



Alice's ARC

CHILDREN'S CANCER CHARITY



help us make
change FOR
the future





Who We Are

Alice's Arc is a UK registered children's cancer charity. We fund research into more targeted and less harsh treatments for children affected by rhabdomyosarcoma. Our ultimate goal is to help find a cure for this type of childhood cancer. We also support the children and families impacted by the disease. An example of this is through the provision of drugs that make the treatment process easier to cope with.

Sarcomas' are cancers that can resemble bone or soft tissues. Rhabdomyosarcomas are the most common soft tissue sarcomas that occur in children and they tend to arise in muscle or fibrous tissue. There are around 80-100 new cases in the UK each year.

We work in collaboration with The Institute of Cancer Research (ICR), Great Ormond Street Hospital (GOSH) and the Royal Marsden (RM) to help improve outcomes for children with rhabdomyosarcoma. We fund the salaries of key scientists, the provision of equipment required for research, research nurses and other ad-hoc requests.

We also aim to increase awareness of childhood cancer by working with research centres and cancer charities. We lobby together to make changes for the future that can help to improve the understanding of rhabdomyosarcoma and enhance the level of collaboration across institutions.

To find out more please visit our website at www.alicesarc.org

Why do we do it?

THE JOURNEY OF ALICE

Alice's Arc was founded by Alice's parents and is inspired by her ongoing cancer journey. Alice was diagnosed in March 2015 with stage 4 alveolar rhabdomyosarcoma, at the age of 3. She underwent 20 months of intensive and maintenance chemotherapy at Great Ormond Street Hospital and also travelled to Florida, US for 10 weeks to have proton radiation.

Alice remained cancer free for a year but the cancer returned in February 2018. She endured six months of chemotherapy and spent three weeks in hospital in Amsterdam having a specialist procedure known as AMORE which included two surgeries and three days/nights of brachytherapy. Alice is currently cancer free and has check up scans every 3 months.

VERY FEW AND VERY HARSH TREATMENT OPTIONS AVAILABLE

There are limited and harsh treatment options available, especially on relapse when survival odds become very poor. Also, long term side-effects from treatments can be severe.

We would like to see better treatment options available for children diagnosed in the future. This would enable a dramatically better quality of life for the child and the family and smoother paths to recovery. For example, Alice spent over 100 nights in hospital during her first six months of treatment.

The different medical treatment protocols available in the UK, US and Amsterdam also offered an insight into the different approaches (and similarities) to treating the disease. We aim to use these experiences to help families impacted by rhabdomyosarcoma.

LACK OF FUNDING INTO RESEARCHING RHABDOMYOSARCOMA

The statistics below tell the story of why specialist charities funding research in to the complex world of childhood cancers are so vital. The charity would also like to see changes in current legislation around the limited access to drugs for children with cancer.

- Only 3 new drugs have been approved in the last 20 years to treat childhood cancers.
- UK children treated for rhabdomyosarcoma are on a treatment protocol that has changed little in decades.
- 46 children across the globe are diagnosed with cancer per day.
- Childhood cancer is the number 1 killer of children under 14 years old.
- There is very little investment in to researching childhood cancers. For example, only 4% of Cancer Research UK's funding goes towards research in to childhood cancers.
- R&D budgets for children at pharmaceutical companies are close to zero compared to 60% for adult cancer drugs.

LACK OF AWARENESS OF RHABDOMYOSARCOMA AND CHILDHOOD CANCER

Exposure to the world of children with cancer provided an insight in to the lack of awareness into these cancers. We aim to raise the profile of the experiences of the children fighting cancer in order to make a change for the future.

Where do your funds go?

Your money goes towards helping the laboratory and clinical research work of highly valued institutions such as **The Institute of Cancer Research (ICR)** and the **Royal Marsden NHS Foundation Trust**, who in combination are rated in the top four centres for cancer research and treatment globally, and **Great Ormond Street Hospital (GOSH)** which is an international centre of excellence in child healthcare.

👋 We fund a specialist cancer research team at the **ICR** in Sutton. This team are researching the behaviour of rhabdomyosarcoma and how to treat it more effectively. Funds are used to supply the salary for two key roles in the team for a period of three years – a **Clinical Research Fellow** and a **Postdoc** position. These individuals coordinate and analyse samples of tumours and look at gene sequencing to determine how the tumours are wired. They then experiment with drugs that target these molecular defects and could be used to treat rhabdomyosarcoma patients. These individuals are currently testing new drugs which will be used in the launch of a new rhabdomyosarcoma treatment protocol (expected 2019).

👋 Funds are also provided to the **ICR** team to source laboratory equipment and consumables that they need to conduct their research effectively. This involves cell culture, drug sensitivity screening and preclinical testing including animal models.

👋 A pledge has been made to **GOSH** to fund the role of a **Research Nurse** working on the new clinical trial. This role will support the collection and processing of blood and other samples for the study including molecular pathology, circulating tumour DNA and pharmacokinetics (PK).

Your money also helps support the children and families impacted by a cancer diagnosis. Funds can be deployed in a number of ways to meet this goal.

👋 Funds can be provided to families to help aid their child's recovery after chemotherapy. For example, there is a drug that isn't available on the NHS but can be accessed privately. This is known as neulasta and it helps blood counts to quickly recover following chemotherapy. This is very effective as it can mean that the child avoids infections and further hospital stays in order to administer antibiotics to treat the infection.

👋 Alice's Arc takes the lead and provides funds in order to locate and source funding for children's cancer forums involving parents of children with cancer. For example, in conjunction with EpSSG, a three-day global children's cancer conference focusing on sarcomas and bringing together around 140 paediatric oncology experts. A parent-focused afternoon during the conference will provide a unique opportunity for parents of children with rhabdomyosarcoma to come together.

how do we fundraise?

WE ARE CONSTANTLY EVOLVING THE WAY WE RAISE FUNDS AND DEVISING NEW IDEAS. OUR FUNDS TEND TO BE RAISED THROUGH THE FOLLOWING SOURCES:

- 👋 Families of children with rhabdomyosarcoma
- 👋 Alice's Arc charity events – annual fire walk and family fun run
- 👋 Corporate business support – annual contributions and company events
- 👋 Local fundraising – schools, businesses, community initiatives
- 👋 Individuals – sporting events/challenges and unique ideas
- 👋 Events associated to 'go gold' for childhood cancer awareness month (September)
- 👋 Shopping platforms such as Amazon Smile UK and Easyfundraising.

get in touch!

- 👋 If you are a family who have a child with rhabdomyosarcoma
- 👋 If you like what you see and want to raise money for children with cancer
- 👋 If you have any questions or suggestions about Alice's Arc
- 👋 If you want to make change for children with cancer



Alice's ARC





Alice's ARC

CHILDREN'S CANCER CHARITY

PLEASE GET IN TOUCH!



alicesarc.org/



[@alicesarccurerhabdomyosarcoma](https://www.facebook.com/alicesarccurerhabdomyosarcoma)



[@alicesarc](https://twitter.com/alicesarc)



[@sacraddo](https://www.instagram.com/sacraddo)



078 8070 1217



sara.wakeling@alicesarc.org

