Opening evening at our ‘My cancer journey’ art exhibition for Childhood Cancer Awareness Month 2017
Welcome

Our Annual Review highlights some of our key activities and achievements during 2017, demonstrating the difference we’re making for children and young people with cancer and their families.

2017 marked the 40th anniversary of CCLG. In 1977, our 14 founder members came together to form the United Kingdom Children’s Cancer Study Group (UKCCSG), with the aim of establishing clinical trials in childhood cancer, collecting data and offering an important clinical forum to advance knowledge into children’s cancer.

In the intervening 40 years, the field of childhood cancer has changed dramatically, and CCLG (formerly the UKCCSG), has been integral to this development. From the establishment of a national network of specialist children’s cancer centres to the emergence of paediatric oncology as a medical specialism, the development of a large number of clinical trials leading to improvements in treatment and outcomes, and the launch of the national CCLG Tissue Bank to support specialist research, our work has contributed to the improvement in survival rates from fewer than 3 in 10 children before 1970 to more than 8 in 10 today.

But... we didn’t come this far, to only come this far. For some types of childhood cancer, we haven’t seen the same improvements in outcomes and survival. Many patients who do survive are left with lifelong, life-changing disabilities or other challenges as a result of their treatment. Further research is needed to ensure that all children diagnosed with cancer not only survive, but go on to live happy, healthy and independent lives.

Our annual review gives an insight into how we’ve been working towards this goal over the past twelve months. From supporting our professional membership to provide the best possible treatment and care, to supporting families with expert information, helping to make a positive difference to their daily lives. We’ve also increased our investment in research, with the support of our Special Named Fund and our friends at the Little Princess Trust.

For CCLG, 2017 was a time to reflect on all we’ve achieved over the past 40 years. But it was also a time to look forward. During the year we developed our new strategy (launched in January 2018), clearly setting out our aims for the coming years, and beyond. We know what needs to be done. CCLG will continue to provide leadership and expertise for the treatment and care of children and young people with cancer. We will improve the pathway to diagnosis, ensuring children have a better chance of surviving their disease. We’ll support more families through our expert information, and we’ll continue to fund and support world-class research so that every child diagnosed with cancer has the best chance of reaching adulthood.

We can only do this with your continued support.

Dr James Nicholson
CCLG Chairman

David Oxnam
Chair of CCLG Board of Trustees

Ashley Gamble
CCLG Executive Director
40 years of saving lives

We were proud to celebrate the 40th anniversary of CCLG (formerly known as UKSCCG) in recognition of the pioneering work of our members over the last four decades. We published our 40-year timeline to mark our achievements over the years.

Treatment for children with cancer pre-1970:

- NO paediatric oncologists
- NO specialist treatment centres
- NO national care network
- NO support workers
- NO training programme for professionals
- NO resources for treatment of cancer for children

Over 8 in 10 children now survive their disease

If I’d had cancer as a child, I probably wouldn’t be here today. This timeline highlights the achievements of CCLG and how far we have come over the last 40 years. But there is more to be done, as we continue to work hard to improve the chance of cure and quality of survival for all children.

Dr James Nicholson, Consultant Paediatric Oncologist and Children’s Cancer and Leukaemia Group Chairman

Visit www.cclg.org.uk/40 to read our full timeline
Our members are working hard for better treatment options and care

We are the UK and Ireland’s only professional association dedicated to childhood cancer. Our purpose is to bring together all those who work within childhood cancer in the medical community and provide a space for them to share knowledge, develop ideas and drive through change at a national level.

Supporting community cancer care
An online information resource for health and social care professionals and education staff is available on the CCLG website.

The CLIC Sargent Outreach Information Resource, developed in partnership with CCLG, gives bite-size, easy-to-read information on a wide range of topics that help support a child with cancer and their family. www.cclg.org.uk/outreach

New e-learning module for GPs
We provided expert input and reviews for a new e-learning module for GPs, developed by CLIC Sargent and Teenage Cancer Trust for the Royal College of General Practitioners. The new online course supports GPs, trainees, nurse practitioners and allied health professionals to pick out the potential signs of childhood or young adult cancer.

Our national meeting for childhood cancer professionals
Nearly 200 delegates gathered together in January in Leicester to attend our annual two-day Winter Meeting.

This UK event offers the only opportunity for a wide range of healthcare professionals to come to network with colleagues across the country, learn from each other’s work, share best practice, spark ideas and catch up on all the news and results from the latest research.

This year, our main presentation was entitled ‘Mapping cancer origins – beyond the brain’.
Held every year as part of the Winter Meeting, the Adam Hay Lecture embarked on an interactive journey into medical conflict. Theatre company Clod Ensemble performed a series of thought-provoking examples of how communication can break down between healthcare professionals and families and ways in which this can be avoided.

“It was interesting to see from the outside an interaction that could have been me... in a safe space where people could then unpick it.” Delegate

Stronger leadership for all children, teenagers and young adults with cancer

CCLG and Teenagers and Young Adults with Cancer (TYAC), a professional healthcare association for this age group, joined forces at the end of 2017 to merge two specialist areas into one, strong unit to achieve the best possible care for teenagers and young adults. Both CCLG and TYAC will retain their separate memberships and brand identity, but will share each other’s experience, knowledge and expertise giving increased efficiency across the two groups.

“I am delighted we are in a position to forge our collaboration with CCLG. I am now more confident than ever about the future of TYAC and how we can ensure the best care and opportunities for young people with cancer.”

Dr Dave Hobin, Consultant Paediatric Oncologist, TYAC Chair
Becoming a member of AMRC

In January 2017, CCLG became a member of the Association of Medical Research Charities (AMRC), the national membership of leading medical and health research charities.

What does this mean?

AMRC membership is the hallmark of quality research funding. We have demonstrated that we follow the AMRC’s rigorous standards in peer review to ensure the research we fund is of the highest quality.

We recognise that collaboration for research in childhood cancer is vital, and we aim to form partnerships that increase the impact of our research funding.

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Making sure that every child and young person with cancer will be cured in the future requires research through laboratory experiments to clinical trials. We are funding and supporting world-class research into childhood cancer.

AT A GLANCE

£1m
of grants awarded through the Little Princess Trust partnership to research projects including studies into Wilms tumour, lymphomas, neuroblastoma, leukaemia, brain tumours and rhabdomyosarcoma.

25
research projects
supported including studies into specific types of cancer, improving quality of care and the quality of survival

Launch of 4
CCLG Tissue Bank pilot grants using tissue samples for studies into leukaemia, craniopharyngioma, hepatoblastoma and a project into multiple cancers

Launch
of 40th anniversary research grants
Filling the research gaps

We are committed to ‘filling the gaps’ in research funding by supporting projects that meet our research priorities but are often not eligible for funding from elsewhere.

To mark our 40th anniversary, we created a special fund for researchers to submit high quality and innovative research applications that will improve the patient pathway. We awarded funding to four projects.

- To look at how to give children a voice in their healthcare
- To find the evidence on how National Advisory Panels are useful for children’s cancer
- To discover whether regular monitoring and screening is useful or doesn’t confer enough benefit to warrant the stress of going for a scan and waiting for results.
- To design a tool to help young adult survivors of childhood cancer involved in physical activity

Bringing together parents and professionals

Our annual UK Childhood Cancer Conference took place on Friday 9 June, bringing together parents, researchers and health professionals working in the field of children’s cancers.

Organised jointly by CCLG and Bethany’s Wish, the aim of the annual event is to involve parents in the most up-to-date and innovative paediatric oncology research, provide professionals with the opportunity to network, collaborate and view oncology research from a parent’s perspective, and draw attention to the issues that prevent more effective treatments and better outcomes for children.

This year’s programme featured a wide range of topics, with speakers on supportive care, immunotherapy, drug repurposing and much more.
Research projects

Research focus on a type of rare aggressive childhood cancer

Malignant rhabdoid tumours (MRTs) are rare and aggressive, often fatal tumours of early childhood and infancy. Current treatments are often ineffective. In partnership with The Grace Kelly Ladybird Trust, and using funds raised by The Hollie Taylor Fund (a Special Named Fund at CCLG), we were able to fund two projects investigating this devastating disease.

Understanding why a specialised treatment worked for some neuroblastoma patients and not others

Funded by CCLG, researchers at University College London and Great Ormond Street Hospital studied nearly 100 neuroblastoma samples from the CCLG Tissue Bank to see why a specialised form of treatment called 'molecular radiotherapy' worked for some patients and not others. The study concluded that a combination of two drugs may work better than one alone. Further testing will need to take place in a clinical trial.

Detecting early relapse in brain tumours to improve treatment results

A grant award was made to University of Nottingham for research into biomarkers in the blood that are unique to a certain type of brain tumour called ependymoma. We are currently not able to detect brain tumours at a very early stage, to know whether the tumour has been completely removed after treatment or if it has come back. This project will look at how to detect 'minimal residual disease' and build up a biological profile of the tumour.

Edie’s Butterfly Appeal, a CCLG Special Named Fund, awarded a £111,000 grant to this project.

CCLG Tissue Bank

The UK’s largest unique collection of tumour, DNA and other tissue samples from childhood cancer patients.

Thanks to donated samples from patients, scientists have the best chance to get as close as possible to the disease by working on real-life tumour cells to find new methods of diagnosis, treatments and cures.
With funds raised by Edie’s Butterfly Appeal, we awarded a research grant of £111,000 to a project that is building up a ‘fingerprint’ of a type of brain tumour called ependymoma.

This will help doctors to better monitor the disease during treatment and detect relapses earlier. Edie’s family set up a special named fund with CCLG called Edie’s Butterfly Appeal to raise funds for research into ependymoma.
Supporting families with expert information

When faced with a devastating diagnosis such as childhood cancer, families need clear, accurate and relevant information at the right time to help make a positive difference to their daily lives.

We offer a range of high-quality, award-winning information resources covering all aspects of childhood cancer, from diagnosis to life when treatment has finished. All of our booklets and factsheets are available free of charge in hospitals where children are treated for cancer or to order directly from us.

Two new publications added to CCLG’s information portfolio

‘When your child’s cancer comes back or does not respond to initial treatment’

We identified a clear information gap for parents whose child has relapsed or where first treatment hasn’t worked. Being told that your child’s cancer has come back or hasn’t gone away can come as a huge shock bringing back many emotions from the first diagnosis. Sometimes, it feels even worse. Reviewed by two clinical psychologists, this new resource acknowledges these feelings and gives information to help parents cope with the experience once again.

“Parents reading this find themselves once again where they hoped they and their child would never be. This booklet gives helpful answers to general questions and useful suggestions. You are not on your own walking down this unexpected path.”

Dr Martin English, CCLG member
‘Complementary and natural therapies for your child’

Being in hospital and having treatment is scary, and children and teenagers can become stressed and anxious. Used alongside standard treatment, complementary therapies can play a part in supporting children through treatment by offering relaxation, calmness, and relief from symptoms.

This new booklet provides information about different complementary therapies, as well as advice about what to avoid.

‘Highly Commended’ BMA awards

We were delighted that three of our patient information resources were ‘Highly Commended’ at the British Medical Association (BMA) Patient Information Awards 2017 held in London.

Contact magazine: free quarterly magazine for families

We are the proud publisher of Contact, the only UK magazine dedicated to families of a child with cancer featuring patient experiences and information written by experts. **Specific themes for 2017 included:**

- Body image and appearance
- Eating and nutrition during treatment
- Communication
- Childhood cancer across the world

26,000 copies were printed in total during 2017
Families funding research through our Special Named Funds

We are honoured to have over 40 Special Named Funds at CCLG, giving families an opportunity to raise money for a research cause of their choice in celebration, support or memory of their child.

Each fund has its own identity and logo to reflect the unique personalities of each child. We offer excellent support and resources for all of our families to help make a difference and they choose exactly where any funds raised should be spent. We were delighted to welcome 10 new Special Named Funds to CCLG during 2017.

- **Elliott’s Warrior Fund** - Raising money for leukaemia research in celebration of Elliott, diagnosed with ALL in 2014 aged 5. He is now cancer-free.

- **Little Heroes Fund** - Raising money for osteosarcoma research in celebration of Ben, diagnosed aged 17. He is now cancer-free.

- **#Pearl Power** - Raising money for early diagnosis of bone cancer in celebration of Pearl, diagnosed aged 9.

- **Super Sofia** - Raising money for leukaemia research in celebration of Sofia, diagnosed aged 11.

- **Kieran Maxwell Legacy** - Raising money for bone cancer research in memory of Kieran, diagnosed with Ewing’s sarcoma.

- **The Mia Pyari Smile Appeal** - Raising money for leukaemia research in celebration of Mia, diagnosed aged 7 months old.

- **Ollie’s Star** - Raising money for rhabdomysosarcoma in memory of Ollie, diagnosed aged 2.

- **#teamkai** - Raising money for AML in memory of Kai, diagnosed aged 2.

- **Ammaar’s Transformers Appeal** - Raising money for neuroblastoma research in celebration of Ammaar, diagnosed aged 4.

- **The Sky David Fund** - Raising money for brain tumour research in memory of Sky.
We want to help continue the fight to end this awful disease and wish for a day where no parent ever has to go through this painful journey.

Anja and Simon’s daughter Mia was diagnosed with leukaemia (ALL) in July 2017. They set up a special named fund with CCLG called the Mia Pyari Smile Appeal to raise funds for research into infantile ALL.
Art exhibition to mark CCLG’s 40th anniversary

We invited patients, survivors, family members and those working with children with cancer to submit art, poetry and photography exploring their cancer experiences through creative expression.

Submissions were showcased in an art exhibition at New Walk Museum and Art Gallery in Leicester during the whole of September.

- **Expressions of Chemotherapy (2)**
  Mattia Guarnea MaCcarthy (aged 18)

- **The Hand of Toti Worboys**
  Nick Worboys (aged 44)

- **The Happiness Tree**
  (Paper collage)
  Patients at Great Ormond Street Hospital (various ages)

- **Beads of Courage**
  Siobhan O’Flynn (aged 44)

- **The Orange Bead**
  Rosalind Davies (aged 4)

All entries can be viewed online at www.cclgart.org
Dr J P and Dr ‘Big Hair’ Playing Football
Ava Rose Le Blanc (aged 5)

Lots of Brave
Kyle Hutchings (aged 30)

You Know Nothing
Maria Xanthopoulou (aged 12)

Alone
Megan McKenna (aged 20)

Steroid Week
Rosalind Davies (aged 4)

Methotrexate
Siobhan O’Flynn (aged 44)

Jolie: Pretty One
Karen Young (aged 29)

Self Portrait
Thomas ‘Toti’ Worboys (aged 9)
Gold Ribbon Appeal

Every year, we launch our Gold Ribbon Appeal to encourage everyone to wear one of our gold ribbon pin badges in support of Childhood Cancer Awareness Month. Our most popular was our exclusive gold glitter version.

All funds raised go towards vital cancer research. We thank all of our CCAM supporters for 2017! Here are some CCAM supporter stories:

AMAZON GOES GOLD
RAISING OVER
£1,600

Amazon team goes gold for CCAM
The team at Amazon Gourock in Scotland decked out the fulfilment centre in glitter and gold to mark CCAM and raised money through our gold ribbon appeal. They organised a number of fun activities such as bake sale, planting a gold garden, raffles, sponsored silence, sponsored head shave and some even wore pyjamas and dressed up in gold for the day. They raised over £1600 for our Gold Ribbon Appeal.

‘Go Gold Glitter Ball’ for childhood leukaemia research
The first ‘Go Gold Glitter Ball’ in aid of Elliott’s Warrior Fund at CCLG took place during CCAM and raised over £11,000 to support research into childhood leukaemia.

Sisters Helen and Becky organised the event in honour of Becky’s son Elliot (now aged 8) who was diagnosed with ALL when he was five years old.

ELLIOTT’S WARRIOR FUND
RAISES OVER
£11,000

The Gold Ribbon Appeal is such a great cause. It’s important to raise cancer awareness however we can. Everyone on the team had a fantastic day trying to raise money for the campaign. “

Gavin, General Manager at Amazon Gourock
We couldn’t do it without you...

We rely on the generous support of all our fundraisers and volunteers, who give their time, energy and commitment to help raise money for our important work.

We would like to say a huge thank you to everyone who has supported us and our Special Named Funds during the year.
In April, Ed took on a gruelling 156 mile Sahara Desert Run to raise money for the Georgie B Fund. Temperatures reached 50°C and the race took place over six days.

Georgie successfully completed treatment in 2015 and his family set up the Georgie B Fund to raise funds for research into Wilms tumours.

Ed is friends with Georgie’s parents and decided to take on the challenge in aid of the Fund.
Where our income came from and how we spent our funds

The following information is an extract from our 2017 audited accounts. A full copy of our accounts is available to download from the Charity Commission website.

We are grateful to the University of Leicester for their continued support. During the year, they provided CCLG with free office accommodation and other support in-kind.

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<tr>
<th>Income</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Donations and Legacies</td>
<td>£348,593</td>
<td>£709,425</td>
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<tr>
<td>Restricted Donations and Legacies</td>
<td>£482,515</td>
<td>£299,153</td>
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<tr>
<td>Charitable Activities</td>
<td>£191,448</td>
<td>£179,780</td>
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<tr>
<td>Grant Income for Research</td>
<td>£1,213,246</td>
<td>£531,626</td>
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<tr>
<td>Investments</td>
<td>£818</td>
<td>£7,871</td>
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<tr>
<td>Donated Goods and Services</td>
<td>£34,915</td>
<td>£23,061</td>
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<tr>
<td><strong>Total Income</strong></td>
<td><strong>£2,271,535</strong></td>
<td><strong>£1,858,536</strong></td>
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</table>

<table>
<thead>
<tr>
<th>Expenditure</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support for Research</td>
<td>£1,840,903</td>
<td>£688,937</td>
</tr>
<tr>
<td>Information for Patients and Families</td>
<td>£132,927</td>
<td>£100,301</td>
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<tr>
<td>Improving Treatment and Care</td>
<td>£290,371</td>
<td>£284,658</td>
</tr>
<tr>
<td>Raising Funds</td>
<td>£160,005</td>
<td>£114,542</td>
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<tr>
<td><strong>Total Expenditure</strong></td>
<td><strong>£2,420,411</strong></td>
<td><strong>£1,188,438</strong></td>
</tr>
</tbody>
</table>

**Restricted donations** are where the donor specifies funds are to be put to a specific use. Many of our Special Named Funds raise money to support research into a specific type of cancer, and we treat these funds as ‘restricted’. We are always happy to restrict donations to a particular area of our work. ‘Charitable activities’ includes membership subscriptions from our professional members, subscriptions from Principal Treatment Centres to support the production of information for families, and fees paid by professionals to attend our educational and scientific meetings. ‘Grant income for research’ comprises funds from charities with whom we work in partnership to fund research. ‘Donated goods and services’ reflects the value of the services provided at no cost to CCLG by the University of Leicester, namely rent-free accommodation and telecommunications.

‘Improving treatment and care’ includes the activities of CCLG as the professional association for those working in the field of childhood cancer, including producing treatment guidelines, educational and scientific meetings, and the CCLG members’ website – a vital resource for professionals.

The cost of generating funds accounts for 6.6% of our expenditure, a figure we are proud of.
We know how far we have come but there is still more to be done:

- Over 250 children still die from cancer each year in the UK and Ireland – it is the biggest cause of death by disease in children
- Of those who survive, many will have a lifelong health condition as a result of their treatment

With our long-standing history and experience in childhood cancer, our established and growing network of professionals can respond to these challenges and influence positive change.

Our vital work in children’s cancer care and treatment will continue with a number of exciting projects in 2018 with the ultimate goal of saving more young lives from cancer.
**Children’s Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.**

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.