

# Our impact in 2019

We won't stop until  
every child survives





# Chairman's foreword

## Foreword by our Founder and Chair of Trustees

**Welcome to our 2019 annual review. It's been another exciting year for the charity, with investments into a broad range of vital research and projects that have enabled us to reach more children and young people affected by cancer.**

Understanding the causes of childhood cancer so that fewer children and young people receive life-changing diagnoses, is a personal passion of mine, having lost two children to cancer within months of each other. Following our 2018 grant call of £2.5m for projects investigating causes and prevention of childhood cancer, I'm pleased to announce that in 2019, we awarded nine new grants in this area. These projects will look into the impact of environmental factors such as pollution and exposure to radiation on childhood cancer.

Survival rates for the most common type of childhood cancer – acute lymphoblastic leukaemia (ALL) – have significantly risen during the charity's existence. Today, thanks to sustained investment in research and improvements in treatments, in which Children with Cancer UK has had particular impact, survival rates for young patients with ALL is around 90%. 2019 marked an important step forward in treatment for previously incurable relapsed ALL. A trial using CAR T-cell therapy that started in June 2016 and was jointly funded by Children with Cancer UK and Great Ormond Street Hospital Children's Charity, bore promising results just three years later. CAR T-cell therapy is a highly complex and innovative new treatment which harnesses the patient's own immune cells to treat their condition. This has led to more targeted, more effective and ultimately less harmful treatments for children and young people. The trial was so successful, that in 2019 the therapy was approved for use by the NHS for relapsed or refractory ALL in people up to the age of 25 years. This is a shining example of how research really does save lives.

Whilst this is incredible news for children and young people diagnosed with ALL, the outlook sadly isn't as positive across the wide spectrum of childhood cancers. For bone cancers such as osteosarcoma, survival rates sit at just 65% and brain

and spinal tumours – the most common type after ALL – claim more lives than any other childhood cancer.

In light of this, our 2019 research funding has also focused on harder-to-treat and rarer types of cancers, to bring hope to children and young people faced with less promising diagnoses. We pledged £1m for research into brain and spinal tumours and partnered with Bone Cancer Research Trust to host an osteosarcoma symposium that brought together world leading experts to share learnings and promote collaboration. We will continue to dedicate resource to and raise awareness of harder-to-treat cancers, building it into our long-term strategy moving forward.

Alongside our dedication to funding high-quality research, we are committed to supporting children and their families through the hardships of a cancer diagnosis. 2019 saw the advent of an exciting partnership with Beads of Courage UK, which helps children in all 110 children's cancer wards in the UK visualise and articulate their cancer journey. You can read more about the programme and its positive impact on the mental health and wellbeing of young cancer patients on page nine.

We also granted £288k to Ronald McDonald House Charities, which provides free accommodation near hospitals so that families can stay close to their children during treatment. Our funds will be used to build a Day Room in their home at Oxford Children's Hospital, which will provide respite for family and friends away from the clinical hospital environment. You can find more about what this room will offer families on page 10.

Lastly, 2019 saw the publication of our Impact Report – a culmination of independent research by The King's Fund, which was commissioned as part of our 30th anniversary celebrations in 2018. I was immensely proud to read about Children with Cancer UK's vital role in pioneering research that has gone on to save and improve thousands of young lives. [You can read the full report on our website.](#)

A portrait of Eddie O'Gorman OBE, an elderly man with white hair, wearing a dark suit, white shirt, and a patterned tie. The portrait is set within a hexagonal frame.

**Eddie  
O'Gorman OBE**

Founder and  
Chair of Trustees



It goes without saying that our impact in 2019 and indeed our 32 years' history could not have been made possible without the generosity of our valued supporters. Thanks to your help, more children and young people are ringing the end of treatment bell and returning home to their families.

At the time of writing this foreword, we are in the midst of the COVID-19 pandemic, which has thrown the world into a period of uncertainty and instability. This will have an undeniable impact on our charity, with an estimated 40% of our income under threat. What concerns me most however, is the added pressure this pandemic is placing on children with cancer and their families.

Whilst the world's attention is understandably consumed by the virus, 12 children and young people are still being diagnosed with cancer every day in the UK. Many of these children are in the vulnerable high-risk group and face uncertainty around their treatment.

We want to ensure that during these worrying times, we can continue to fund life-saving research and essential support services to give hope to children with cancer and their families. I would like to pay tribute to our staff who adapted immediately to working from home, which we implemented on 13th March, a good 10 days in advance of the Government's decision to announce a UK-wide lockdown. I would also like to convey my sincerest thanks to all those who have continued to support us during these trying times.

*Charlie Johnson*



# How your donations have helped children and young people with cancer

We receive no government funding and rely exclusively on the generosity of our supporters.

We are pleased to report that in 2019 we raised **£17.3m** to fund specialist childhood cancer research and to support families affected by childhood cancer.

For every **£1**  
we spend on fundraising



We raise  
**£4** more



For every **£1** donated we spend 77p on fighting childhood cancer

**37p**

Research projects



**15p**

Supporting families



**25p**

Raising awareness



**23p**

Raising more money



**£1**

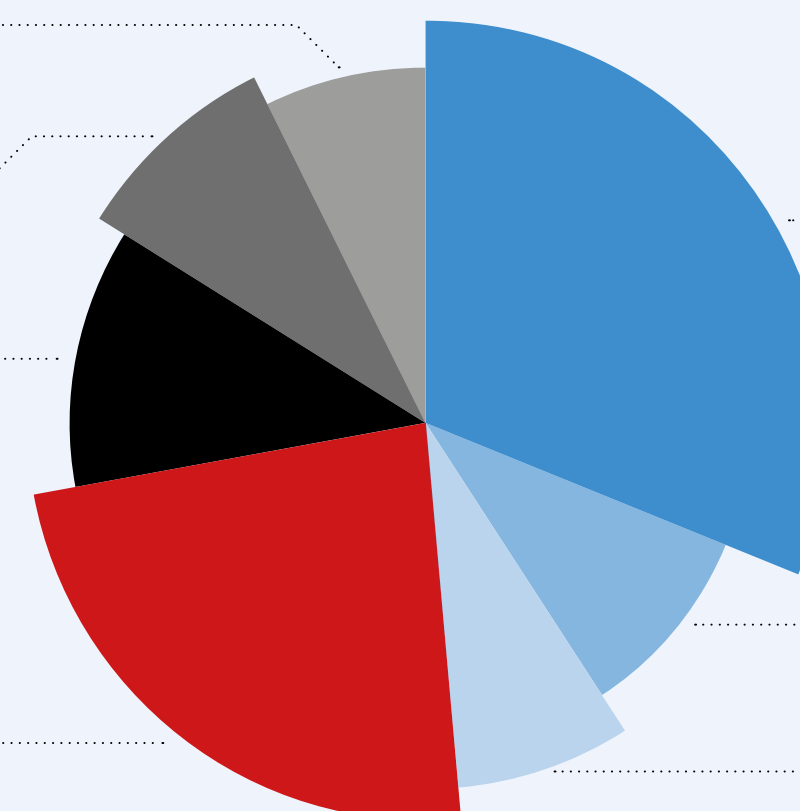
## How we fundraised

Events  
£828,225

Community fundraising  
£1,813,260

Committed giving  
£2,080,202

Appeals and associated donations  
£4,350,563



Sports events  
£4,549,199

Legacies  
£1,396,017

Corporate and trust donations  
£2,188,949



# Our year in numbers

## Research

We're committed to finding cures and kinder treatments for children and young people with cancer



**£3.3m**

invested into vital life-saving research

**32**

new research awards



**2**

scientific conferences



**£250k**

for one clinical PhD studentship

## Supporting families

We help children with cancer and their families through the hardships of a cancer diagnosis



**240**

families attended our amazing days out

**110**

childrens cancer wards given access to the Beads of Courage UK oncology programme



**£288k**

towards free family accommodation close to hospitals



**1,263**

financial grants given to families to help alleviate the costs of cancer

## Awareness

We shine a spotlight on the impact of cancer on children and young people and their families



**22m**

people have seen our social media pages

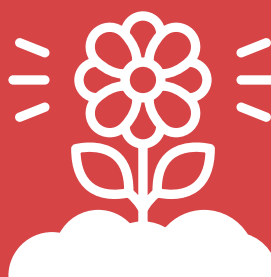
**2bn**

media reach



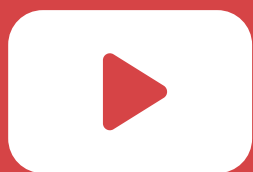
**1**

garden at BBC Gardeners' World Live



**6**

videos made to help families celebrate the end of treatment



# Our year in research

This year we funded 32 new research projects, which means that combined with existing active research grants, we are now funding a total of 69 projects, worth over £25m at centres of excellence around the UK.

The research we fund is aimed at understanding the causes of childhood cancer and how it can be prevented, developing new treatments which are less toxic for children, as well as finding cures for some of the hardest-to-treat cancers.



**Dr Srdan Rogosic**  
UCL Great  
Ormond Street  
Institute of Child  
Health

## Research highlights

### **Improving the safety and effectiveness of CAR T-cell therapy for childhood acute myeloid leukaemia (AML), Dr Srdan Rogosic, UCL Great Ormond Street Institute of Child Health**

AML is a rare condition with around 70 new cases diagnosed in children every year in the UK. Only two thirds of these children are cured, so novel therapies are urgently needed.

CAR T-cell therapy is an immune-based therapy which works by enhancing the body's own immune system to destroy cancer cells more effectively and with fewer side effects from chemotherapy drugs. It's the most promising new cancer treatment since the development of the first chemotherapies in the late 1940s.

Dr Rogosic's research will be addressing the limitations of current CAR T-cell therapies for AML to ensure that they are more effective and targeted. His team will be developing new techniques to better identify AML cells and also ensure that the therapy doesn't damage healthy cells.

If successful, this project will form the basis of a new clinical trial in children with otherwise incurable AML.



**Professor  
Ruth Jarrett,**  
University of  
Glasgow

### **Early diagnosis of classic Hodgkin lymphoma, Professor Ruth Jarrett, University of Glasgow**

Hodgkin lymphoma is one of the most common cancers in young people but diagnosis is often delayed because signs and symptoms are similar to other conditions, such as glandular fever. This may lead to avoidable illness and anxiety, as well as spread of the disease and need for more treatment.

Blood samples from almost all untreated Hodgkin lymphoma patients contain high levels of a molecule called CCL17, which has been proven to be a good predictor of Hodgkin lymphoma in young people.

The research on CCL17 has so far only been carried out in the hospital setting. Professor Jarrett's team now wants to evaluate this test in the primary care setting (i.e. at GP practices) to encourage earlier diagnosis. This would involve a simple and cheap blood test that GPs could carry out to identify potential Hodgkin lymphoma patients presenting symptoms. Those whose test results show a high level of CCL17 would be immediately referred by their GP to hospital for further investigation.

This study will inform the design of a larger study evaluating the value of CCL17 testing for the early diagnosis of Hodgkin lymphoma in the primary care setting. It is hoped that this large study will lead to the introduction of CCL17 testing into routine healthcare, which could in turn result in less intensive treatment and reduced side effects.



# Our year in research

## Bringing world leading experts together

This year we held conferences attended by world leading experts, to promote collaboration and shared learning for the advancement of specialist childhood cancer research.

### Childhood Cancer Conference

We welcomed 125 attendees to our Childhood Cancer 2019 Conference, which was held in Newcastle in September. Twenty-four speakers addressed the topic, “exploiting genomic medicine throughout the patient journey”, providing updates on how genomic medicine is being used to deliver new therapies, reduce toxicity, enable earlier diagnosis and prevent cancer in children and young people.

We also had encouraging updates on the multi-centre INSTINCT programme that we support, which integrates high-risk paediatric brain tumour research at The Institute of Child Health, Newcastle University and The Institute of Cancer Research to deliver improved therapies for children.

Our keynote speaker was Newcastle's MP and Shadow Minister (Business, Energy, Industrial Strategy) Chi Onwurah, who gave strong support for our drive to develop innovative personalised medicine based on genetic profiling.

### International Osteosarcoma Research Symposium

In January 2019, we held the first International Osteosarcoma Research Symposium in partnership with Bone Cancer Research Trust. The event was supported by the Trustees of the Britton Family and was held in memory of 11-year-old Frankie Biggs who sadly passed away from the disease. Paul Britton, from the Foundation, is a close family friend of Frankie's mother Alison, which is why the event was held in his honour.

Osteosarcoma is the most common type of childhood bone cancer and usually develops in the long bones of the arms or legs. It has amongst the lowest survival rates of all childhood cancers (65% five-year survival).

The symposium brought together researchers from across the globe to identify current research progress and challenges in order to identify opportunities to move research forward.

Following the success of the symposium, we announced a new partnership with Bone Cancer Research Trust in Frankie's memory to advance research into osteosarcoma.



Alison,  
Frankie's mum,  
speaking at the  
Symposium,  
standing next to  
Paul Britton.



# Frankie's story

“

Frankie developed a limp when he was nine years old and we were told by four different doctors that it was ligament damage. We eventually took him to A&E and following an X-Ray he was diagnosed with osteosarcoma.

It had broken his knee cap in half and spread round his little body, including both knees and lungs. My son took everything that stood in his path, from MRI scans, a bionic leg, the lower lobe of his lung being removed, to eventually too many brain tumours to count.

This shouldn't be happening to children and in the two years of living and breathing cancer with my son, I also watched six other children die from this awful disease, including Frankie's girlfriend, who he met at the hospital.

Last year we celebrated what would have been his 12th birthday without him. He was my world, my hero, my best friend and my life. Cancer has changed us all, but it made my son the hero he was and still is, in my eyes, today. ”

**Alison, Frankie's mum**

Frankie's story has inspired a partnership with Bone Cancer Research Trust, resulting in the Osteosarcoma Symposium detailed in the preceding pages. Alongside this, we committed £500k of funding towards osteosarcoma research, with Bone Cancer Research Trust committing £450k, all to find more effective treatments for children like Frankie.

**Frankie**

**2006-2018**

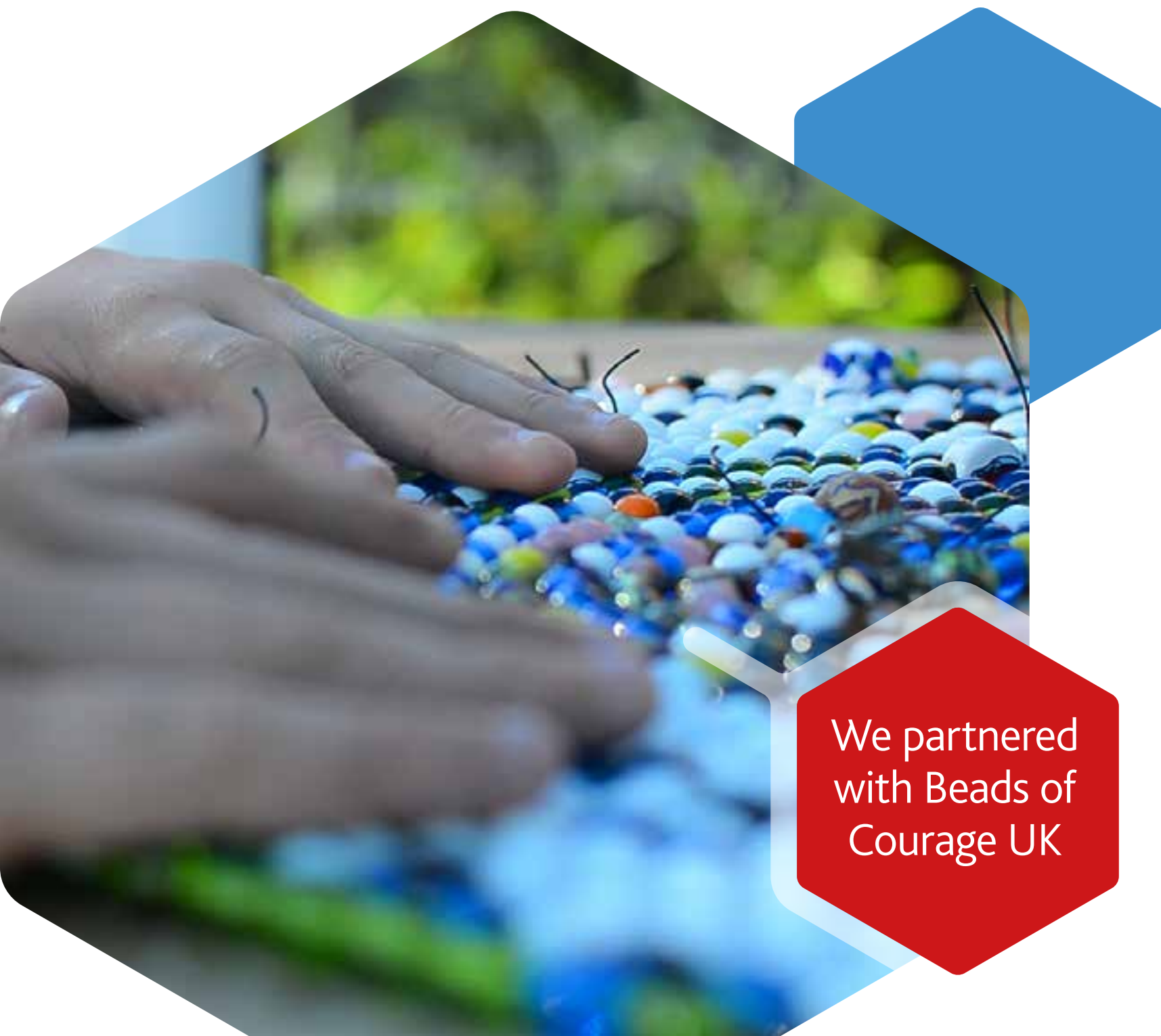


# Supporting families in 2019

**We funded £918k towards projects aimed at alleviating some of the burdens a cancer diagnosis places on children with cancer and their families. We also hosted 240 families at 10 events throughout the year, giving them happy memories and a welcome respite from gruelling treatments and the daily worries cancer brings.**

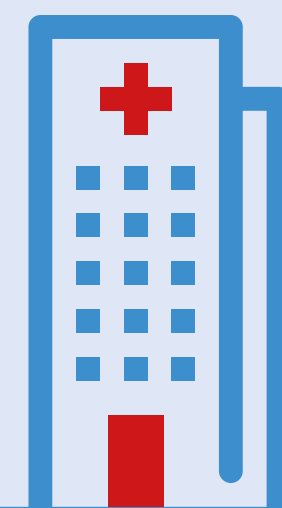
## Beading helps healing

We partnered with Beads of Courage UK in 2019 to allow all young cancer patients being treated in the 110 children's cancer wards across the UK continued access to the Beads of Courage oncology programme.



We partnered  
with Beads of  
Courage UK

The programme promotes positive coping strategies by helping children to visualise and articulate their experiences through a process called beading. Different beads are given to children to represent and record each step of their treatment. For example, a yellow bead represents an overnight stay in hospital, a white bead a course of chemotherapy and a glow-in-the-dark bead a course of radiation therapy. The beads join together to form often long, physical representations of a child's journey to recovery.



**9 million** beads to roughly  
**9,000** children in over  
**100** hospitals across the country

It has also enabled training sessions to hospital staff on how to support individual patients throughout the programme both practically and emotionally.



Beads of Courage UK staff travelled over  
**10,000 miles**  
to deliver training in 2019.

“

The beads have been a visual guide showing how far Luuk has come and what he's endured. They also show him how brave he has been throughout his journey. Luuk's incredibly proud of his beads, as am I. We talk about his journey when we thread the beads on the string – it's almost like turning the pages, getting closer to the end of this difficult chapter in his life. The beads propel him forward as his treatment progresses as they remind him that he's done it before and he can do it again. ”

**Charmaine, mum of Luuk, aged 5**

“

The Beads of Courage helped me to understand how much our young children go through. Seeing all the beads that they gain over the course of their treatment is astonishing. The beads help children understand what they are going through themselves. They help them feel positive and even excited when they receive another bead. Although treatment is hard for our little fighters, they have something amazing to show at the end. Beads of Courage are incredible. ”

**Jessica, Activities Assistant,  
Peterborough City Hospital**





# Supporting families in 2019

## A place to recharge during difficult hospital stays

When a child is in hospital, it is common for families to experience feelings of social isolation and disruption to family routines. Many families require respite from the hospital's clinical setting in order to recharge and sustain the energy required to meet the needs of a sick child.

We've long supported the provision of free accommodation near to hospitals for families whilst their children are receiving treatment. Over the years, we've provided £8.9m of funding towards 10 homes across the UK.

In 2019, we committed to fund a Day Room at Ronald McDonald House Oxford, which is being expanded into a new 62-bedroom house, accommodating an average of 1,000 families per year.

The Day Room is just a few minutes away from the children's ward, meaning that family and friends can very easily move between the two. The space will be complete with a fully-equipped kitchen, dining and play areas to allow families to maintain a degree of normality, re-establish routines and share mealtimes together. Families will be offered activities such as daily coffee mornings, parent pamper days and arts and crafts sessions for siblings, which will help to relieve stress, enhance family cohesion and promote social interaction.

“

We are really grateful to Children with Cancer UK for generously funding the Day Room at our new Oxford House, which is set to open Summer 2020. The new 62-bedroom house next to the Oxford Children's Hospital will provide a much needed 'home away from home' accommodation for families with children undergoing treatment in Oxford Children's Hospital. Thanks to Children with Cancer UK, the Day Room will provide the perfect place for families to rest and recharge. ”

**Jon Haward, Executive Director of Ronald McDonald House Charities UK**

## Financial Hardship Grants

On top of the devastation a cancer diagnosis brings, the financial impact of cancer can be crippling. At a time when many parents have to give up work to help care for their child, expenses on travel, food and bills increase. Research has shown that parents spend an average of £600 extra every month when their child is receiving cancer treatment<sup>1</sup>, which can last for up to three years. That's why, for over a decade, we've been funding CLIC Sargent's Financial Hardship Grant programme to help alleviate the cost of cancer for families.

Our gift of £350,000 in 2019 has resulted in 1,263 grants made to families to help with costs such as travel, hospital parking and food. These grants are lifelines for families, many of whom are struggling to make ends meet.

This year after an unexpected surge for different types of grants, a small proportion of the funding was spent on other grants to help families with the financial impact of cancer. These included 'Registration Grants' to help families cover the initial costs of cancer, 'Home Essentials Grants' to help purchase specialist equipment for children and young people diagnosed with cancer and 'Compassionate Grants', helping to alleviate the financial burden that bereavement can bring.



CGI image of new  
Ronald McDonald  
House, Oxford

<sup>1</sup>According to CLIC Sargent's Cancer Costs Report (2016)



# Amazing days out for families affected by childhood cancer

A snapshot of our much-loved events that allow families to enjoy quality time together and a break from the daily stresses of a childhood cancer diagnosis.



*Alton Towers adventure*



*Christmas parties*



*A trip to the seaside at  
Grand Pier,  
Weston-super-Mare*



*A magical visit to Warner  
Bros. Harry Potter Studios*



*Showtime at Zippos*



# Lily's story

“

When we were given the news that Lily had a brain tumour, it was completely shocking and devastating, but suddenly everything made sense. She had been poorly for some time, drastically losing weight, becoming very lethargic and developing flickering eyes.

After an initial 18 months of chemotherapy, we celebrated the end of treatment in May 2019. We had a four month break before discovering that the tumour had grown along with a number of cysts and that her vision had further deteriorated. A shunt was fitted because the fluid in her brain did not drain as it should due to the tumour. After further chemotherapy, Lily began to walk with a slight limp and a scan showed that the tumour and cysts had continued to grow. She will now need a further course of chemotherapy for another year.

Because of Lily's condition, we find it very hard to think about Christmas or make any plans. We don't know what Lily's health will be like, whether we'll be in a hospital room or celebrating with family. Cancer consumes everything in your life.

We attended Children with Cancer UK's London Christmas party in December. The event was a chance for Lily to enjoy the festivities of Christmas like every child deserves and for us to have a much needed break from hospital appointments and treatment, as well as meet other families affected by childhood cancer. ”

**Lianna, Lily's mum. Lily was diagnosed with an optic pathway glioma in 2017 at the age of one.**

Lily and family  
at our London  
Christmas party



# Putting childhood cancer on the agenda

Our awareness raising activities in 2019 highlighted the impact of cancer on children and young people and their families across social media, our website and via media coverage.

## Childhood Cancer Awareness Month

In September, our campaign for Childhood Cancer Awareness Month (CCAM), 'A child with cancer is not alone', focused on the wider impact of childhood cancer – with a cancer diagnosis not only affecting the child, but the entire community around that child. We commissioned a OnePoll survey of 2,000 adults and found that almost 18% of the UK population have known a child who has suffered from cancer, and more than one in 10 have known a child who has died from the disease.

As part of this campaign, we featured the story of cancer survivor Blue, with emphasis on how his cancer impacted those around him. The campaign reached over two million people, through media coverage and our social media pages.

“

It was painful and just destroys your body. It was scary, but at the same time, I felt like I had someone beside me helping me fight off the cancer. And those people were my doctors and nurses, my mum, my dad, my nan, my grandad and the rest of my family.”

Blue



Blue was diagnosed with acute myeloid leukaemia (AML) in March 2011. As part of our CCAM campaign, Blue spoke about his experiences, his support network and life after cancer.

## The Children with Cancer UK Strength of Humanity Garden

Our garden at BBC Gardeners' World Live illustrated the impact of childhood cancer on young people and their families and was inspired by a young girl called Megan who lost her life to brain cancer in 2016, aged 11. Planting was used to reflect thoughts and feelings associated with childhood cancer and a sculpture in the centre of the garden of an end of treatment bell represented the happy moment when a child finishes treatment. The garden was created by designer Ben Stubbs in collaboration with Megan's parents.

Attracting 100,000 visitors, our presence at BBC Gardeners' World Live was a valuable and creative opportunity to engage with new audiences and raise vital awareness of childhood cancer. Megan's story, the garden and charity messages were featured on BBC East Midlands evening news as well as in local print and radio.



BBC Gardeners' World Live garden, with Megan's parents, Julian and Andrea

## 30 years of impact on children's cancer

To celebrate our 30th anniversary in 2018, we commissioned the publication of a report based on independent research undertaken by The King's Fund. This report, which was published in early 2019, assesses our impact to date on children's cancers and looks at how advances in cancer research and treatments have changed people's lives.

The findings demonstrate the significant impact of our charity, not only in the field of childhood cancer research, but also in the offshoot family support services that are desperately needed once a child receives a diagnosis. The King's Fund identified areas in which Children with Cancer UK has had particular impact and success, some of which include the funding of life-saving and life-changing research such as the Minimal Residual Disease (MRD) test and Precision Medicine and actively promoting collaboration and campaigning across the childhood cancer 'community'.

To accompany the publication of this report, we ran a social media campaign which highlighted our stand-out achievements in our 30-year history, which was seen by 70,000 people.



# Suki's story

“

No one ever dreams of being told the terrifying words, 'your child has cancer.' The first eight months were particularly tough, with regular high dose chemotherapy, blood and platelet transfusions, contracting viruses and infections; there were many admissions and hospital stays.

Suki suffered numerous side effects from treatment, including weight gain and loss, constant nausea and of course losing her hair. Despite a hard few years, Suki remained positive and in August 2019, she finally rang the end of treatment bell. It was such a huge milestone and was wonderful to see her beaming smile.

Children with Cancer UK helped fund research for the treatment Suki received. They've also provided us with memorable family days and special times with other oncology families – people we're now proud to call our friends. We are so grateful for the charity's support and everything they continue to do to make outcomes like Suki's possible. ”

**Rachel, Suki's mum. Suki was diagnosed with acute lymphoblastic leukaemia when she was just four years old.**

We attended Suki's bell ringing and made a special video for her and her family.

[Click here to watch](#)

Suki and family at their bell ringing ceremony





# Your highlights

A snapshot of your greatest achievements this year, that have helped more children with cancer ring the end of treatment bell.

4,300 people participated in challenge events, raising an incredible

**£4.5m**

1,200 runners in the 2019 Virgin Money London Marathon, raised over

**£3m**



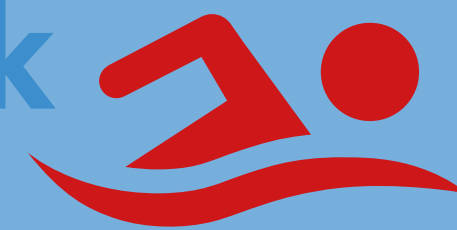
Kwik Fit began fundraising against

**£1m** pledge

**KwikFit**

Over 300 swimmers took part in Children with Cancer UK Swim Serpentine, raising over

**£79k**



Chosen as **charity of the year** by

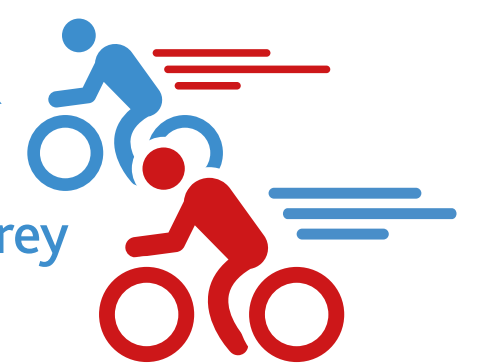
Ladbrokes for 3 years



568 riders raised over

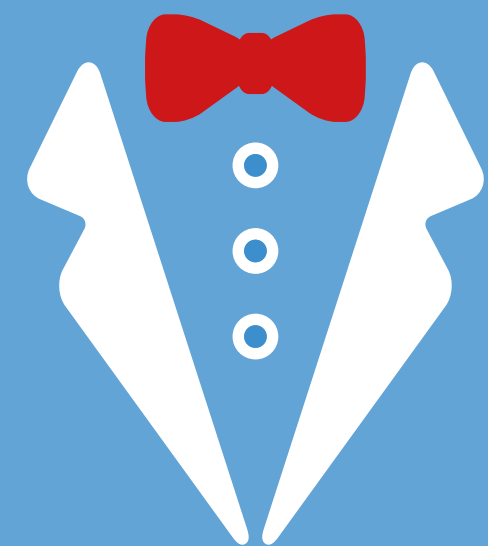
**£311k**

in the Prudential RideLondon-Surrey



The Children with Cancer UK Ball raised

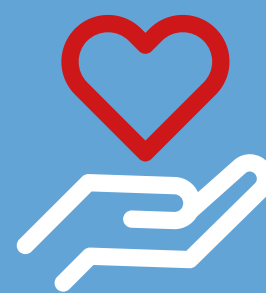
**£631k**



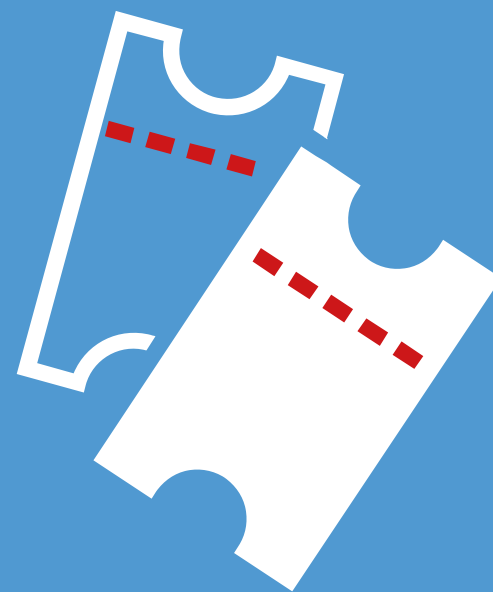
**£611.5k** in Facebook donations



Charity Aid raised over **£23k**



Grand Draws raised over **£1.8m**



**£1.4m** from 143 gifts in Wills



Top Model's 2019 shows raised

**£26k**



RS Components raised

**£250k**

from their Tour de Branch event



Opera at Syon



Raised

**£126k**



Anglers Against Cancer's fishing competitions have raised over

**£220k**

to date



The Sammy Jo Brandon Foundation have raised over

**£80k**

to date



We couldn't do it without you,  
so thank you for your support!

