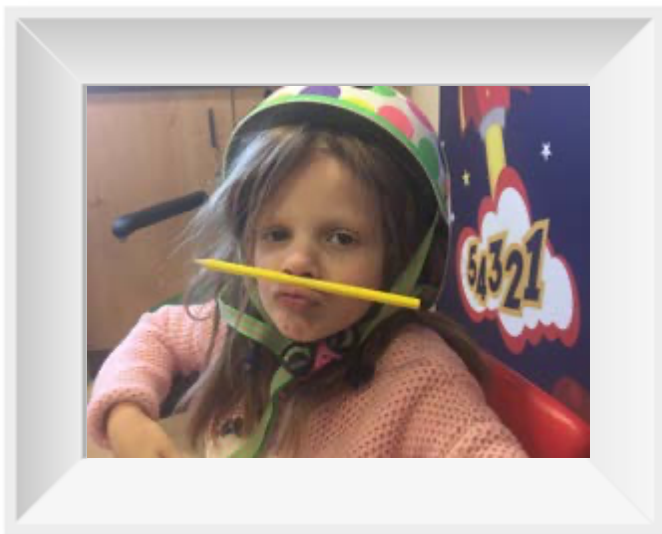
A tribute to...

The death of a child is a life-changing and devastating experience. It impacts all those who knew the child. The loss creates purpose. No family wants another family to go through 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 **Alice, Elsa** and **Jessica**, who lost their lives to rhabdomyosarcoma. Alice's Arc will always remember you and talk about you. You are the inspirations for our work.

Alice Wakeling

24th October 2011 to 8th October 2019



"I wish I could get better. Tell me all about this cancer. When will they find me a treatment?"

ALICE

Snapshot of her story:

Alice was diagnosed with stage 4 alveolar rhabdomyosarcoma, at the age of 3, in March 2015. She had 20 months of chemotherapy at GOSH and proton radiation in the US. Alice spent over a year in remission before her cancer returned in February 2018. She underwent 6 months of relapse chemotherapy and a specialist surgical procedure with brachytherapy, known as AMORE, in Amsterdam. Alice spent almost a year clear of cancer before masses were detected in her abdomen and pelvis in July 2019. There were no treatment options left. Alice died, aged 7, in October 2019, over 4.5 years after her diagnosis.





Fundraising for Alice:

£10K

Alice's funeral received over £10K in donations, in memory of her life

£40K

Allen & Overy raised £40K to honour her life and battle with rhabdomyosarcoma

OVER
£7K

Alice's mother took part in a 'Wing Walk' strapped to the wings of a plane in memory of Alice

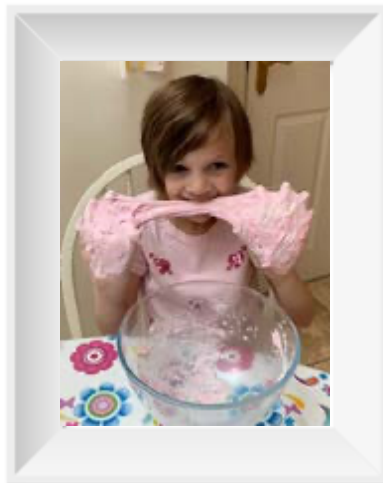
£12K

Alice's school celebrated Alice by hosting a series of fundraisers raising nearly £12K (see fundraising highlight)

Alice's school created and sold the gold 'Alice' bow in recognition of childhood cancer and for pupils to wear at her funeral



"Alice was brave and mischievous and had a tremendous impact on everyone she met. She continues to inspire us every day."



Alice's impact:



Alice is the girl who inspired the creation of Alice's Arc, she is the reason it exists today. She has left her parents with a mission.



Alice provides her parents with the motivation and passion to develop and grow Alice's Arc. This means providing a platform for families to fight together collectively to fund the most innovative and meaningful research and build a powerful voice for rhabdomyosarcoma. This pooling of efforts will ultimately lead to significant changes for a child or young person diagnosed with rhabdomyosarcoma in the future.



Alice's family want to see new treatment options for rhabdomyosarcoma, particularly in the area of immunotherapy. They also want to encourage a focus on uncovering biological discoveries relating to stage 4 ARMS and improving the dismal prognosis (8% on relapse) for this group of children and adolescents.

Elsa McGee

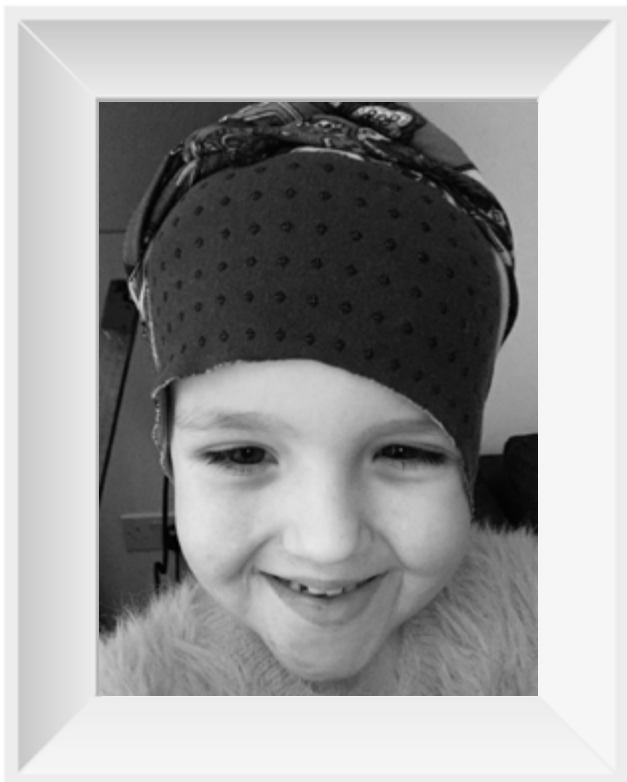
24th June 2013 to 14th April 2020

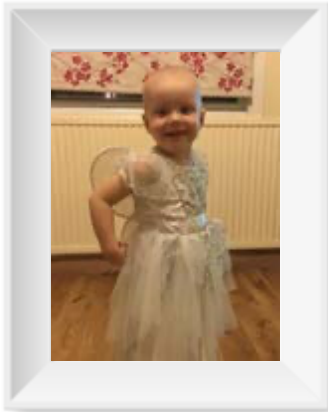
Snapshot of her story:

Elsa, forever 6, diagnosed in April 2016, age 2, with embryonal rhabdomyosarcoma presenting as a small tumour below her right nostril. Thought to be a cyst but post removal biopsy revealed cancer. An unexpected relapse in October 2018 identified a large tumour growing in her right jaw bone. Later identified through biopsy and MRI as spread of the initial cancer. Treatment yet again brutal but successful. In March 2020 stomach pains and a push for ultrasound testing, identified a large tumour on her liver and small growths in her stomach. CT revealed tumours also growing on her lungs. Elsa was almost 10 months into maintenance chemotherapy at this point. With no further treatment available, Elsa passed away 14th April 2020. Elsa's family have been great supporters of Alice's Arc throughout her journey.

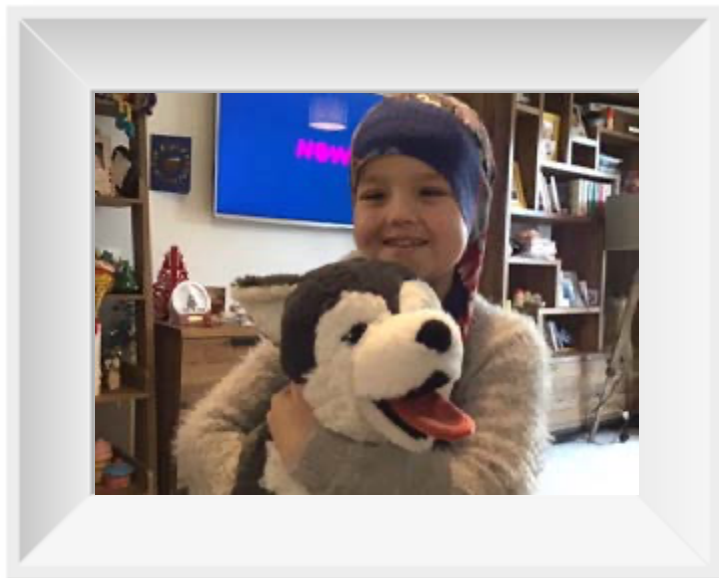


"With a personality that always left a huge Elsa sized impression on the hearts she touched, she will be missed by many"





“Her strong, sassy and sometimes aggressive attitude is what kept us all from falling”



Elsa’s impact:



Elsa has brought a community together. They know about rhabdomyosarcoma and they want to trigger changes for Elsa. When Elsa’s supporters want to fundraise they think of her and the work of Alice’s Arc.



Elsa’s family are interested in money being invested into research which will help develop understanding of ERMS and how to treat it with new, less aggressive treatments than the ones Elsa had to endure.



Funds raised will go towards our new project with the University of Birmingham (see research focus) to tackle fusion-negative Rhabdomyosarcoma with RAS pathway alterations with focus on DNA repair and replication stress.

Fundraising for Elsa:

£30K

Elsa’s parents donated £30K of Elsa’s Trust to Alice’s Arc

£8.4K

Elsa’s funeral was a small, family event due to Covid. However, her community raised £8,425 to celebrate her life

£5K

In August 2020, Elsa’s father, brother and cousins raised over £5K on a 125-mile walk, lasting over five days along the Leeds to Liverpool canal path.

Elsa’s mother has designed several beautiful products in memory of Elsa – Elsa’s candle, Elsa’s mother day boxes and Elsa’s father day boxes. She continues to sell these in support of Alice’s Arc.

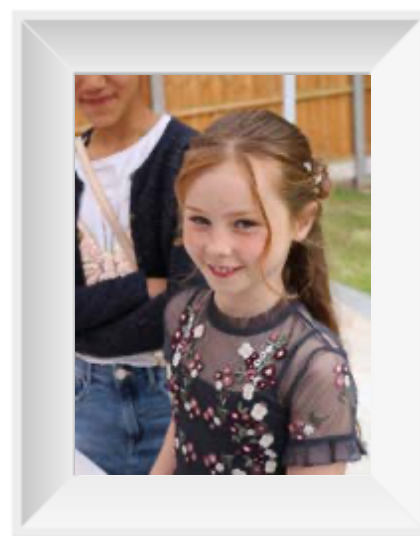
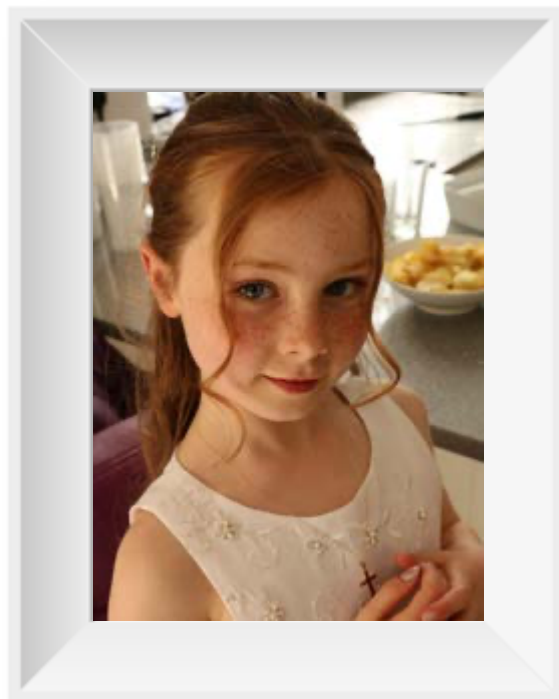


Jessica Macqueen

3rd September 2010 to 18th October 2019

Snapshot of her story:

Jessica, aged 8, was diagnosed with stage 4 alveolar rhabdomyosarcoma, in June 2019. She sadly died 4.5 months after her diagnosis. The cancer had unexpectedly spread to her brain and spine, in spite of scans a few days before showing she was free of disease.



"Jessica's shock diagnosis and the aggressive nature of her illness has left us all traumatised and in disbelief. Her death has left such a huge hole in our family."



“Jess was a strong, determined, clever little girl who should have had her whole life ahead of her. She was passionate and kind and we are totally lost without her.”



Fundraising for Jessica:

On Jessica's diagnosis, her community immediately started fundraising together with a series of events

£20K

A Justgiving page set up in memory of Jessica raised £20K capturing personal donations, businesses donating and other fundraising events by her supporters

£9.3K

A group of 23 parents from Holy Rood School ran the Watford Autumn 10K raising £9.3K

£4.5K

Jessica's aunt and uncle ran the first ever virtual London marathon raising £4.5K between them

Jessica's impact:



Jessica has brought a community together. Her diagnosis and shock death only a few months later drummed home the tragedy of childhood cancer from parents to children.



Jessica's school friends and their families have an ongoing rota of fundraising initiatives.



Jessica's family are interested in money being invested to go towards new treatments such as immunotherapy that can offer a cure for alveolar rhabdomyosarcoma. They also want to see more knowledge of rhabdomyosarcoma amongst GPs/hospitals to enable better and faster diagnosis.

Our year at a glance

Research Focus

We donated £69K to Professor Janet Shipley's rhabdomyosarcoma research team at the Institute of Cancer Research (ICR).

This covered salaries for a Clinical Research Fellow and a Postdoc role. It was the final instalment of our initial three-year pledge to the ICR of £345K. Much of the research we have invested in will be clinically translated for use in the new FaR-RMS clinical trial.



What have these funds contributed to this year?

Testing two novel drugs



a PARP inhibitor that can make rhabdomyosarcoma cells more sensitive to radiation and could help control local disease



A PLK1 inhibitor that has shown promising preclinical results

A collaborative UK/US study

that has led to the genetic discoveries that fusion negative tumours with MYOD1 and TP53 faults had a poorer response to treatment and worse survival outcomes. Fusion positive tumours with too many copies of CDK4 or MYCN which link to poorer outcomes. This is valuable knowledge in terms of predicting and identifying treatment options for these patients.

A pilot study

testing circulating tumour DNA (ctDNA) which has tested samples of blood to find out how to identify and quantify traces of tumour DNA in the blood of rhabdomyosarcoma patients. Key findings are being translated via National and European groups such as the NCRI (National Cancer Research Institute), EpSSG (European paediatric Soft Tissue Sarcoma Group) and the ITTC (Innovative Therapies for Childhood Cancers).

We defined our research priorities



Examine the causes of rhabdomyosarcoma. This means going back to the fundamental biology of the disease to formulate a genetic landscape of the cells that make up these tumours.



Help identify new targets with a view to developing innovative new treatments and new drugs for children with relapsed or metastatic disease where the likelihood of a cure is extremely slim.



Translation into clinical trials such as FaR-RMS in order to test research questions and assess the impact.



Devise kinder treatments that will take into account quality of life.



Share findings across existing platforms for paediatric solid tumour types to establish useful comparison points.

Scientific Advisory Team

We have created a Scientific Advisory Team to help inform, deliver and review our research strategy. The team provides expert guidance primarily on the following:



identifying, setting and evaluating research priorities



assessing projects to fund



regularly reviewing progress reports on projects funded

This team of professionals comprises scientists and clinicians from the rhabdomyosarcoma community as well as medical professionals across other specialisms.



Fundraising highlights

NEARLY
£5K



'Go Gold' Casino Night

Alice's Arc hosted 85 people at St Julian's Club, Sevenoaks on Saturday 14th March 2020 at a 'Go Gold' casino fundraising event. Guests dressed with a dash of gold and enjoyed a 'Go Gold' casino evening complete with glitter bar, band, photo booth, casino, drinks and canapés, sit down 2 course meal and a 'gold' inspired shot. Prizes for winners included 7 nights accommodation in Portugal, a 3 night stay in Dorset, London Theatre Tickets and generous gifts from local businesses.



Team Faye-Bae raise £2.5K by running their own 10km challenge

To mark Faye McEvoy's 5th birthday and as a way of giving back since Faye's cancer diagnosis, her Aunt and Grandad ran 10kms. Faye's twin cousins also joined in for the final kilometre.

Faye was diagnosed with Alveolar rhabdomyosarcoma in September 2019 and is currently on maintenance chemotherapy.



RAISED
£2.5K

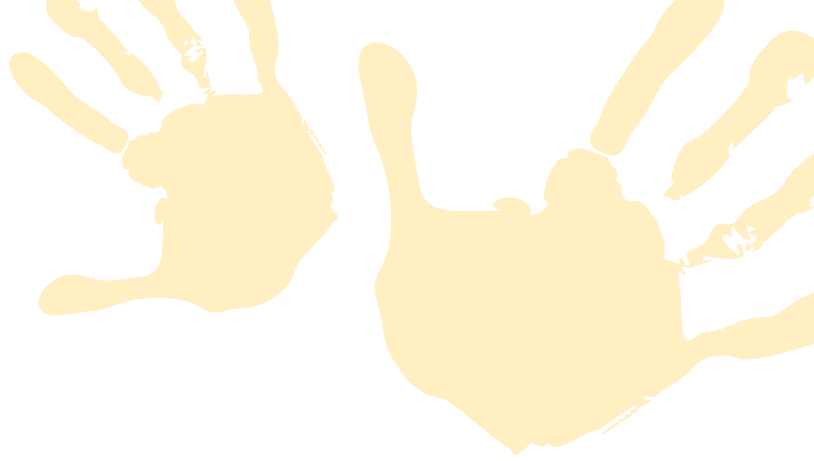
Continued support from International Law firm, Allen & Overy donated over £60K

Following Alice's death, Allen & Overy, launched a campaign to raise funds for Alice's Arc in her memory. They pledged to match every penny donated via the campaign. The response was extraordinary and raised £40K in total.

The Allen & Overy charity foundation also made their annual donation of £20K. They also held several fundraisers including a bake off.

DONATED OVER
£60K

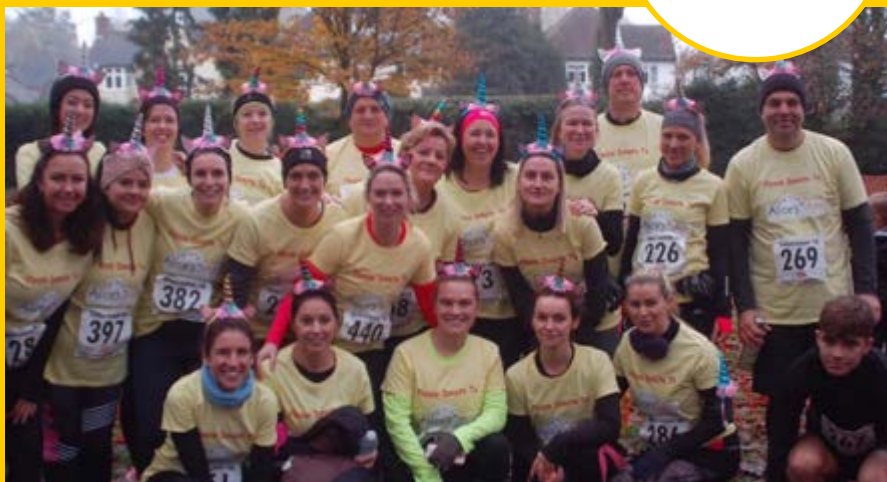
ALLEN & OVERY



Watford Autumn 10K run raises, £9.3K in memory of Jessica Macqueen

RAISED
£9.3K

A group of 23 parents from Holy Rood School, where Jess Macqueen attended, ran the Watford Autumn 10K. They raised a staggering £9.35K and announced this as just the beginning of their fundraising campaign in memory of Jess Macqueen.



Walthamstow Hall School, where Alice attended, raise nearly £12K

RAISED NEARLY
£12K

Alice's school choose Alice's Arc as their charity of the year for the 2019/20 academic school year. They hosted a series of fundraising events for the charity.

They went gold for childhood cancer in September 2019, wearing something gold and participating in a fashion show.

They had a Christmas sing-a-long and Christmas wreath-making workshop. Many food related events including bake sales, fresh lemonade stalls, valentine's chocolates and sweet stalls and a special valentine's breakfast. In addition, there were sporting events including 'Active for Alice' at Knole Park where families and pupils were invited to run for Alice. Several musical events and concerts raised significant amounts as well as house fundraising events. The school magazine was also dedicated to Alice's memory, using her last professional school photo that was taken.



'Go Gold Wing Walk' raises over £7K

Sara Wakeling and Natalie Carpenter took to the skies for a 10-minute flight strapped to the wings of a plane. They did this in memory of their children and to go gold for children with cancer.

RAISED OVER
£7K



Merchandise

The realities of lockdown forced us to reevaluate our fundraising strategies. We created the following products to sell.



Facemasks



Environmentally friendly running vest



Wristbands



By working closely with our network of families and respective local communities and businesses, we raised £30K for 'Go Gold' Childhood Cancer Awareness Month. So many shop windows turned gold across the UK and several landmark buildings in Leeds and Northern Ireland spectacularly glowed gold too.

Childhood cancer awareness month

Sevenoaks Primary School raised £1.3K

hosted a 'go gold' day at school with children wearing a gold/yellow accessory of their choice and providing a donation.



Voices
local MPs issued social media messages about CCAM and shared our childhood cancer awareness posters.

'Gold' products

Several businesses created a 'gold' product for the month of September. Gold scrunchies by CurlyEllie, gold chocolate boxes by the Chocolate Shop, gold cake boxes by Sugar Crush, gold initiatives by Welham Jones Funeral Directors, Fairy Godmother shop and CJ Barbers.



Other

there were many other fundraisers including bake sales by children who had lost their friends to rhabdomyosarcoma and several individual sporting fundraisers such as Claire Carter walking 100km throughout the month of September.



Other news

Appointed Natalie Carpenter as a new trustee (May 2020)

Natalie, a trainee psychologist, is the mother of two boys, both diagnosed with cancer within months of one another. Freddie with embryonal rhabdomyosarcoma and Arthur with a medulloblastoma brain tumour. Sadly, Freddie passed away in October 2018 after his tumour unexpectedly spread to his brain. Arthur, now aged 5, remains in remission following his treatment.

Natalie's unique experience of parenting two children with cancer will be invaluable in her role as a trustee. Also, key to the rationale of Natalie joining as a trustee is her expertise as a trainee child and adolescent psychologist. She will be instrumental in the development of our family well-being arm which aims to provide support for families with a child with rhabdomyosarcoma – from diagnosis, treatment, remission, palliative care and loss/bereavement.

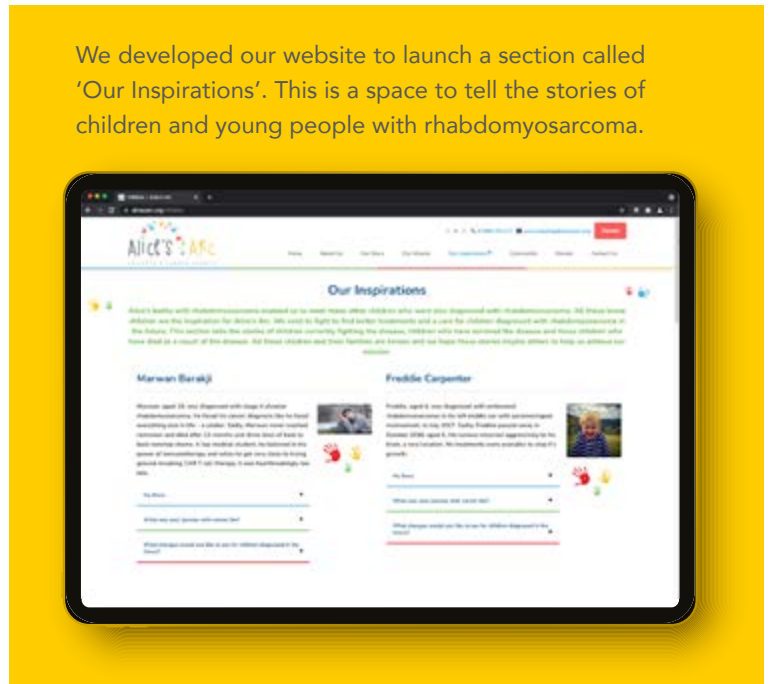


Laura Trott, local MP, invites Sara Wakeling to 10 Downing Street to celebrate International Woman's Day picture and news article (March 2020)


Following the publication of an article about Alice's Arc in the local Sevenoaks press (27th February 2020), Laura Trott, local MP for Sevenoaks and Swanley, invited Sara to this Women's Reception on the 8th March 2020 at Number 10 Downing Street. This was a great opportunity to take the issue of childhood cancer to Number 10 and to share children's cancer stories with Laura and other female MPs. Also to discuss ideas to help progress research and support for families affected in the future. Boris Johnson gave a speech on creating greater opportunities for women in the UK.



Newspaper article entitled 'Over £500K raised for ground-breaking drugs in Alice's memory', published in Sevenoaks Chronicle on 27th February 2020



We developed our website to launch a section called 'Our Inspirations'. This is a space to tell the stories of children and young people with rhabdomyosarcoma.



We opened an additional bank account to diversify our funds

Alice's Arc co-hosts European Paediatric Soft tissue sarcoma Study Group (EpSSG) Winter Meeting 2019

The EpSSG meeting brings together international professionals devoted to treating children with soft tissue sarcoma. The meeting was hosted at law firm Allen & Overy's office, in London. Professionals from Europe and the USA attended the event. Scientists, Doctors, Radiologists and Parents shared information regarding clinical trials, scientific research, challenges they face and the future. This opportunity to collaborate and share information globally is vital in making progress treating soft tissue sarcomas like rhabdomyosarcoma.

The event was sponsored by Alice's Arc, Children's Cancer and Leukaemia Group, Children with Cancer UK, Allen & Overy and the Royal Marsden and the ICR Biomedical Research Centre.



We delivered 'Well Being Goody Bags' for Valentine's and Childhood Cancer Awareness Month to Great Ormond Street Hospital

These were designed to provide useful items whilst a child is receiving chemotherapy and to put a smile on these families' faces. Goodies included generously donated, high-quality headphones, Chillies water bottles, body shop soaps, branded biscuits, branded sweets, branded balloons and super-hero masks.



Hope With Gaspard

We formed a collaboration with named fund, Hope With Gaspard and they will raise funds for Alice's Arc. Their son, Gaspard, was diagnosed with Stage 3 rhabdomyosarcoma of the prostate and bladder in December 2018.

Gaspard has completed his frontline treatment which involved intensive chemotherapy and proton radiation in the USA and maintenance chemotherapy. He is currently almost a year off treatment. His parents, Caroline and Benjamin Ronsseray have been fundraising for Alice's Arc for a few months previously and have formally joined forces with us through the creation of a fund dedicated to their son, Gaspard's journey with cancer.

Working with other families to achieve our mission is critical. We are stronger together and are all so passionate about making change for the future. Watching your child fight cancer is life changing. We all became aware how little investment goes into research and these factors are huge motivators.



RAISED
£12.9K



Tom Hart raised an enormous £12,860 in his Tiger King Challenge for the little tigers

Covid-19 inspired Tom to grow his hair and transform himself into the Tiger King to raise funds for Hope With Gaspard. Tom Hart spent several months deliberately growing his hair in response to Covid-19 and being unable to visit the hairdresser. With traditional charity fundraising unable to go ahead, Tom then took the decision to inject some fun into this tough situation and transform himself into the Tiger King who shares his passion for fluffy animals and furry men! During Tom's journey he shared videos and photos tracking his incredible transformation. His huge effort has raised an enormous £12,860, demonstrating how creative fundraising during Covid-19 can have a significant impact.

RAISED
£4K

GRANT OF
£10K



Credit Agricole's 'Helping Hand' initiative donates £4K to Alice's Arc

On Wednesday 11th December 2019 we attended Credit Agricole's 'Helping Hand' initiative to receive the donation and to share more about Alice's Arc, why we do it and where the funds will go. We were one of 8 charities chosen and it was great to hear more about some fantastic causes close to the hearts of the bank's employees.

Edith Murphy Foundation provides £10K grant

In conjunction with Hope With Gaspard, we provided information on the charity and most importantly, where the funds go. We were delighted to be awarded a grant of £10K from the grant making charity, the Edith Murphy Foundation, which supports organisations carrying out research, supporting individuals in need and relieving suffering for unwanted animals.



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.



A new approach to networking via the Arcs: Launch and roll out our new approach to family networks and pooling of efforts in 2021. In recognition that the key to future growth is families working together, we will be launching the Arcs in 2021. An Arc can be created in the name of a child (e.g. Freddie's Arc) with rhabdomyosarcoma by a family to tell their story, fundraise, advocate and demonstrate the impact they are making. The funds are pooled with Alice's Arc and all other Arcs to invest in major research projects by the best scientific institutions.



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.



Fund innovative research: We have identified five novel research projects to invest in over the next three years across leading UK institutions. We will continue to manage our existing research projects robustly and formulate new research opportunities. We will appoint a Scientific Advisory Board to help us assess and monitor progress and ensure our funding is contributing to diversifying effective treatment options.



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





Report and Financial Statements

For the Year Ended 30 September 2020

Charity number 1164253



Alice's Arc

Report of the Trustees for the year ended 30 September 2020

The trustees present its report and financial statements, examined by an independent examiner, for the year ended 30 September 2020.

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

Natalie Carpenter (appointed May 2020)

Independent Examiner

Alice Hagell, Head of Financial and Regulatory Assurance, Metro Bank PLC

Banker

Metro Bank 1 Southampton Row London WC1B 5HA

Our aims and objectives

Purposes and aims

Our charity's purpose as set out in the objects contained in the company's constitution is: the relief of sickness of people suffering from childhood cancers with a focus on rhabdomyosarcoma by:

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

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

Ensuring our work delivers our aims

We review our aims, objectives and activities each year. This review looks at what we have achieved and the outcomes of our work in the period to 30 September 2020. The review looks at the success of each key activity and the benefits they have brought to those groups of people we are set up to help.

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

The focus of our work

Our main objectives for the year have been focused on helping 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 Institute of Cancer Research, Great Ormond Street Hospital and the Royal Marsden NHS Foundation Trust. We have now fulfilled this three-year pledge which amounted to £345,084. This was less than anticipated due to staffing changes during the time period. We are currently in the process of agreeing the next three-year pledge and respective research projects. The charity has raised or received commitments for over £930K to date in incoming resources to meet these disbursement commitments (over £200K of which since 30 September 2020).
- b) The money was used for the employment of a Clinical Research Fellow and a Postdoc to undertake research into the genetics and behaviours of Rhabdomyosarcomas and other sarcomas and how they respond to different drugs and innovative treatment methods. It is also being used to obtain key laboratory materials necessary for this research. These roles will work closely with the Professor in charge of the research unit at the Sutton campus of the Institute of Cancer Research. The aim is to roll out a relapse Rhabdomyosarcoma treatment protocol for children based on this research that will be translated into practice to increase survival rates of children suffering from Rhabdomyosarcoma.
- c) Funding part of the work for devising an immunotherapy treatment approach led by UCL Great Ormond Street Institute of Child Health and the Wellcome Sanger Institute. This will look at 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.
- d) Funding work with the University of Birmingham which will look at fusion negative rhabdomyosarcomas and understanding the role of RAS genes within this patient cohort.
- e) Raising awareness and lobbying for change. We have forged connections with other children's cancer charities and are in the process of forming formal collaborations with several named funds who intend to raise funds for Alice's Arc.
- g) We have continued to increase our fundraising activities during this period. This has been via corporate organisations, families who have a child with rhabdomyosarcoma, families whose children passed away from rhabdomyosarcoma and initiatives relating to go gold for childhood cancer awareness month.

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.

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 £340,142 including Gift Aid. This enabled total disbursements of £68,784 to the Institute of Cancer Research in respect of the collaboration, bringing total disbursements to date to £345,197. After these disbursements, total funds of the charity stood at £349,194 at the end of the year to 30 September 2020.

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.

Natalie Carpenter was appointed as a new trustee of the charity in the year to 30 September 2020.

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

Company law requires the trustees 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 company 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 3].

- 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 16 July 2014.

Approved by the trustees on **18 June 2021** 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 2020

	Notes	Unrestricted Funds to 30/9/20 £	Unrestricted Funds to 30/9/19 £
Incoming resources			
Voluntary income: donations	2	335,945	160,248
Gift Aid on donations	7	2,752	8,632
Investment income		1,445	430
Total incoming resources		340,142	169,310
Resources expended			
Costs of generating voluntary income	3	26,446	3,365
Charitable activities		68,784	170,868
Governance costs	3	-	-
Total resources expended		95,229	174,233
Net Income for the year		244,912	(4,923)
Reconciliation of funds			
Total funds brought forward		104,282	109,206
Total funds carried forward		349,194	104,282

All incoming resources and resources expended derive from continuing activities.

Balance Sheet as at 30 September 2020

	Notes	30/9/20 £	30/9/19 £
Fixed Assets		-	-
Current Assets		349,194	104,282
Debtors	7	7,769	5,018
Cash at bank and in hand		341,425	99,264
Creditors		-	-
Net Assets		349,194	104,282
General Funds		349,194	104,282
Total Funds		349,194	104,282

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 16 July 2014.

Approved by the trustees on **18 June 2021** and signed on its behalf by:

Mr Nick Wakeling (Treasurer)

Notes forming part of the Financial Statements for the year ended 30 September 2020

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 16 July 2014.

(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 £18,305 in supplier charges for fundraising events, £6,020 for materials (charity-branded facemasks and running vests), £1,287 for design, print, postage, places at sporting events such as The Royal Park Half Marathon and other miscellaneous, £70 for social media, and £764 in fees to Virgin Money, Just Giving and other donation platforms.

Charitable activities comprise £68,784 relating to the charity's ongoing collaboration with the Institute of Cancer Research, The Great Ormond Street Hospital and the Royal Marsden NHS Foundation Trust 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 the amount of 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 from HMRC during the year to 30 September 2020 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 2020, which are set out on pages [10 to 14].

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 Company'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: Institute of Chartered Accountants in England and Wales (ICAEW)

Address: One Southampton Row, London, WC1B 5HA

Date: 18 June 2021

Please get in touch:



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