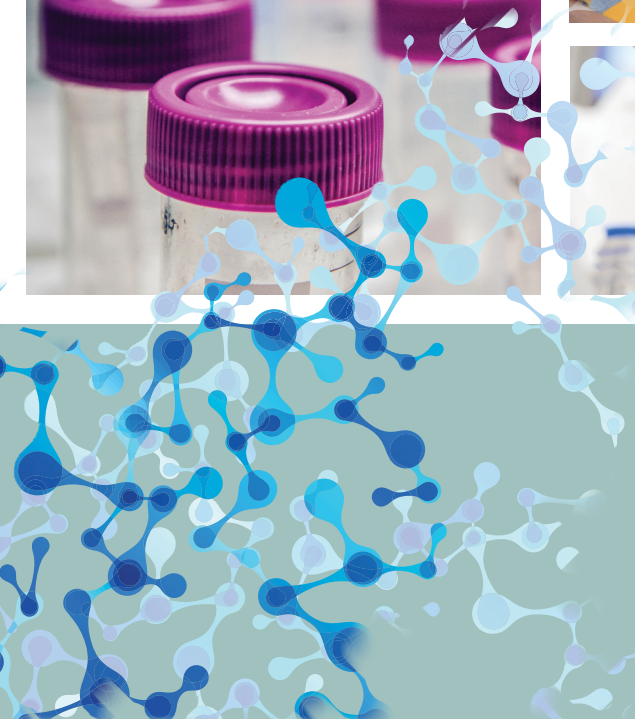




Children's
Cancer and
Leukaemia
Group
Working together to
beat childhood cancer

Research strategy

September 2015



Background

Children's Cancer and Leukaemia Group has long supported and funded research into childhood cancers. In recent years, much of our funding has been to support projects through small grants that have applied to us on an ad-hoc basis or through our Special Interest Groups, working groups of clinicians and researchers with an interest in a specific cancer. Projects have included biomarker studies, support for clinical trials, systematic reviews and basic science projects.

We have also funded a number of small pilot grants to promote use of the CCLG Tissue Bank, and used our networks and infrastructure to support the grant making activities of other children's cancer charities.

CCLG occupies a unique position in the landscape of children's cancer charities, being also the professional association for those involved in the treatment and care of children with cancer. This medical and scientific expertise puts us in a strong position to identify areas of need, support and fund research, and engage with the research community in the UK and Ireland, and internationally. CCLG is well placed to act as a 'bridge' between research and patients, parents and families, promoting research to the scientific and clinical community and the general public, as demonstrated by our successful annual Childhood Cancer Conference, which has a research theme.

CCLG also offers 'Special Named Funds' as a fundraising option. These funds, often set up by families in support of, or in memory of, a child with cancer, allow fundraising in a child's name to be restricted, to be spent only on a specific area of our work. The majority of our Special Named Funds are restricted to 'research' into a specific type of childhood cancer. This gives donors reassurance that their fundraising will be spent on the disease they have chosen, and not put into a 'pot' of general research funding.



Our current support for research is modest, but we will be working diligently to achieve best value from it. In the last two financial years, we awarded grants to institutions totalling c£140,000. We also supported research through the CCLG Tissue Bank (funded by Cancer Research UK and CCLG, see www.cclg.org.uk/tissue-bank) and in a number of other ways, for example supporting the costs of UK clinicians and scientists to be involved in international groups developing clinical trials and other research activity.

We are now in the process of establishing a more formal research function, in compliance with the standards of the Association of Medical Research Charities (AMRC), to which we will be applying for membership in due course. Our current research spend is the starting point for our future research programme, and through an increase in the activity of our Special Named Funds, partnerships with other children's cancer charities, and an increase in general fundraising activity, we expect to soon be able to significantly increase our funding of research, through a more structured programme of activity.

This is our first research strategy.

Research priorities

CCLG aims to fund world-class research into the prevention, diagnosis, treatment and consequences, including late effects, of childhood cancers. All aspects of research will be considered, including (but not exclusively) basic laboratory research investigating disease mechanisms, preclinical experimental studies and clinical research (including but not limited to novel treatments, supportive therapies, epidemiology and psychological impact). CCLG will also consider participating in the funding of clinical trials.

It is recognised that CCLG is currently a modest funder of research, albeit with ambition to grow our research funding programme, and that we have identified a broad variety of research we will consider funding. No area of research is given greater priority over any other, but we will always award competitively on the basis of the scientific quality of the proposed studies. As this is our first research strategy, we will use the outcomes of our research funding programme, and consultation with the research, clinical and parent/patient communities to refine our funding priorities in future years.

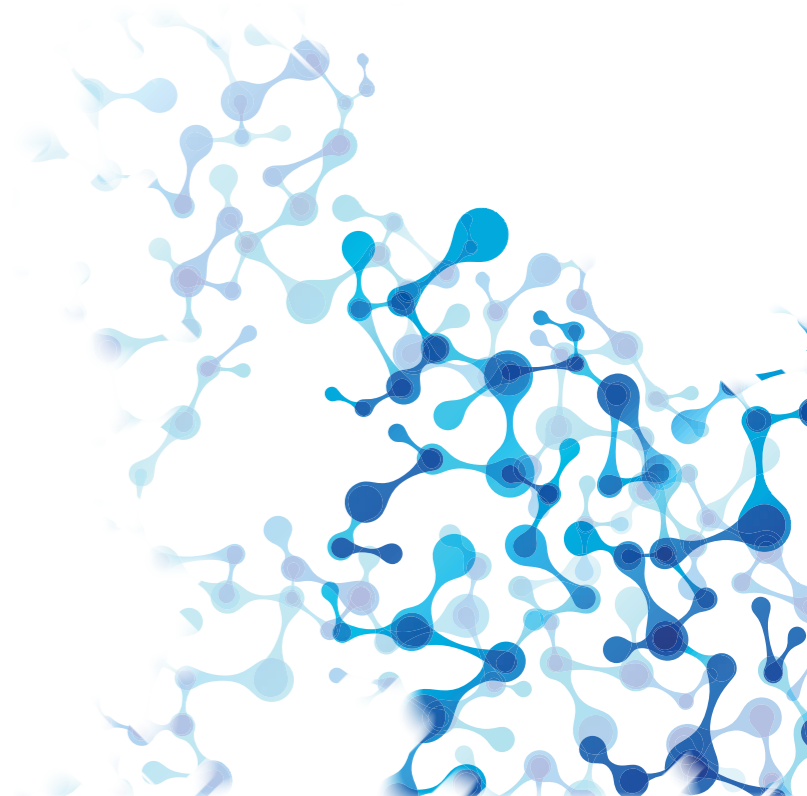
CCLG also aims to fill the 'gap' in available research funding, supporting projects that meet our research priorities as described above, but are not eligible for funding from other sources. We are also interested in 'pump-priming' new ideas of enquiry that may lead to more substantial investment by larger research funders. We are keen that the outcomes of research we fund are applied to provide clinical benefit.

CCLG will fund research projects that will

- Broaden and deepen knowledge of childhood cancer, or
- Assist in transferring research progress from the lab to a clinical setting, or
- May improve treatment or patient care in the short, medium or long term
- Investigate the long term effects of treatment with an aim to reduce these

CCLG also recognises the importance of collaboration in planning and undertaking research, in childhood cancer. The relative rarity of many childhood cancers means that clinical trials are often international. Our membership is already involved in many international collaborations and working groups, and we are active in the International Society for Paediatric Oncology Europe (SIOPE), putting us in a strong position to collaborate. Applications are particularly welcomed from collaborative research proposals both with the UK and beyond.

CCLG also aims to encourage the dissemination of research to both professional and lay audiences. Our unique position as both a funder of research and the professional body for childhood cancers puts us in a strong position to facilitate information sharing and dissemination among the clinical and scientific communities to which our work is of relevance, as well as our network of parents of a child with cancer and others.



How we fund research

CCLG will fund research through open calls for applications. The nature of grants we are able to offer will vary with our income and the wishes of our donors, however we aim to support:

- Pilot projects and other projects for which 'pump-priming' is sought that are likely to lead to larger pieces of research
- Larger project grants

Allocation of some grants will be determined in part by the wishes of the donor, for example a number of our Special Named Funds are fundraising to support PhD studentships.



The current nature of our fundraising (particularly through our Special Named Funds) means that grants we offer may be restricted to specific types of childhood cancer. Our long term aim, through our own fundraising activity and through building partnerships with other charities, is to be able to offer a range of grants that can be applied for to fund projects into any childhood cancer.

Our Special Named Funds do mean that we are also well placed to support research in a reactive manner. In addition to our open grants calls, researchers can submit proposals for small projects to CCLG at any time. Often these come via the CCLG membership, and in particular our Special Interest Groups, (tumour-specific networks comprising clinicians and researchers in a given type of cancer), where research priorities are best known. We also

may make use of this expertise to actively seek out projects to fund where we have restricted funds held for a particular type of childhood cancer. These applications will be subject to the same standards of peer review as our open applications.

CCLG will only support projects that are specific to children's cancers. However, any projects we fund may subsequently have a wider application, in other cancers or other conditions.

Our pilot grants will generally be one year in duration, and our project grants three years. CCLG grants will cover the direct costs of conducting research, but not the indirect and infrastructure costs, which are met by the research institutions.

We will also consider co-funding research with other funders.

Applications to CCLG will be reviewed by our Research Advisory Panel and, where appropriate, externally peer reviewed in line with our peer review guidance.

Our values and beliefs

- Our research funding is driven by the needs of patients and carers, whether outcomes are likely in the short or longer term
- Effective partnership working – between clinicians, scientists and patients/parents is vital to our research programme
- While we may only be a small research funder at present, we will value each pound and increase our capacity for supporting more research year on year.

Funding our research

CCLG has three primary sources of funding for research:

Our own fundraising for research among our existing and potential supporters. Some of the funds we raise are restricted generically to research or more specifically to research into a particular type of cancer. The Trustees may also allocate general funds to our research programme. Our long term aim is to increase our fundraising so that further 'general funds' can be made available for research.

Our 'Special Named Funds'. These are restricted funds, often for a particular type of childhood cancer, and often in support or memory of a child. Our Special Named Funds enable parents and families to support research into a specific disease, and to focus on raising funds, without the administrative and resource burden of setting up and running their own charity. Some of our supporters with Special Named Funds have a specific project in mind, others are happy to be guided by CCLG as to how funds are spent. We will always respect the views of our supporters, and where possible and depending on their own wishes, involve them in the decision making process as appropriate.

Working in partnership with other charities. CCLG is well placed to support other (particularly smaller, parent-led) charities to



achieve their research aims. Using the scientific and medical expertise of our membership, and our existing networks and infrastructure, we can support and manage a charity's research programme as appropriate, including calls for applications, review, grant award and grant/research monitoring. We can also facilitate collaboration between charities to increase the size of the potential available funds. The details of each partnership may differ, but we have successfully run and managed a project grant on behalf of the Tom Grahame Trust, and are currently supporting The Little Princess Trust to establish a research funding programme.

Who we will fund

We will only fund research based at or led by higher education establishments and the NHS in the UK and Ireland. Where a collaborative project exists with an overseas partner, whether led by the UK end or not, any financial commitment by CCLG must be managed through the UK institution.

We will accept applications led by clinical and non-clinical scientists, and other UK registered health professional. All project proposals will be assessed on an equal footing in the same competition.

Awarded grants

The call for applications and terms and conditions for each grant round will define timescales for all grants, including payment intervals.

All awarded grants will be reviewed on a regular basis to ensure that award criteria are being met.

Reviewing our research strategy

Our research strategy is a dynamic document, and we will review it at least every three years.



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Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Two out of ten children will not survive their disease.

Over the last 35 years, CCLG has played a key role in the major improvements in survival rates and the standards of care for children. We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care.

There are still some childhood cancers with a poor outlook, and many treatments can have long-lasting side effects. Further research is therefore vital, and the ultimate aim of CCLG is to cure as many children as possible while reducing the short and long-term side effects of treatment. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

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