



**Children with
Cancer UK**

Keeping families together



January 2019

30 years of impact on children's cancers

This report is based on an independent
review carried out by The King's Fund.

TheKingsFund>

Children with Cancer UK is a registered charity (charity no. 298405). Its main aims are to understand what causes children to develop cancer, to develop improved treatments and to provide care for affected children and their families.

The King's Fund is an independent charity working to improve health and care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible care is available to all.

Children with Cancer UK commissioned The King's Fund to produce an impact report to mark its 30th anniversary, which took place in January 2018. The purpose of the report is to illustrate the impact of advances in cancer treatment for children – particularly advances that are associated with funding granted by the charity. The report is entirely editorially independent and all views are those of the authors.

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Emma's story

Emma was two years old when she was diagnosed with stage four high-risk neuroblastoma in 2006. Her mum, Samantha, tells their story so far.¹

“

It all started when Emma turned one. She developed a cough [and] had really bad stomach pains. We saw a doctor in A&E and he found a lump in Emma's belly. Our lives changed forever. We were told that they had found a tumour on her right kidney and they thought it was one of two types – either a Wilms tumour or neuroblastoma. I didn't have a clue what either of these were.

Our little girl was really ill and needed treatment ASAP. She needed eight rounds of chemotherapy over a period of 80 days, with each round being just over 10 days. She also needed a stem cell transplant. Once she had undergone all this, she would need maintenance chemotherapy for nine months.

Emma responded well to all the chemotherapy she was given and the tumour shrank by more than half its size in just four rounds. Her bones and bone marrow were all clear, which was amazing.

More recently Emma started suffering with anxiety, but she doesn't let this hold her back. She's a fun, loving and caring little girl. She doesn't allow anything to set her back, she doesn't moan and she never feels sorry for herself. She gets through everything with a smile. Thanks to so many charities including Children with Cancer UK, we have been lucky enough to make some amazing memories over the past 10 years. The help we receive from charities makes a massive difference to families. It gives us something positive to look forward to.

We still have bad days and scary days but we also have a lot of good days with lots and lots of laughs. I hope sharing Emma's story can give other families hope. Children with Cancer UK do amazing work to fund research into finding new drugs and treatments for children with cancer. I can only hope that one day their researchers find a treatment that doesn't leave these beautiful and brave children with so many side effects and disabilities. ”

Emma during treatment



Introduction

“

We say children are just 30 per cent of the population – but they are 100 per cent of the future. ”

Professor Shai Izraeli, Director of the Department of Hematology-Oncology, Schneider Children's Medical Centre in Israel and grant recipient.²

Around 1,800 children and 2,600 young people are diagnosed with cancer each year in the United Kingdom and will undergo difficult treatments, with potentially life-altering side effects. Their families will experience emotional, logistical and financial challenges. Both will need support of different kinds at different stages.³

Cancer is the most common cause of death for children under 15 years.⁴ Children's cancers are different to adult ones – they occur in different parts of the body, they are different at a molecular level and they respond differently to treatment. Children and young people experience psychological changes that can influence their emotional response during and after cancer treatment.

The most common types of cancer in children are acute leukaemia (a cancer of the blood) and cancers of the brain and spinal cord. Rare cancers in children include neuroblastoma (a cancer of the nerve cells) and Wilms' tumours (in the kidneys). The different types of cancer are discussed later in the report.

Children with Cancer UK is a charity dedicated to improving survival rates and the quality of life in young cancer survivors and to finding ways to prevent cancer in the future. The charity was founded by Marion and Eddie O'Gorman as 'Children with Leukaemia' in memory of their son Paul who died from the disease at the age of 14 and his older sister Jean who also lost her life to cancer just 9 months later. Princess Diana inaugurated the charity on 12 January 1988.

Turning their grief and shock into action, the O'Gorman family started raising money to fund research into new treatments. This was a family effort, with mail-outs prepared around the O'Gorman family table.

Very soon, the O'Gormans reached and engaged a wide range of stakeholders, including families, researchers, doctors, charities and celebrities. Within four years, they had raised their first £1 million. Its successful fundraising enabled the charity to support a wider range of children's cancers and was subsequently renamed Children with Cancer UK.

During those 30 years, the charity has grown and developed its remit and has touched thousands of young lives. Supporters have raised more than £230 million in total so far. This money is vital in supporting research programmes, building research facilities, raising awareness and directly helping children and families affected by cancer by funding welfare projects and practical support.



Paul and Jean
New Years Day 1987
Royal Free Hospital,
London

A snapshot of Children with Cancer UK



The charity's vision is of a world where no child dies of cancer.



Its mission is to improve survival rates and the quality of survival in young cancer patients and to find ways to prevent cancer in the future.



So far it has raised over £230 million.



Over 30 years it has grown to become a major funder of research. In 2018 it was providing funding to 55 research projects totalling £14 million and five research fellowships.



The charity also funds patient hotels, facilities for NHS services, research centres, conferences, financial support for families affected by cancer, VIP days out and awareness raising activities.



It aims to grow further, to become the UK's largest not-for-profit contributor to research into children and young people's cancers, and to grow its net charitable activities income to £20 million by 2020.

Children with Cancer UK asked The King's Fund to produce a report to mark its 30th anniversary and this is the result. In the following pages we look at how advances in cancer treatments have changed people's lives – thanks in part to funding from Children with Cancer UK.

We've looked at what has changed for children with cancer in the 30 years since Eddie and Marion set up the charity and what the main reasons for change have been – including Children with Cancer UK's role in this. We've spoken to doctors, researchers and other experts in the field. We've looked at the research that has helped to shape more effective and kinder treatments, as well as into causes of children's cancers. It is not easy for very young children to talk about having cancer treatment, so we've looked at what parents have said about their experiences to understand the impact of cancer on the whole family.

There is lots of good news to tell: there have been dramatic improvements in survival rates for some children's cancers, mainly driven by better understanding of how the disease itself works and how best to treat it. There are now more than 30,000 survivors of childhood cancers living in the United Kingdom.⁵

However, we found that in 30 years survival rates for some children's cancers have changed very little. Also, some of the good news has a clear downside – the side effects. For some children who survive cancer, treatment can seriously affect their long-term physical and mental health. Important work for the future will be to find out how to lessen and prevent these side effects.

Children with Cancer UK has a strong commitment to improving the lives of children and their families affected by cancer. The charity plans to support work to identify what causes children's cancers, find safer, more effective treatments for children and young people and support children and families during and beyond cancer treatment.



It's genuinely fair to say that Children with Cancer [UK] have played a big part in the success of the cancer teams at Great Ormond Street. They're providing better clinical facilities, they're funding the research to look into new treatment. ”

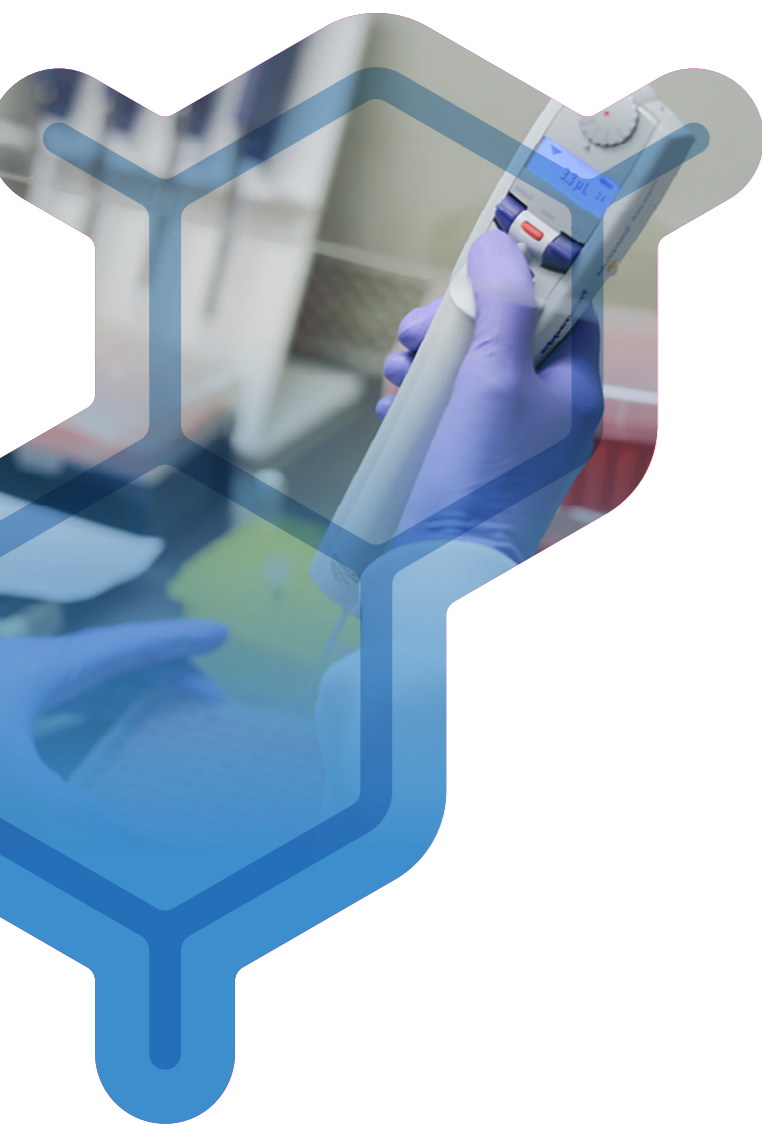
Tim Johnson, Chief Executive of Great Ormond Street Hospital Charity⁶



Executive Summary:

Thirty years of achievement

Children with Cancer UK commissioned an independent charity (The King's Fund) to look at how advances in cancer research and treatments have changed people's lives. The King's Fund found that Children with Cancer UK has had particular impact and success in the following areas:



Funding life-saving and life-changing research

Children with Cancer UK has a strong track record of investing in research with the potential to transform how children and young people are treated for cancer.

- **Minimal Residual Disease (MRD) testing**
Funding from charities like Children with Cancer UK and Bloodwise in the early 2000s enabled researchers to develop a test that makes treatment more effective for the most common children's cancer (acute lymphoblastic leukaemia, or 'ALL'). MRD testing is now used in the NHS as part of standard care for ALL.
- **Precision medicine**
Children with Cancer UK funding has enabled researchers to develop expertise and capacity for 'precision medicine' – tailoring treatment to an individual's cancer, and sparing them intensive treatment they don't need or could cause further harm.
- **Wide-ranging research**
The charity's panel of scientific experts runs robust assessments to determine funding for a wide range of research – both large- and small-scale.
- **'Seed-funding'**
The charity has often 'seed-funded' research projects that have been a springboard for much wider investigations, leading to discoveries that will ultimately change what we know about children's cancers and how to cure them.
- **Responsive to researchers' needs**
Children with Cancer UK recognises that infrastructure for research is just as important as outcomes. It has funded four research centres to give researchers access to the best laboratory facilities to do their work.

Supporting children with cancer and their families

- **Funding hospitals and other charities**
Children with Cancer UK responds to requests for funding to support and care for children, young people and their families.
- **Funding temporary 'patient hotels'** where parents can stay free of charge, so they are close to their children during treatment.
- **Providing welfare support to families** in financial difficulties during the treatment process, when expenses like travel and accommodation can run into hundreds of pounds a month.
- **Funding days out and activities for children with cancer** to have something fun to distract them from their treatment.

Understanding the causes of children's cancers

- **Children's Leukaemia International Consortium ('CLIC')**
Children with Cancer UK has helped to launch CLIC, which pools epidemiological data and DNA samples from research studies conducted in 12 countries. This gives researchers a unique opportunity to fill gaps in understanding how environmental and genetic factors might cause cancer in children.

Collaborating and campaigning

- **Uniting the children's cancer 'community'**
Children with Cancer UK is highly regarded for bringing the children's cancer 'community' together.
- **Organising** annual conferences and events where researchers share learning and collaborations with other organisations. This is vital to keep children's cancers in sharp focus as a serious issue in its own right.
- **Children and Young People with Cancer Coalition**
Children with Cancer UK was instrumental in forming this network of cancer charities. It plays an important role in campaigning and shaping policy for children and young people with cancer.

How Children with Cancer UK's funding has translated into real impacts



Children with Cancer UK's aims



Activities funded by Children with Cancer UK



Impacts

Causes

- To understand more about **why** children develop cancer
- To **find explanations** for the increase in risk of cancer
- To establish whether **prevention** is a possibility

- Ran **international scientific conferences** on causal research
- Helped to **launch and supports** the Childhood Leukaemia International Consortium (CLIC)
- Funds research** into causes

Improved knowledge base thanks to the establishment of a data collection centre to pool data from international studies to advance understanding of what causes cancer in children

Treatment – driving forward developments on:

- New approaches to diagnosis
- Identification of markers of likely outcomes
- Improvements to tackle those forms of childhood cancer still eluding successful treatment
- Minimising the risk of adverse, treatment-related effects

- Runs clinical workshop meetings and conferences on **research and advances in treatment**
- Funds the development** of the minimal residual disease (MRD) test that individualises treatment for most common form of childhood leukaemia
- Funds ground-breaking research** into more effective, kinder treatments with fewer long-term side effects

The MRD test has **allowed greater precision in deciding how much chemotherapy is needed** to treat individual cancers. Avoiding excessively intense chemotherapy where possible can substantially enhance the patient's experience and **reduce the likelihood of developing harmful side effects later in life**. The MRD test is now part of standard NHS treatment for this type of leukaemia.

Long-term risks

- To understand more about the long-term risks faced by childhood cancer survivors, of whom there are now more than 30,000 in the United Kingdom.

- Fertility preservation** in pre-pubertal boys treated for cancer

The setting up of the **first and only UK-based service** to collect and preserve samples from boys (taken before treatment). This offers these boys the chance of restoring their fertility and of having a family in the future.

What we know about cancer in children and young people

“ Until we [are] ... curing every child with cancer, or preventing every child [from] getting cancer, why should we be complacent? ”

Professor Sir Mike Richards, National Cancer Director 1993–2013

Cancer is the most common cause of death in children under 15.⁷ Each year, around 4,400 children and young people are diagnosed with cancer in the United Kingdom each year.⁸ That's equivalent to 12 families on average each day getting the news that their child has cancer.⁹

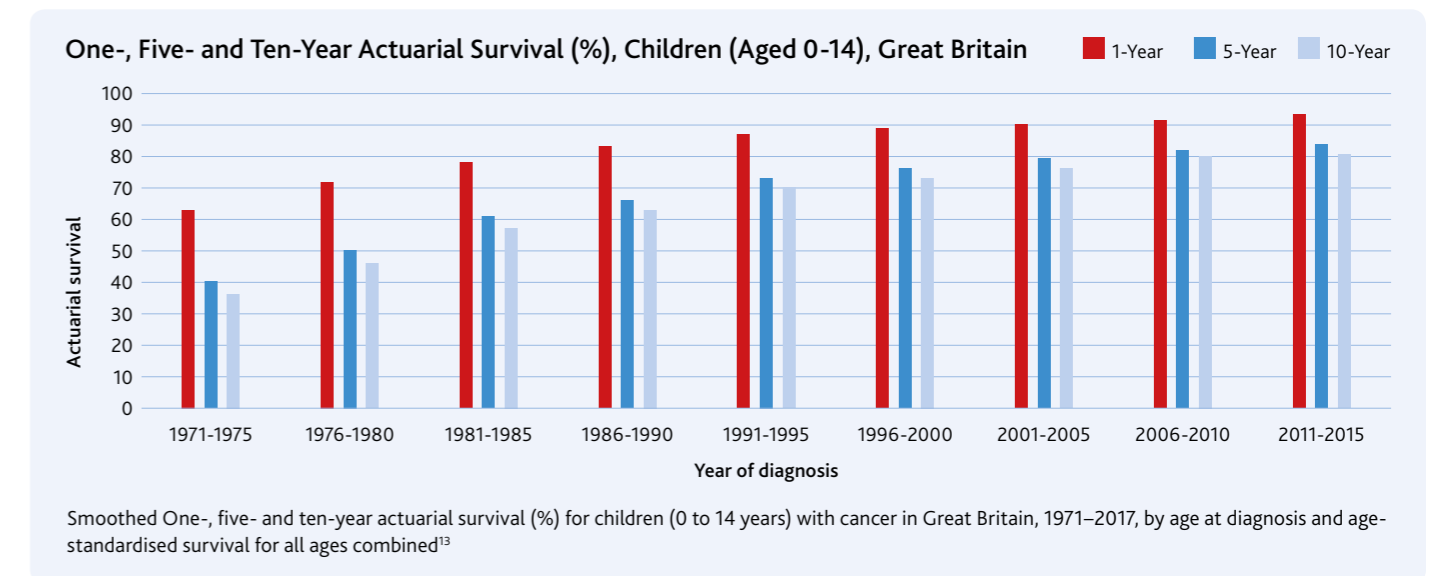
How likely are children and young people to survive cancer? If they do survive, how will their lives be affected? Can all types of cancer be cured? What is Children with Cancer UK doing to help? Here we take a closer look at the data to answer these questions.

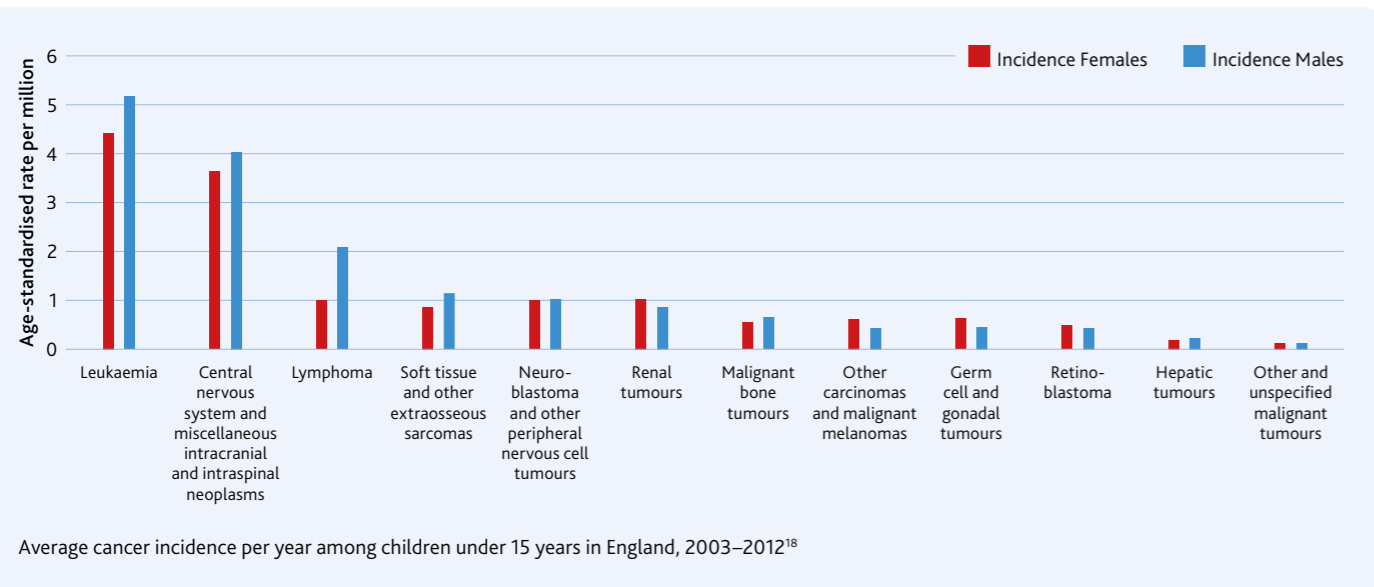
Treatment and survival – positive trend for many
Treatment for cancer in children is one of the great success stories of health care in the past 50 years but much more progress is still needed. Cancer survival is usually measured as the percentage of patients who are living at five and ten years after diagnosis. In the early 1970s, the five-year survival rate for children under 15 in Great Britain was 40 per cent and the ten-year rate was 36 per cent. By the time that Children with Cancer UK was established in 1988, these had risen to 66 per cent and 63 per cent respectively.¹⁰

That positive trend has continued – survival is now more than double what it was in the 1970s. Today 83 per cent of children with cancer survive for five or more years and 80 per cent survive for ten or more years.

However, the data also shows that for certain types of cancer (such as neuroblastoma and bone tumours) there has been little increase in one- and five-year survival rates, and no increase in the ten-year survival rate.¹¹

To increase the proportion of children who survive cancer we're likely to need more breakthroughs from research. There is also potential for improvement by reducing inequalities in survival between socio-economic groups.¹²





Incidence of cancer – on the rise

The incidence of cancer in children and young people is increasing, although some of this increase may reflect improvements in detection and diagnosis. Incidence increased by 13 per cent for children between the early 1990s and 2015.¹⁴

As with children, the proportion of young people aged 15 to 24 surviving cancer in the United Kingdom has improved. Nowadays more than eight in ten young people are living five years after diagnosis.¹⁵ But further progress is also still urgently needed in this age group.

The incidence of cancer in young people has increased by 33 per cent over the past 20 years, and the increase has been greatest in young women. Around 2,600 young people in the United Kingdom are diagnosed with cancer each year, equivalent to seven young people per day.¹⁶

Some studies suggest that survival is significantly lower than the European average for young people with cancer in England, although the data used for comparison is not recent and further research is needed to test this.¹⁷

Given that the rate of improvement in survival rates for children and young people has slowed in the last decade or so, and has remained broadly static for certain cancers, it is becoming increasingly urgent to reach a fuller understanding of what causes children's cancers – and what can be done to prevent them.

Funding research into the incidence of cancer in children and young people

No one has a definitive answer as to why the incidence of cancer is rising in children and young people. Technology and clinical skills have improved so more cancers are detected now which might have been missed in the past. But that is only part of the picture – the rest is still unclear.

That's why Children with Cancer UK plays a vital role in raising funds for and championing more research. The smaller numbers of children's cases mean that research into what causes children's cancers can be overshadowed by research into what causes adult cancers. A specialist grant-giving body like Children with Cancer UK can help to redress the balance.

There are many different views on what causes cancer and on how different risk factors contribute. For instance, those risk factors could include certain pre-existing medical conditions, genetic predisposition, exposure to ionising radiation and chemical pollution in air, food and the environment generally. Thanks to its specialist Scientific Advisory Panel, Children with Cancer UK makes independent assessments of what research to fund rather than advancing a particular viewpoint.

Since 2004 Children with Cancer UK has also organised major annual scientific conferences that bring the charity's unique network of experts together to share and disseminate the latest research findings on causation. In doing so, Children with Cancer UK is instrumental in raising the profile of the cancer prevention agenda and ensuring it is evidence-based.

The main forms of cancer differ markedly between children and young people. Leukaemias (cancers of the blood) are the most common form of cancer in children under 15 in the United Kingdom. For young people aged 15 to 24 cancers of the lymphatic system are the most common.¹⁹

Treatment outcomes – a mixed picture

Outcomes of treatment vary significantly by form of cancer. In children, survival of brain tumours, neuroblastomas and bone cancers has not improved by as much as it has for children with leukaemia. Among leukaemia types, survival is better for some forms than others. Moreover, treatment can be complex and intense – potentially involving giving children multiple forms of treatment (surgery, chemotherapy, radiotherapy and immunotherapy) in order to cure them.

Devon's story

Devon was two years old when he was diagnosed with neuroblastoma with bone and liver metastases.



Devon had a large solid aggressive tumour growing in his belly into his liver and into his kidneys. Devon endured months and months of hospital stays to treat his cancer including eight cycles of chemo, removal of the main tumour and removal of his kidney, stem cell harvest and stem cell transplant, radiotherapy and six months of immunotherapy.

On Devon's fourth birthday, he finally got to ring the end of treatment bell at hospital, and we received the best news ever – that Devon was in remission. He still has problems due to the treatment; he has to wear hearing aids in both ears because [of] the effects of the chemo and he has just been diagnosed with stage 3 kidney disease – again, because of the chemo. But I try to always remain positive and I consider myself [lucky] that he has not only survived the cancer itself but the treatment to cure it as well. ”

Devon's mum, Deborah²⁰, tells his story.

Devon during treatment



Even among those who survive cancer, there may be other impacts on their health and wellbeing in the long term. For example, it is estimated that more than half of children who are treated for a brain tumour will develop a learning difficulty.²¹ Among young people, the overall figures mask significant variation in incidence by age: for example, there is more than a 100-fold difference between rates of cervical cancer in 15- and 24-year-old young women.²²

Children and young people can also have quite different emotional and physiological needs as they undergo treatment. As more children and young people survive cancer into adulthood, the long-term effects of treatment and the implications for their adult health status are only beginning to be understood.

Dr Owen Williams is Section Head at the Molecular Haematology and Cancer Biology Unit, at the Institute of Child Health, University College London and is a Children with Cancer UK grant recipient. He says the problem is these medicines are not specific. So they are toxic to cancer cells, and for similar reasons they are toxic to some normal tissue, and different people respond differently to them. So, some people will have quite severe side effects, whereas other people won't, he explains.

Changes in treatment – the next breakthroughs?

For many years surgery, chemotherapy and radiotherapy have been the most familiar trio of treatment for cancer. Now innovative new approaches are exploring other treatments for certain forms of cancer in childhood and early adulthood. Children with Cancer UK shares the view that treatment should not only cure cancer but should enable children to go on to live happy, healthy lives without side effects. The charity is directing funds towards research that will make this kind of difference as well as potentially being game-changing in terms of efficacy.

Precision medicine involves profiling the unique set of DNA changes as an individual patient's tumour grows. Treatment is targeted to match that specific genetic profile. Precision medicine is widely regarded as promising, especially for aggressive tumours that are currently difficult to treat effectively. Children with Cancer UK has developed a major five-point plan to support the development and roll-out of precision medicine for children's cancer services in the NHS by 2020.

Immunotherapy treatments harness and bolster the body's own immune system to target and destroy specific cancer cells, leaving other parts of the body unaffected. They offer the prospect of highly effective treatment with milder side effects. To date, only a handful of immunotherapy drugs have been licensed and they may need to be given in conjunction with chemotherapy. Children with Cancer UK is funding a number of projects to help advance understanding of immunotherapy's potential and the drugs and services that could be developed.

Immunotherapy and precision medicine could be the next big breakthroughs for some cancers. However, both are still at early stages of development. Significant and sustained research is needed along with investment in facilities, equipment and training for health care professionals.

Zunairah's story

Zunairah was only one when she was diagnosed with acute lymphoblastic leukaemia (ALL).

“

Zuni's treatment lasted over three years. The chemotherapy caused various dramatic changes in Zuni's appearance. It started with Zuni gaining a large amount of weight. As soon as we got used to this change, we faced another: [her] hair began to fall out due to the chemotherapy and soon she had no hair left. Our bubbly Zuni soon became moody. As a family we had to keep up with her anger and mood swings. Zuni even forgot how to walk. With the help of the nurses and doctors, as a family we worked together to get her walking. ”

Zunairah's dad, Ayaze²³, tells her story.

Zunairah and her family celebrated her cancer being in remission with a day out to see 'Disney on Ice', courtesy of Children with Cancer UK.

Zunairah during treatment



Leading the way in funding innovative research

There has been huge progress in treating some children's cancers. But researchers still need to find answers to some major, life-affecting problems – such as the rising incidence of children's cancers and the serious side effects of treatment.

Innovative research is needed to understand how to fight all children's cancers, how to give children the best chance of leading happy, healthy lives and what causes children's cancers.

Children with Cancer UK is one of the leading funders of research in the country. Here's what they are doing in different ways to improve the outlook for children and young people.

View from the lab:

“

Twenty years ago, we would often just identify a cancer from how they looked down a microscope and then [it was] ... pretty much “one size fits all” [in terms of] treatments that we used for those patients. And ... in the last 20 years, we've been able to ... really understand the key pathways and the key processes that cause cancers to develop. We can start to understand which of them could potentially be targeted with new therapies, we can start to understand just how they're driving the cancer and we can start to see if there's anything about them that we can use to predict how the cancer will behave ...

What the new biology is doing is that it's allowing us ... to start to tackle that much more pragmatically and [with] design therapies which truly are based on an individual's cancer, rather than these “one size fits all” approaches. ”

Professor Steven Clifford

Director, Northern Institute for Cancer Research, Newcastle University and grant recipient²⁴



Professor
Steven Clifford

Developing better and kinder treatments: now

Children with Cancer UK has an established history of investing in and supporting research into cancer biology as part of its overall aim to help save the lives of children and keep families together.

Five-year survival rates for childhood cancer are improving mainly because of better understanding of cancer biology and collaborative clinical trials in the United Kingdom and internationally.²⁵

“

A lot of this [improvement] is due to the same drugs, but used in different ways and used more effectively, but it's also due to science being better than it was and us knowing a lot more than we did in the past”

According to grant recipient Dr Owen Williams from University College London's Institute of Child Health.

Researchers have been investigating the biological differences between normal cells and cancer cells. They have focused on the mechanisms that underlie cell growth, the transformation of normal cells to cancer cells, and the spread of cancer cells (metastasis). Advances in whole genome sequencing (the mapping of DNA) have also enabled researchers to identify more accurately sub-types of cancers that might respond to different types of drugs or treatment, or combinations of them.

Children with Cancer UK has co-funded important elements of a major, ground-breaking clinical trial that has significantly contributed to better outcomes for young patients. It was particularly valuable in proving the reliability of the minimal residual disease (MRD) test for risk of relapse that is now part of standard NHS care for the most common form of leukaemia in childhood.

“

I think there's a really strong story ... about the ... systematic way that clinical trials have been set up in this country, [with] every child [with cancer] getting access. Children with Cancer UK along with Bloodwise have paid for some of that and have paid for the development of some of the tests that are helping doctors now put children on different treatment paths.”

Dr Alasdair Rankin, Director of Research and Patient Experience, Bloodwise²⁶

Studies show that in general, clinical trials have saved the lives of many children and young people, shown whether treatments are safe and effective and have made it possible to develop best practice guidelines to improve the experience of treatment.²⁷



Children with Cancer UK and the minimal residual disease (MRD) test



Leukaemia is the most common cancer in children. Almost four out of every five cases involve the type called acute lymphoblastic leukaemia (ALL). Improving treatment for ALL has the single greatest potential to save the lives of children with cancer. Survival rates for childhood leukaemia have improved dramatically since the 1960s due to effective intensive chemotherapy. But this intensive treatment is distressing and has serious side effects that can last into adulthood.

In one of its largest research investments to date, Children with Cancer UK contributed more than £3.5 million across two rounds of a major national clinical trial to improve ALL treatment, known as UKALL2003 and UKALL2011. Children with Cancer UK worked in partnership with the leukaemia charity Bloodwise (previously known as the Leukaemia Research Fund). The two charities have enjoyed a close and collaborative working relationship going back almost 30 years.

The results of UKALL2003 were ground-breaking both in terms of saving the lives of most of the children and young people who were recruited and of learning how to personalise treatment. The trial has been recognised by the All Party Parliamentary Group on Medical Research for the excellence of the research and its impact.²⁸

Researchers first approached the two charities in the early 2000s. Children with Cancer UK and Bloodwise both saw that there was significant potential benefit in developing a test that could predict (and then check) how well each child responds to chemotherapy.

UKALL2003 developed a way of tailoring treatment to individual children's needs and their risk of relapse. As a result, treatment can now be adjusted to be only as intensive as it needs to be – with the least distress and the fewest side effects as a result. The ability to predict risk of relapse means that treatment can be better designed to prevent this occurring.²⁹

Key to this tailoring is the 'minimal residual disease' (MRD) test. This test measures to a very high degree of accuracy how much of the leukaemia remains at a molecular level, and therefore shows how high the risk of relapse is. It enables doctors to reduce the intensity of treatment in many cases, giving children and their parents greater clarity and reassurance about what the treatment is likely to involve and for how long. It also saves the NHS money by avoiding unnecessarily intensive treatment.

As part of the UKALL2003 trial, researchers were able to prove that the MRD test is a highly reliable tool that can predict the risk of relapse. The MRD test has now been adopted as standard care for ALL in the NHS thanks to successful testing and evaluation within UKALL2003. Children with Cancer UK's funding was crucial in enabling this breakthrough.

“ [My son] tested MRD-positive and was given the more intense chemo he needed. I'm so grateful that this test was available for us. To know he was at high risk of relapsing and be able to change his chemo protocol to match what he needed, is amazing. ”

Parent of a child treated for acute lymphoblastic leukaemia³⁰

A further clinical trial (called UKALL2011) is now under way to build on the pioneering development of the MRD test. The new trial is using the MRD test to evaluate the potential of new chemotherapy treatments to further improve outcomes and reduce relapse. Children with Cancer UK is again providing funding towards this research in partnership with Bloodwise.

Developing better and kinder treatments: the future

Although treatment can save many children's lives, it can have significant and long-term impacts on some survivors. Due to being treated with intensive therapies such as chemotherapy or radiotherapy (or a combination of those), children are at risk of developing various 'late effects' that can persist into older age and for many years after the end of treatment. Late effects may include developing a different type of cancer, cardiovascular disease, damage to brain functioning and infertility.

Fertility preservation in pre-pubertal boys treated for cancer

Radiotherapy and chemotherapy can both cause physiological damage that could mean a child who survives cancer treatment may not be able to have children of their own later in life. Options exist to help to preserve fertility in adults (for example, storing sperm) and the evidence is building for doing the same for pre-pubertal girls. However, there are very limited prospects for preserving fertility for pre-pubertal boys.

With funding from Children with Cancer UK, Dr Rod Mitchell at the Centre for Reproductive Health in Edinburgh and his team are exploring fertility preservation for pre-pubertal boys. They are investigating the best way to preserve testicular tissue taken from boys deemed to be at high risk of infertility in the future due to their cancer treatment. With consent obtained during a pre-treatment counselling session, the tissue is taken from a biopsy of the testes before treatment for storage (by freezing) until adulthood. The team is building up evidence about how to engage children and family members in discussions about future fertility. This will help to develop best practice guidelines.

This is the first UK service of this type and has been running for around two years, with some 100 samples already collected between the Centre for Reproductive Health and another research centre.

The research group is also investigating how to develop the germ cells in the tissue so that they can eventually produce sperm; and whether tissue can be transplanted back to a patient. This aspect of the research is at a very early stage and it could take 10 to 20 years to develop a standard clinical option for children.

This research study also involves investigating what effect chemotherapy has on the testes. This knowledge will contribute towards efforts to modify treatment and reduce the likelihood of damaging a child's future fertility.

As well as driving forward research into more effective, less toxic cancer cures, Children with Cancer UK also funds research into how treatment might affect children's physical and mental health in the future – and into finding ways to help them to live up to their full potential.

Chemotherapy targeted at the brain to fight leukaemia carries the risk of killing healthy brain cells as well as cancerous ones. This can lead to problems with intelligence development, reduced attention span and impaired memory.

With funding from Children with Cancer UK, Dr Christina Halsey and her research team in Glasgow are conducting an innovative research study to predict which children are at the greatest risk of developing these types of problems. The aim is to establish whether simple

computer-based programmes, genetic or cerebrospinal fluid (CSF) tests can identify children at risk of brain complications during therapy for acute lymphoblastic leukaemia (ALL).

Still in its early stages, the research could demonstrate how to predict which young patients are at risk of developing late effects related to brain functioning. With that knowledge, researchers could design interventions (such as brain-training programmes or new drugs) to reduce or prevent the damaging effects of chemotherapy on the brain.

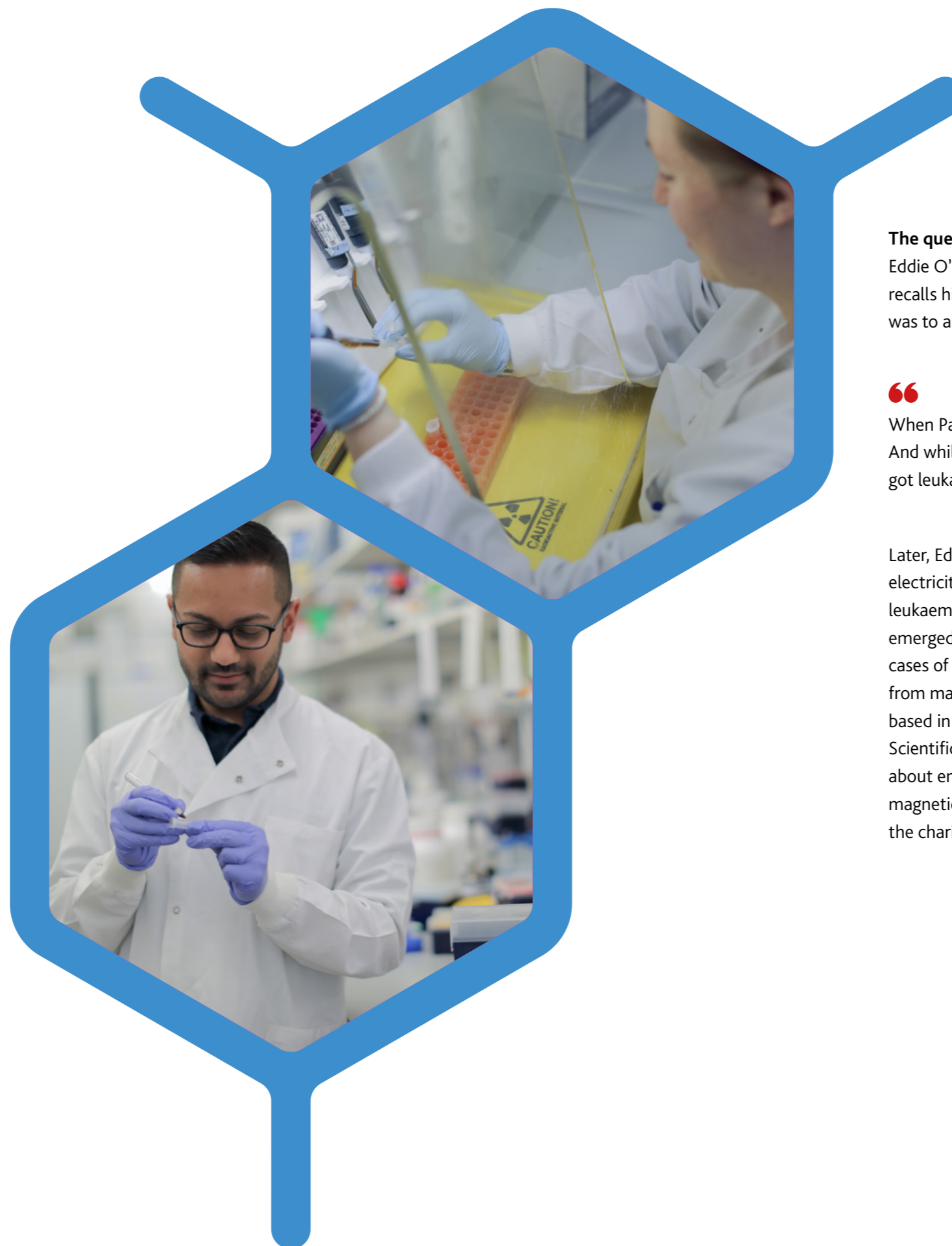


Exploring the causes of children's cancers

Since 1995, Children with Cancer UK has invested significantly in research on potential causes and prevention of children's cancers. Understanding the causes of children's cancers is challenging therefore researchers are pooling data from international studies to gain better insights.

In 2007, Children with Cancer UK contributed substantial funding to set up the Childhood Leukaemia International Consortium (CLIC)³¹. CLIC aims to promote investigations of the role of environmental and genetic risk factors in various sub-types of leukaemia among children³². Funding from Children with Cancer UK continues to help CLIC with key activities. For example, in 2013 it helped to establish a central data collection centre at the International Agency for Research on Cancer (IARC, part of the World Health Organization). This collects research results from around the world on environmental and other causes of childhood cancer.

Children with Cancer UK is proactive in seeing the value of funding research activity such as this. Funding means that researchers can continue investigating what causes children's cancers, so that we know how they might be prevented. In the United States, researchers like Dr Mark Miller (who contributes regularly to Children with Cancer UK's scientific conferences) have used the data to develop evidence-based education and awareness programmes³³ – something we don't have in the United Kingdom for children.



The quest to understand causes, from the charity's beginnings

Eddie O'Gorman, Founder and Chairman of Children with Cancer UK, recalls his son Paul asking why he had got cancer – and how difficult it was to answer that question.

“

When Paul was diagnosed ... he went straight to the Royal Free Hospital. And while we were waiting there, he said, "hey dad, why me, why have I got leukaemia?" And I said, "I don't know, son, I don't know". ”

Later, Eddie drew a possible connection between the presence of an electricity substation within the grounds of the family home and Paul's leukaemia and wanted to investigate this further. A body of evidence emerged during the 1980s about the potential link between some cases of childhood leukaemia and exposure to electromagnetic fields from mains electricity cables and transformers. Eddie engaged experts based in the United Kingdom such as Professor Denis Henshaw, now Scientific Director at Children with Cancer UK. Examining evidence about environmental causes of children's cancers, including exposure to magnetic fields and radon, was very important from the earliest days of the charity's history.

Supporting researchers

Children with Cancer UK is distinct from other funders in that it invests in numerous research programmes at various stages of their development.

It is part of the charity's ethos to encourage and support 'early stage' research to test whether an idea can move forward to something like a national clinical trial. Thanks to this funding, researchers can carry out clinical investigations to answer critical questions before testing a new type of treatment more widely in a clinical trial. This is particularly important for cancers that we know less about and where survival rates have not improved.

Other key funding streams from Children with Cancer UK include five-year Postdoctoral Research Fellowships and Clinical PhD Studentships. These awards help individuals to drive forward the research needed to understand the causes of children's cancers, how best to diagnose and treat them and what the long-term risks faced by survivors are. Funding of this type helps to build capacity in research centres and, in the longer term, to develop the careers of researchers and clinicians.

Supporting the infrastructure for children's cancer research

Infrastructure, such as research facilities and access to robust data, is vital to successful research. Children with Cancer UK has played a key role in enabling the robust study of children's cancer by investing in infrastructure that enables research discoveries to be made and disseminated widely. The charity has provided funding towards the costs of setting up five research centres in England and Scotland.

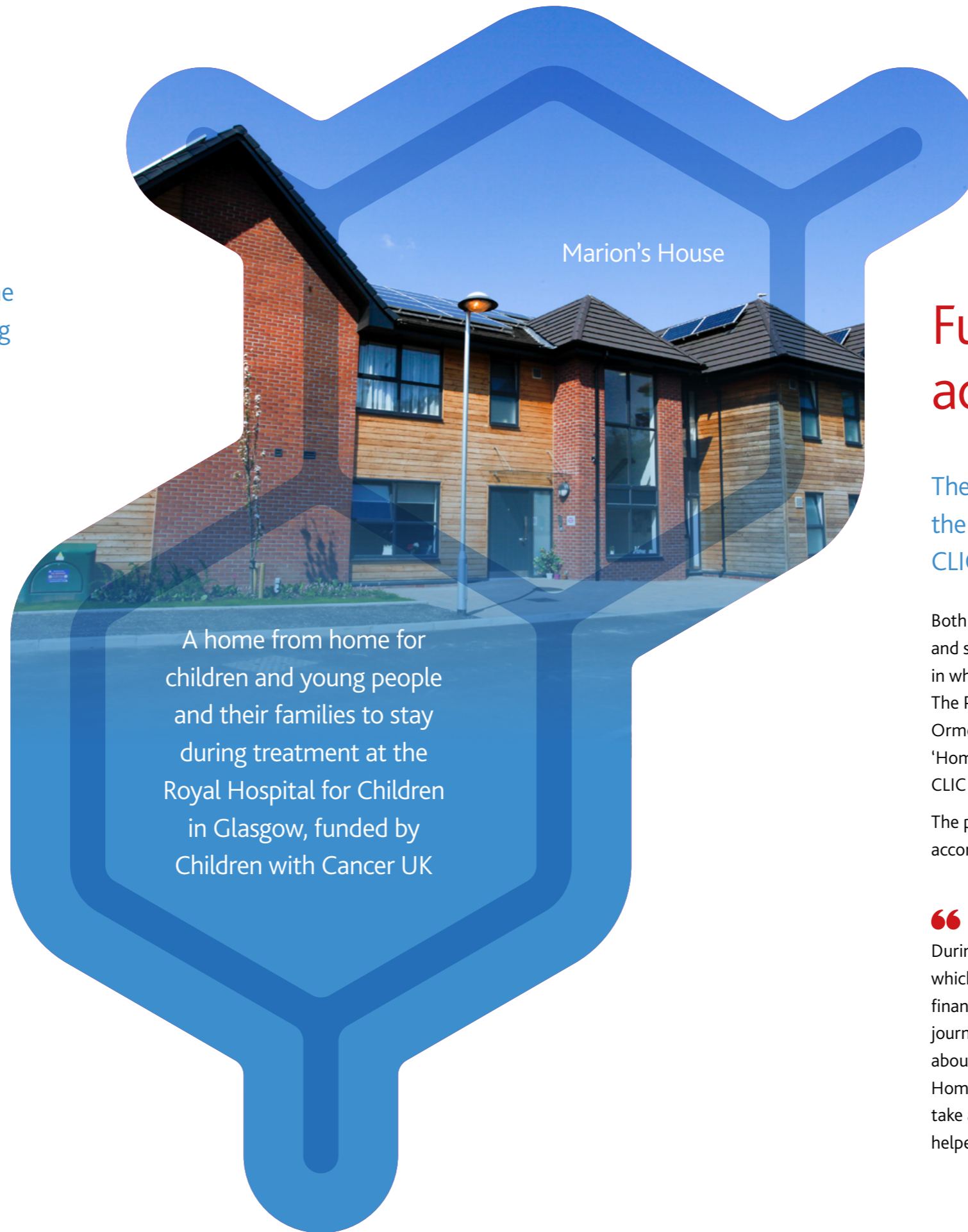
It has a long record of investing in this area. During the 1980s it raised £2 million to establish the Paul O'Gorman Childhood Leukaemia Research Centre at Great Ormond Street in 1995. Since then, the research centre has grown and, combined with the Institute for Child Health (based at the University College of London, UCL), is now the largest paediatric research centre in Europe. In 2007, Children with Cancer UK also provided funding for the nearby UCL Cancer Institute's building. The other English research centres are in Newcastle upon Tyne and Manchester. In Newcastle, Children with Cancer UK provided funding towards the building, which opened in 2004 and is used for pre-clinical trial drug development and basic research, while in Manchester it funded equipment for a molecular diagnostic laboratory in 2006. In Scotland, the charity provided funding towards a major new leukaemia centre in Glasgow, which opened in 2008.



Helping children and families through tough times

From the outset, Children with Cancer UK has valued its partnerships with others in the children's cancer community. Understanding that one organisation alone cannot do everything, Children with Cancer UK works with valued partners in the voluntary and community sectors to fulfil its simple but important aim to help the families of children with cancer.

Members of the O'Gorman family can relate to the difficulties experienced by families during treatment. Marion and Eddie slept on chairs in the hospital to be close to Paul whilst he was being treated.



A home from home for children and young people and their families to stay during treatment at the Royal Hospital for Children in Glasgow, funded by Children with Cancer UK

Funding temporary accommodation

The charity has made substantial donations to the Great Ormond Street Children's Charity and CLIC Sargent (not to be confused with 'CLIC').

Both have used the funding towards the costs of buying properties and setting them up as temporary accommodation for parents to stay in while their children are being treated in specialist centres nearby. The Paul O'Gorman Patient Hotel is within walking distance of Great Ormond Street Children's Hospital. Similarly, there are five temporary 'Homes from Home' in England, Scotland and Northern Ireland run by CLIC Sargent, based within short distances of treatment centres.

The parent of a child being treated for cancer describes what the accommodation means:

“

During the first weeks of treatment we basically lived in the hospital, which was 75 miles from our home. We hadn't thought about the financial impact, but we certainly noticed it when it hit us. Every journey was costing about £20 and that is before you're worrying about feeding yourself. When we were offered accommodation in the Home, the difference it made was just unbelievable. Suddenly you can take a moment to rest. The exhaustion can be overwhelming and this helped so much. ”

Easing financial hardship

Another form of support is the exceptional grants programme that is fully funded by Children with Cancer UK annually and administered by CLIC Sargent to feed into the social care service they provide.

Parents experiencing financial hardship related to their child's cancer treatment can apply for a grant and use it to pay for essential living costs. In 2017, some 1,510 families received this financial assistance.³⁴ CLIC Sargent social workers report that the grants are particularly valuable because the money can be tailored to individual needs.

“

Those funds are incredibly important... nobody wants to fund your gas bill or to buy you an Oyster Card so that you can actually afford to get from Great Ormond Street Hospital to a cheap supermarket. Nobody want to fund those things – it's really gritty, boring stuff, but it's absolutely vital to families. ”

**Kate Lee, Chief Executive,
CLIC Sargent**

Enhancing centres of care

Children with Cancer UK has also donated substantial funds to NHS cancer centres like Great Ormond Street Hospital, Bristol Royal Hospital and Birmingham Children's Hospital to enhance young patients' experiences of care.

The funding helps to buy equipment like an intraoperative MRI scanner, and to turn out-dated buildings into more comfortable, pleasant environments. This is particularly important given how long some children and their carers spend at hospital.



Remembering to have fun

Treats are important too. Since its earliest days, Children with Cancer UK has arranged for children affected by cancer and their family members to attend special performances of Zippos Circus as VIP guests. The idea is for children to have something fun to distract them from their treatment. It makes the event very popular with children and parents alike.



Family day out at Zippo's Circus organised by Children with Cancer UK

“ Zippos Circus was such an amazing day out from start to finish! They made [my daughter] feel super special. It was a totally wonderful family day out. [She] enjoyed the circus so much she got invited back a few weeks later to be a VIP at the show in Bath. It is so lovely to just have a normal fun day out with lots of smiles. We are excited to come back this year and see it all again. ”

Funding assistive technology

Children with Cancer UK partners with the charity Lifelites to support children with cancer, including those whose cancer can't be cured, with assistive technology to enable them to communicate.

This equipment plays an important role in helping children and their families towards the end of life. Children use the technology to communicate with family members, friends or care staff, to regain a degree of control or independence, or to distract themselves while experiencing difficult symptoms. In 2017, Children with Cancer UK funded assistive technology for more than 1,000 children and young people with cancer in hospices across the country.³⁵

View from a family: a mother describes her daughter's delight at being given an iPad by Lifelites³⁶

“ It might seem strange that a tablet can have such a huge impact, but it really has changed her life. It gave her a voice, the one she so desperately wanted and deserved. To hear her giggling is the most beautiful thing ever, to see her smile makes my day, and to see her face as she tells me she loves me using the software on the iPad is the best feeling in the world. I could go on forever about how important this technology is to her, it has made such a difference to her life. It gave her back the twinkle in her eye, and we couldn't have hoped for anything better. ”

Complications during surgery to remove a brain tumour left Heavenly non-verbal and with limited mobility. She uses a Lifelites iPad to communicate and stay in touch with her friends, among other things.



Raising awareness about children's cancers and collaboration

Impact through raising awareness

Children with Cancer UK has built a high profile over the past 30 years as a champion for children and families affected by cancer. In 2017, the charity was in the newspapers 630 times, had 9,000 Twitter followers and its website was visited nearly half a million times. Using this influence, Children with Cancer UK campaigns to keep children's cancer high up on public and policy agendas. For example:

- Children with Cancer UK raises awareness in ongoing or annual fundraising events. The Virgin Money London Marathon and the Great North Run combined raised more than £3 million for the charity in 2017, which helps to fund more research and welfare work.³⁷
- During Childhood Cancer Awareness Month (an annual, national event every September), Children with Cancer UK launched a 'Golden Moments' social media campaign to highlight the experiences of children with cancer through videos and podcasts on their website.
- Children with Cancer UK launched its Precision Medicine Initiative at the House of Commons in 2017. Before an audience of MPs and stakeholders, the charity announced funding for a £1.5 million research initiative to develop less toxic cancer therapies for children that could become standard care in the NHS. In October 2018, Children with Cancer UK boosted the funding to a total of £3.74 million.³⁸

Impact through collaboration

To maximise impact and ensure best value for money, organisations must actively seek out alliances with each other. Children with Cancer UK often teams up with other charities working in this sector and formed a network for the chief executive officers of cancer charities to share information and co-ordinate the efforts of their respective organisations. That informal network has evolved into the Children and Young People with Cancer Coalition, launched in May 2018. The coalition will strengthen the voice of the charities in campaigning and shaping policy. Already, the coalition has sent a joint letter to the Secretary of State for Health, urging for more action on key areas, including:

- Improving the experience of diagnosis
- Improving access to clinical trials
- Developing a tailored recovery package for children and young people with cancer
- Ensuring every child or young person has access to a cancer nurse specialist
- Developing an education programme about cancer for schools
- Ensuring access to psychological support
- Improving access to palliative care.³⁹

One of the main strengths is working with and financially supporting other, sometimes lesser-known organisations in the children's cancer community. In 2016 Children with Cancer UK was approached by the Brains Trust charity for help. Brains Trust was struggling to find the funding for a specific initiative to help the families of children with brain tumours. Children with Cancer UK saw the potential to support another charity in

directly helping families of children diagnosed with brain tumours. Children with Cancer UK provided the seed funding that helped to establish the Little Brains Trust. The funding means that parents of children diagnosed with brain tumours can access personalised coaching-led support – particularly important given the relatively poor outcomes for this type of cancer. The Brains Trust is working towards building a sustainable support mechanism to help people who may be feeling fearful and isolated.

Conferences and workshops

Children with Cancer UK has been running conferences and specialised workshops since 2004, when it ran a five-day international scientific conference on the possible causes of child cancer, held at Church House Westminster. The keynote speaker was Sir William Stewart, a former Chief UK Scientist and the then chairman of the UK Health Protection Agency. He welcomed the conference and congratulated the charity on having the vision to organise such a meeting.

Since then Children with Cancer UK has run conferences and workshops exploring advanced research into causes and better, kinder treatments.



To future achievements

Although childhood cancer is in many ways one of the big success stories of the health and care system over the past three decades, there is still a long way to go in reducing its impact. Here we identify key considerations likely to be important for Children with Cancer UK over its next 30 years.



Children with Cancer UK should continue to develop its role as a major fundraiser supporting research that has direct impacts on treatment, prevention and quality of life for all those affected by childhood cancer.

The UKALL trials, co-funded by Children with Cancer UK, are examples of research breakthroughs that led relatively quickly to the introduction of new, more effective clinical practice. But in other cases, the research process can involve many more stages over several years before it is clear how safe and effective a new treatment approach will be. Significant funding may then need to be raised before the necessary training, equipment and medicines can be secured. It is important that there is no let-up in the scale and pace of research, so that we continue to see new treatments for childhood cancers. Children with Cancer UK's funding of research will have an important role in helping to maintain this pace over future years.

View from a grant recipient: Dr Gordon Strathdee, Lecturer in Genome Instability, Northern Institute for Cancer Research

We have recently detected widespread alterations in DNA methylation that are induced rapidly by exposure to chemotherapy and then retained throughout treatment. We now need to do further research, to investigate if these can be used to predict late effects in childhood cancer survivors.

Children with Cancer UK should further develop its unique seed-funding role by working in partnership with others. This will maximise the impact that its resources can have, especially in enabling access to large-scale entities such as national bodies and pharmaceutical companies.

Children with Cancer UK's funding programme has paid particular attention to supporting early-stage studies, that are often under-served by other funders. This complements the funding of major clinical trials, which are the main focus for other research funding bodies. These early-stage trials are often small in scale but can be essential in enabling researchers to go on to develop proposals for major trials.

Similarly, Children with Cancer UK provided seed funding for four research centres, which yielded a 'proof of concept' and enabled them to bid successfully for ongoing funding to operate at a larger scale. Children with Cancer UK fulfils a specific role by targeting its resources in this way – supporting good ideas in their early stages that have the potential to develop into major research. In doing so, the charity works in close partnership with other charities, funders and universities to encourage findings to be taken up and to co-ordinate efforts.

Without Children with Cancer UK, there would likely be a gap in research funding in this early stage of innovation. Many good ideas would not progress to the next stage or develop sufficient evidence to make the case for funding a full clinical trial. There is a continuing need for Children with Cancer UK to fulfil this specific role of identifying and supporting early-stage innovation – without it, important ideas may never get off the ground.

View from a grant recipient: Dr Matthew Murray, Academic Consultant Paediatric Oncologist, University of Cambridge

Our research aims to improve non-invasive diagnosis of cancer to avoid: a) surgical biopsy in difficult-to-access tumours such as back of the abdomen, centre of the chest, brain; and b) repeat CT scans for disease-monitoring and follow-up – this will reduce cumulative radiation burden and reduce second cancer risk. From our funding by Children with Cancer UK we have established a partnership with a global pharmaceutical company, secured five years of funding for further research and applied for funding to support a clinical trial in the UK (outcome awaited).

Children with Cancer UK should continue to develop a range of support and services for families affected by childhood cancer, as a core part of its purpose.

We are still on the long journey towards a cure or non-invasive treatments for many forms of cancer. There is also only a limited understanding of prevention. Given this context, there will be a continuing need to provide care and support to children and their families after a diagnosis.

The main types of support that Children with Cancer UK has developed are: direct activities for children; practical and financial support for families to help them care for a child with cancer and be involved in their treatment; and fostering partnerships with other charities to join up the support that is available. It is hard to see the need for this support diminishing over the next 30 years. Indeed it is in providing this type of support where charities excel – they are uniquely able to adapt and respond to individual cases compared to statutory organisations.⁴⁰ This is likely to carry on being a fundamental element of Children with Cancer UK's role.

View from a partner: CLIC Sargent⁴¹

On average, parents and young people had an average additional annual spend as a result of a cancer diagnosis and its treatment of £4,400 for parents and £3,325 for young people. The number of parents who said that money was “often” or “frequently” a worry increased eight-fold after a diagnosis from 8 per cent to 65 per cent.

As well as funding research into treatments and causes of cancer, Children with Cancer UK should aim to improve understanding of the broader health, social and emotional impact of childhood cancers for survivors, especially over the long term.

More young people are now surviving cancer and living into adulthood, meaning that new needs will also emerge. We know that we are still in early stages of understanding the long-term health and emotional effects of a diagnosis and treatment for childhood cancer, and understanding what types of support or clinical services the survivors may need as adults and in older age.

Similarly, people now live for longer with the effects of childhood cancer alongside other long-term conditions needing treatment (such as diabetes, heart conditions or mental health issues). So we are still developing our understanding of the best ways to organise and join up the different hospital and community services and to manage drug interactions. We know that there is potential to significantly improve early diagnosis of many cancers, with possible opportunities from medical education, specialist roles in nursing and other professions, and emerging new technologies.

Children with Cancer UK should develop its role – in partnership with others as appropriate – to support advances both in research and in broader understanding of rare cancers, so that they are not overshadowed unduly by more common cancers.

Given the changing health and care landscape (including new technologies), continued effort will be needed to raise awareness and understanding of childhood cancers and to ensure that the public, the NHS and government understand what the priorities are. This is especially important because most of the types of cancer are individually rare, and do not generate such high levels of research and publicity as adult cancers.⁴² Very small numbers at a local level may not be very visible or well understood – but they are still important.

Two themes have strategic importance for Children with Cancer UK. First, Children with Cancer UK

will need to keep its priorities under review to be able to respond to changes in people's needs. Second, the potential areas of new development are large in breadth and scale, and could involve significant programmes of work rather than one-off projects.

View from a grant recipient: Professor Shai Izraeli, Director of the Department of Hematology-Oncology, Schneider Children's Medical Centre, Israel

There are extremely few foundations that give serious support to the study of children with cancer in general and in particular for children with leukaemia. As these are rare cancers and given the crisis of research funding, it is up to Children with Cancer UK to provide such essential grant funding.

Professor Tariq Enver
Director, UCL Cancer Institute
Long term collaborator with Children with Cancer UK and worked with Dr Shai Izraeli on the causes of childhood leukaemia



Working in partnership rather than alone – whether by bringing together experts in conferences, or formal programmes of joint work with other charities – is key to Children with Cancer UK's impact. The charity should continue this approach in the coming years.

The relatively small numbers of childhood cancers also mean that networking among clinicians and researchers, both nationally and internationally, is vital. This could be co-ordination or partnerships when conducting research and bidding for research funding. It will be important to continue to encourage networking and collaboration of this kind so that studies cover a sufficiently large sample and priorities are communicated effectively.

Regular conferences organised by Children with Cancer UK create opportunities for researchers to share their latest thinking and to identify common priorities. A key future direction will be for cancer charities and research funders themselves to go further in working in partnerships: the Children and Young People with Cancer Coalition, formed in 2018 and bringing together 14 charities, is an example of how working together could lead to a stronger voice and more consistent focus.

Children with Cancer UK should continue to support research into causes of cancer, but with a prudent long-term approach that avoids 'putting all the eggs in one basket'.

Understanding the causes of cancer in children and young people, and therefore what might prevent them, is of course the ultimate goal. But there is a vast range of potential risk factors, with a lack of consensus among researchers on their combined effects. Furthermore, understanding these factors requires innovation at the cutting edge of molecular and epidemiological analysis. A long-term commitment to research is essential, which covers multiple aspects and encourages researchers to come together and share findings.

Children with Cancer UK should build on its achievements by continuing to demonstrate dynamism, commitment and clarity of purpose.

Finally, it is clear that Children with Cancer UK will itself continue to develop and evolve as an organisation. Research suggests that charities that are set up by individuals driven by a personal passion must take care in how they manage a transition to another leader when the founding individuals step back or when the charity's activities broaden out.⁴³ The charity will need to continue to demonstrate the clarity of purpose and dynamism which characterised its early years, even if its specific activities and leadership style evolve beyond the founders' original vision in order to fit with a changing landscape. It should also measure its impact over time and continue reporting back to those who donate to it on the difference it makes to the lives of children, young people and their families.

Conclusion

Children with Cancer UK began 30 years ago as one bereaved family's commitment to children with cancer and their families. It has grown into a major research and support organisation that is known internationally as well as across the United Kingdom.

We have found a range of achievements in all of its charitable objectives and seen how Children with Cancer UK has developed roles which complement, rather than duplicate, those of other organisations in the cancer field. Making a difference to improve the quality of children's lives and relieve their suffering is the thread that binds the wide range of examples together.

What makes these achievements all the more extraordinary is that they had their starting points in one family's determination to make life better for other families coping with childhood cancer. What they also reveal is the potential to go further still into areas where our understanding is lacking. There is an ongoing need for Children with Cancer UK to achieve even more in the future.

Precision medicine and immunotherapy have so far given just a tantalising glimpse of the radical improvements that could be around the corner in cancer treatment.

Far more research is needed to develop these treatments and to make them affordable. The practical requirements of equipment, training and facilities to deliver them will be substantial. Children with Cancer UK can play a major part in helping to realise this potential.

Financial pressures in the NHS and universities, the current uncertainty about international collaboration in research as we approach Brexit, and the lack of consensus on cause and prevention of childhood cancers all highlight the importance of continuing to develop partnerships as a way to meet Children with Cancer UK's charitable objectives. The charity's independence and unwavering focus on improving children's and families' lives mean that it is ideally placed to help draw the various strands related to treating children's cancer together, without the intensely competing priorities that those at the front line of health and care have to balance. Collaborating with other charities and funders, sharing knowledge among researchers and supporting hospitals to provide the best care have never been more important.

Bella-Rose and her mum Abbie. Bella rung the end of treatment bell in October 2016



Endnotes

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Contact us

020 7404 0808

info@childrenwithcancer.org.uk
childrenwithcancer.org.uk

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Children with Cancer UK, 51 Great Ormond Street, London WC1N 3JQ

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