



# Children's Cancer and Leukaemia Group

*Caring for children – curing their cancer*

## Annual Review and Accounts 2010

The CCLG is committed to research and development in the treatment of cancer in children and younger teenagers, the ultimate goal of which is to maximise cure while minimising the early and late side effects of treatment.

The mission statement of CCLG is:

To promote and improve on the best standards of care for children and younger teenagers with cancer and leukaemia by bringing together all relevant healthcare professionals in the British Isles to:

- Advocate excellence and equity of access to cancer care
- Promote research and development
- Advise governments and other bodies
- Form networks of colleagues with shared interests in cancer types and aspects of care
- Share and guide best practice
- Advance education, training and professional development
- Produce information for patients and families
- Raise funds to support these activities.

#### Patrons:

Professor Sir Robert Burgess  
Baroness Masham of Ilton

#### CCLG Trustees:

Dr Dan Ford, CCLG Executive/Treasurer  
Mrs Gill Thaxter (parent) (*from December 2010*)  
Mrs Rachel Wilcox, ACA, DChA (*from October 2010*)

#### CCLG Executive:

Dr Mark Gaze, Chairman  
Dr Martin English, Secretary  
Dr Dan Ford, Treasurer  
Dr Phil Darbyshire  
Dr Juliet Hale  
Dr Angela Thomas  
Professor Josef Vormoor  
Professor Sue Ablett, CCLG Executive Director, *ex officio*,  
Mr Chris Gibbs, NACCPO Chair, *ex officio*

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#### Bankers and Auditors:

HSBC Bank, Leicester  
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Mark Gaze, CCLG Chairman

The calendar year 2010 has witnessed the greatest changes in the 35 year history of the Children's Cancer and Leukaemia Group and its predecessor organisations the Childhood Leukaemia Working Party and the United Kingdom Children's Cancer Study Group. The re-structuring was preceded by at least three years of discussion, consultation and planning which was certainly difficult and at times painful. That the transition was, in the end, smooth and efficient is a tribute to the determination, professionalism and hard work of many individuals. These include both those in leadership roles and others at a lower but no less important level, in both the old CCLG and the host organisations that have taken on some of its previous responsibilities. The work is not yet complete. Nevertheless, we have a healthy organisation, fit for the future, lead by an enthusiastic Executive supported by the small but skilled Leicester-based secretariat.

The new CCLG is substantially different from the old CCLG. It remains an association of healthcare professionals devoted to the care and cure of children and younger teenagers with leukaemia and cancer; but, as doctors and scientists cannot do this by themselves, the membership has now been opened up to the wider multi-professional team essential for that purpose. It is important that we never lose sight of the patients, who are at the heart of our mission, so a new category of association has been created, *Friends of CCLG*. This is for parents and others who believe in our cause and wish to support our work (see page 14).

Scientific and clinical meetings remain a core CCLG activity. Regular winter and summer general meetings will continue. The principal purpose of these is to allow the membership to be kept informed of developments in paediatric haematology and oncology. Discipline and Interest Group Meetings will continue to provide further opportunities for in-depth continuing professional development and networking on specific topics.

Treatments for our patients will not improve without ongoing academic endeavour. The Executive has therefore supported a review, due to report in 2011, of academic paediatric oncology in its widest sense. This piece of work is engaging other stakeholders including Cancer Research UK and the Royal College of Paediatrics and Child Health. The aim is

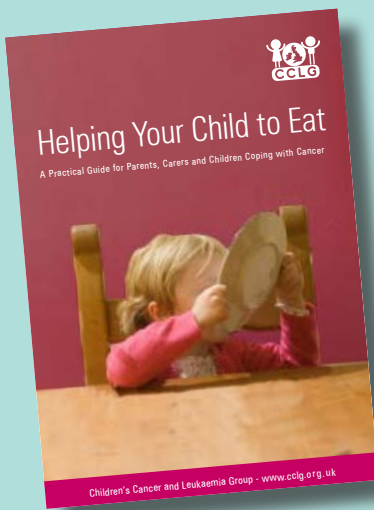
to demonstrate the need for academic development and to show areas requiring additional work and added investment. This should then stimulate a re-invigoration of this field.

The British Isles do not exist in a vacuum. In recognition of the international nature of paediatric oncology, CCLG is hosting the International Paediatric Oncology Society 2012 Congress at the Barbican in London from 5-9 October 2012. Much work is going into making this an educational event of great importance.

CCLG continues to work to represent the needs of children and younger teenagers with leukaemia and cancer to governments, and national bodies. Examples of this include the successful lobbying of government to secure exceptional funding for the production of monoclonal antibody for neuroblastoma; representation on the National Commissioning Group for proton beam radiotherapy, and the Department of Health group for the implementation of Improving Outcomes Guidance and the ongoing review of paediatric neurosurgery services.

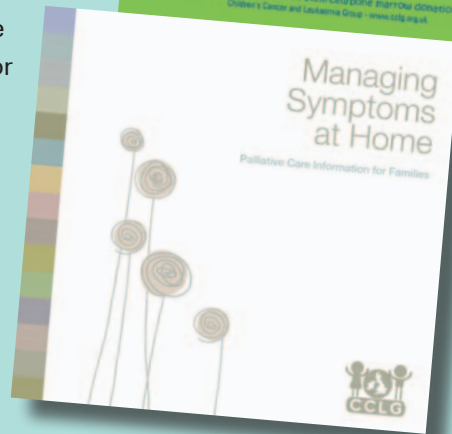
In summary, the Executive has been involved in a wide range of activities supporting its members and through them *caring for children – curing their cancer*.

## Information for families and others



The CCLG Publications Committee has again had a productive year with new publications in print:

- Helping Your Child to Eat
- Will and Sophie have Radiotherapy
- Donating your stem cells to your brother or sister
- Managing Symptoms at Home – Palliative Care Information for Families



The very popular booklet, Children's cancer and pets, was reprinted for the second time.



Two booklets were Commended in the BMA Patient Information Awards 2010:

- Jess's Bone Marrow Donation (for donors under 10)
- Ruby's Stem Cell Journey (for High Dose Therapy)

*Contact* magazine continues to meet the needs of its readers with many positive comments received in terms of value of articles. The new look design for 2010 has also attracted positive feedback.

## Late effects and survivors

Several members of the CCLG Late Effects Group are part of the Pan European Network for care of survivors after childhood and adolescent cancer. The aim of the Network is to establish equality of, and equal access to, long-term follow up across Europe.

## 2010 McElwain Prize

Congratulations to Dr Matt Murray, winner of the 2010 McElwain Prize for his poster: 'The two most common histological subtypes of malignant germ cell tumour are distinguished by global microRNA profiles, associated with differential transcription factor expression.'

The McElwain Memorial Fund also supported the attendance of a UK trainee at the European School of Oncology Paediatric Oncology Masterclass in Rome in June 2010.



## Neuroblastoma

It's not every day that the CCLG gets a mention at Westminster, however on 16th March 2010 Peter Bone, MP for Wellingborough, did so when he introduced a parliamentary debate about access to monoclonal antibody treatment for one of his constituents.

In reply, Ann Keen, then Parliamentary Under-Secretary of State for Health, promised to find funding for a new Phase II study of monoclonal antibody. That resulted in £750,000 being made available, and the continuous infusion Phase II study should open in 2012.

On 20th July, in a meeting organised by Mark Gaze, CCLG Chairman, and hosted by CCLG, representatives of 11 charities involved with neuroblastoma came together for the first time to discuss areas of common interest. The most tangible outcome of this meeting is that two small family based charities have agreed to pay the UK contribution to the running

of the international Neuroblastoma (SIOPEN) studies, an obligation met in previous years by CCLG.



“*There is now clear evidence, presented at the American Society of Clinical Oncology meeting last May, and shortly to be published in the New England Journal of Medicine, that immunotherapy schedules containing monoclonal antibody produce a significantly improved chance of survival in children with high risk Neuroblastoma.*”

Peter Bone,  
MP for Wellingborough



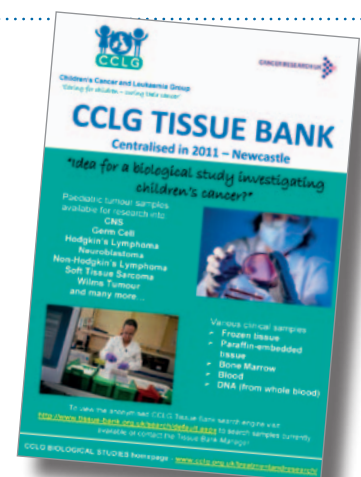
## CCLG Today

September 2010 saw the launch of CCLG Today – a new quarterly Newsletter for members, aimed at updating on key developments both within the organisation and outside. Issue 2 was 4 pages longer than the 1st issue, backing up the words of one overseas member. “A very nice production. It’s good to keep up with what’s happening on home turf – obviously lots!”

## CCLG Tissue Bank and Biological Studies

Another successful year:

- A further 595 samples added to the Bank in 2010 (252 paraffin embedded and 343 frozen). The total number of samples registered and available for release is now 7,005.
- 6 applications for use of samples from the Bank were approved
- 13 peer-reviewed publications from research using Tissue Bank material
- Tissue Bank awarded membership of two biobanking organisations – the Confederation of Cancer Biobanks and the International Society of Biological and Environmental Repositories
- Finally, an exciting decision by Cancer Research UK, funders of the Tissue Bank, that, following an external review process, the current ‘virtual’ CCLG Tissue Bank will move to a centralised Bank – located at



the University of Newcastle-upon-Tyne, with continuing coordination by the Leicester-based team.

## Introduction

To support the day to day activity of CCLG, much work has traditionally been undertaken by different groups, some of which revolved around specific tumour types, some around the disciplines involved in the treatment of childhood cancer, and some more generic groups, such as Publications Committee, and some very specific groups such as Paediatric Oncology in Developing Countries. With the changes in the CCLG, the work of discipline groups and generic groups continues much as before. However the tumour working groups ceased to exist in their previous format from April 2010, when the National Cancer Research Institute Clinical Study Groups and their subgroups took on responsibility for clinical trials (*see page 12*). New tumour special interest groups have been formed, under different chairs from the CSG subgroups, to carry on the educational and clinical governance activities in a new, multi-professional setting. As these are new, not all have yet become fully active, but those with approved workplans for 2011 are:

- **Neuroblastoma:** Chair – Debbie Tweddle
- **Central Nervous System:** Chair – Steve Lewis
- **Soft Tissue Sarcoma:** Chair – Helen Rees
- **Liver:** Chair – Milind Ronghe
- **Renal Tumours:** Chair – Lisa Howell

## Radiotherapy Group

- Nicky Thorp – Chair
- Eve Gallop-Evans – Secretary

The Children's Cancer and Leukaemia Radiotherapy Group is the national voice of paediatric radiotherapy in the UK. Any doctor offering paediatric radiotherapy must be a member. Its remit is to maintain the highest possible standards of treatment delivery and ensure a consistently high quality experience for the patient and their family. It promotes multidisciplinary working, shares best practice, provides a platform for discussion and offers general support to its members, enabling them to do their jobs effectively. It campaigns for adequate resources including

the provision of state of the art equipment and appropriate staffing levels in paediatric radiotherapy centres. The group offers an ongoing education programme and discussion forum through twice yearly multi-professional meetings and, under the auspices of the group, members also contribute to national and international research protocols and inform relevant national policy.

In addition to organising meetings, the Group's main aims for the coming year are: to work co-operatively with colleagues in Manchester, London and Birmingham to develop high energy proton beam therapy within the UK; to continue development of the Radiotherapy database; and to publish the Paediatric Radiotherapy Good Practice Guide.

## Paediatric Oncology in Developing Countries Group

- **Chairs:** Dr Mary Taj, Dr. David Hurman

The group was founded 13 years ago; the rationale being that, while the Western World can now cure 70-80% of children with cancer, 80% of the world's children have no access to this treatment. The aim of the group is to support paediatric cancer hospitals in the developing world and to provide a forum for individual members to come together and discuss the projects they support and to encourage different centres to work together. The projects supported by the group are as follows:

1. To support individual trainees when they go back to their home countries and, in future, to have an email group so that all members can give an opinion when a consultation is made about a difficult case.
2. To support junior doctor training through the Royal College of Paediatrics and Child Health International Paediatric Training Scheme. Drs Sucheta Vaidya, Lynley Marshall and Toni Peterson to take forward.
3. To be involved in nurse training in the projects the Group supports. Louise Soanes will lead and work closely with SIOP (International Paediatric Oncology Society) and WCC (World Child Cancer).
4. To introduce a membership donation with gift

aid that will support future projects like those supported in the past in Malawi, Cameroon and Nepal by individual centres.

The Group had its annual meeting in London in November with 31 members present. Talks covered the projects supported by WCC and the French Wilms Tumour study from Marrakesh. In addition there were project updates from Malawi and Cameroon, and data from two centres in Pakistan.

## Soft Tissue Sarcoma Group

■ Chair: Helen Rees

The Group plans to meet twice annually, with an annual educational meeting. It will: propose treatment guidelines; encourage dialogue with adult colleagues from a teenage and young adult perspective; provide feedback from, and input into, the NCRI Sarcoma CSG; provide a multidisciplinary forum for discussion and provision of advice on complex cases nationally; promote clinical trials and audit; link with the European Soft Tissue Sarcoma Study Group through members who attend meetings in Europe; and make the broader membership of CCLG aware of publications, new guidance and good clinical practice in the care of patients with sarcoma.

## Liver Tumours Group

■ Chair: Milind Ronghe

The Liver Tumours Group provides a forum for discussion for all aspects of malignant and non-malignant paediatric liver tumours and promotes collaboration with similar groups internationally. The work of the group is conducted principally through involvement with SIOPEL, the International Children's Liver Tumour Strategy Group.

The group will develop guidelines for paediatric liver tumours for high-risk hepatoblastoma following closure of the previous trial for this group (SIOPEL 4), as there is no open clinical trial. There will be an annual educational meeting.

## Neuroblastoma Group

■ Chair: Debbie Tweddle

The purpose of the group is to enable all CCLG members interested in neuroblastoma in the broadest sense, ranging from epidemiology through biology to clinical aspects, including trials, imaging, pathology etc, to have a forum for meeting to discuss latest developments in neuroblastoma in all these areas as well as provide a forum for education and research.

Specifically: it will provide updates on advances in neuroblastoma; enable researchers and clinicians to interact and collaborate over potential future research studies; provide a training programme for paediatric oncology trainees regarding the clinical management of patients with neuroblastoma; develop guidelines for treatment of patients with neuroblastoma; and link with SIOPEN (International Society of Paediatric Oncology European Neuroblastoma) to provide details of meetings, activities and overlapping research interest in other European countries.

## Renal Tumours Group

■ Chair: Lisa Howell

The Renal Tumours Group is for all clinicians, scientists and allied health professionals with an interest in renal tumours of childhood and adolescence. It's main roles relate to: multi-professional education; creation of clinical management guidelines; discussion of current issues and challenges faced by the UK treating community; discussion and update regarding genetic and tumour biology developments; contribution to CCLG website; and participation in the research agenda.

CCLG is a registered charity and is heavily reliant on the growing number of individual and corporate fundraisers who work tirelessly to support our work. The following are just some of the many people who have given their time willingly to raise funds for CCLG.



◀ **Megan Luck** – raised £262.30 from a sponsored kickathon. Megan, who is just 8 years old, managed 1,000 kicks in 50 minutes.



◀ **Reena Kumar** – was the first of the CCLG skydivers to take to the air this year, raising over £1,000 in sponsorship. Reena rated the skydive as a “fantastic experience”. She was also glad to have made a difference to the CCLG charity. Her confidence so impressed the instructor, that he invited her to become an instructor – not bad after just one jump!

**Richard Diskin and Kevin Lynch** – completed the Scotland Coast to Coast cycle ride in September 2009, raising funds for CCLG. This photo shows them, proudly sporting their CCLG t-shirts, at the lighthouse at Ardnamurchan Point – the end of their ride.



**Pyrenean Trek** – David Curnow (left) with friend, Bruce, undertook a gruelling 550 mile trek from the Atlantic to the Mediterranean through the Pyrenees. The walk, in memory of David’s son, Matthew, and friend, Richard, took 7 weeks, generated a large number of blisters, but raised £381 for CCLG.



**Steve Horton** is one of a large number of fundraisers, raising money for the Emily Bailes Fund – Fundraising for CCLG. In April this year Steve did a sponsored 5k swim, raising almost £2,000. His training statistics make interesting reading: 5,230 training lengths, training distance 131 km (or 82 miles), time in the pool – 53 hours! He was delighted to complete the swim in just under two hours. For Steve, this was a great achievement, having survived a heart attack 11 years previously.

**Sue Ablett** – CCLG Executive Director, Sue was one of a growing number of runners competing over a range of distances and raising funds for CCLG. For Sue, having the chance to run the 2010 London Marathon, was a lifetime ambition. When sponsorship topped £3,000, Sue was very clear that the best use of those funds was to support production of a new CCLG booklet on sport and exercise for children and young people with cancer. That booklet will be in print in 2011.



**Jo-ann and Nick Ellis** – when Jo-ann and Nick lost their son, Jake, to rhabdomyosarcoma in November 2008 at the age of just 5, they committed to fundraising to support research into the disease. With tremendous support from family, friends, work colleagues and complete strangers, they have already raised over £30,000. The annual charity ball is a firm fixture (photo showing Jo-ann left with Jake's banner), as is participation by 'Team Jake' in the annual Keswick to Barrow Walk (photo showing Jake's dad, Nick, right).



**Benny's Walk** – This event, organised in September 2010, involved a 10k (for adults) and 3k (for children) sponsored walk along Ayr Beach, and raised almost £7,000. The walk, organised by Siobhian Brown, was inspired by her friend's son, Benny Watters, who lived in the United States and had been diagnosed with a brain tumour. Sadly Benny died just before the walk took place.



## Thanks also to...

**Martin and Liz Vernon** – started fundraising for CCLG to support research into Ewing's sarcoma, after the death of their son, David. A keen, fisherman, Martin raises money through selling trout caught in his local reservoir; he has chickens and sells the eggs, which are known as 'Trooper Eggs' after a computer game David used to enjoy. Plum chutney, complete with CCLG label, is the latest line.

**Sam Giles** – 15 year old, Sam, successfully completed a cycle ride from Land's End to John O'Groats in July 2010, raising over £4,000, which was split between CCLG and CLIC Sargent. Sam cycled alone, though with great support from his parents who drove the route and met up with him throughout the days. Sam achieved his goal of completing the ride in 13 days, averaging 80 miles a day. He was inspired to undertake the ride following the death of two school friends – Rob Bailey from leukaemia and Joe Perrett from a brain tumour. A remarkable achievement!

**Scot Beachell** – walked up Ben Nevis in October 2010, raising almost £300. Scot has been cancer free for eight years, but suffers from arthritis making this a particularly hard challenge. He was delighted to have successfully completed the walk.

**Marianne Pritchard-Jones** – Marianne was the mother of Professor Kathy Pritchard-Jones, a long-standing and very committed member of CCLG. When Marianne died in 2010, she left a small legacy to CCLG. Her family also decided that donations in lieu of flowers at the funeral should come to CCLG. Those funds have been ringfenced to cover the costs of reprints of a range of CCLG publications, all of which will be available free of charge to delegates at the 2012 International Paediatric Oncology Society Meeting in London.

**T**hese Summarised Financial Statements are not the statutory accounts, but a summary of information relating to both the Statement of Financial Activities and the Balance Sheet. The full accounts from which this summary is derived have been externally scrutinised, the report did not contain any concerns or qualified opinions. A copy of the full financial statements, the Trustees' Annual Report, and the Independent Auditors Report can be obtained from CCLG, and will be submitted to the Charities Commission in due course when they will be available for downloading from their website [www.charity-commission.gov.uk](http://www.charity-commission.gov.uk).

The financial statements were approved and authorised for issue by the trustees on 14th January 2011.

Signed on behalf of the trustees



**Dr D Ford**

## Independent Auditors' Statement to the Trustees of Children's Cancer and Leukaemia Group

We have examined the summarised financial statements of Children's Cancer and Leukaemia Group.

This statement is made solely to the trustees, as a body in accordance with the terms of our engagement. Our work has been undertaken so that we might state to the trustees those matters we have agreed to state to them in this statement and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity's trustees as a body, for our work, for this statement, or for the opinions we have formed.

### Respective responsibilities of trustees and auditors

The trustees are responsible for preparing the summarised financial statements in accordance with the recommendations of the Charities SORP.

Our responsibility is to report to you our opinion on the consistency of the summarised financial statements with the full financial statements and trustees' report. We also read the other information contained in the summarised annual report and consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the summarised financial statements.

### Basis of opinion

We conducted our work in accordance with Bulletin 2008/3 'The auditors' statement on the summary financial statement' issued by the Auditing Practices Board for use in the United Kingdom. Our report on the full annual financial statements describes the basis of our opinion on those financial statements.

### Opinion

In our opinion the summarised financial statements are consistent with the full financial statements and the trustees' report of the Children's Cancer and Leukaemia Group for the year ended 30 November 2010.

We have not considered the effects of any events between the date on which we signed our report on the full annual financial statements (14th January 2011) and the date of this statement

### PKF (UK) LLP

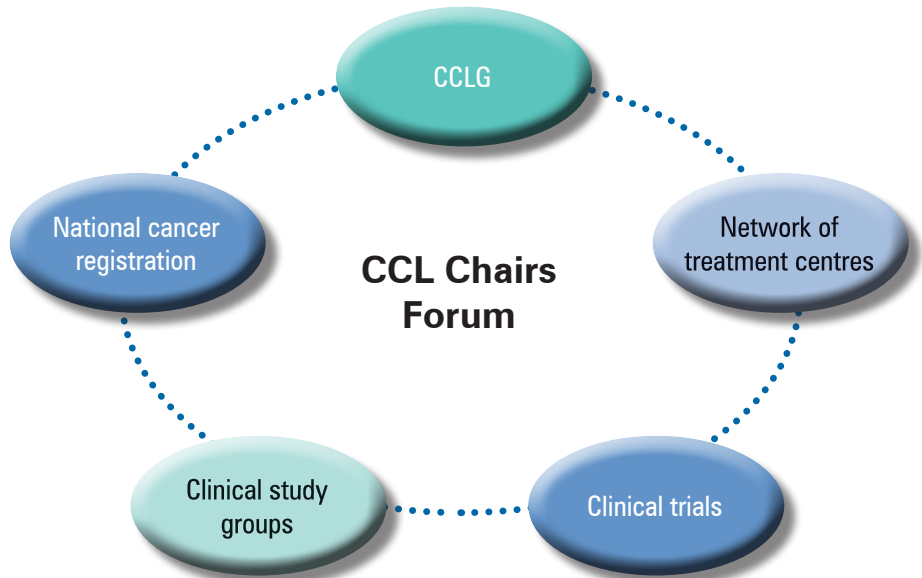
Statutory auditors  
Leicester, UK

## Summarised Statement of Financial Activities (Incorporating the Income and Expenditure Account)

	Unrestricted Funds £	Restricted Funds £	2010 Total Funds £	2009 Total Funds £
<b>INCOMING RESOURCES</b>				
Voluntary income:				
Donations and legacy income	173,872	66,545	<b>240,417</b>	353,835
Subscriptions	225,111	–	<b>225,111</b>	224,385
NCRN income	41,333	–	<b>41,333</b>	122,834
Activities for generating funds	1,721	–	<b>1,721</b>	9,064
Investment Income	821	–	<b>821</b>	2,346
Incoming resources from charitable activities:				
Meetings	26,316	–	<b>26,316</b>	23,988
Contact magazine income	–	26,748	<b>26,748</b>	40,000
Training income	–	–	–	300
Contribution towards accomodation costs from University of Leicester	50,000	–	<b>50,000</b>	75,000
Sundry income	7,733	–	<b>7,733</b>	2,230
<b>TOTAL INCOMING RESOURCES</b>	<b>526,907</b>	<b>93,293</b>	<b>620,200</b>	853,982
<b>RESOURCES EXPENDED</b>				
Costs of generating funds	7,757	–	<b>7,757</b>	5,059
Charitable activities	437,663	94,602	<b>532,265</b>	734,312
Governance costs	13,661	–	<b>13,661</b>	33,514
<b>TOTAL RESOURCES EXPENDED</b>	<b>459,081</b>	<b>94,602</b>	<b>553,683</b>	772,885
<b>NET INCOMING/(OUTGOING) RESOURCES</b>	<b>67,826</b>	<b>(1,309)</b>	<b>66,517</b>	81,097
<b>Total funds brought forward</b>	759,128	295,433	<b>1,054,561</b>	973,464
<b>Total funds carried forward</b>	<b>826,954</b>	<b>294,124</b>	<b>1,121,078</b>	1,054,561
<b>SUMMARISED BALANCE SHEET</b>				
			2010 £	2009 £
Tangible fixed assets			<b>19,417</b>	72,794
Net current assets			<b>1,101,661</b>	981,767
Provisions			<b>(4,000)</b>	–
<b>NET ASSETS</b>			<b>1,121,078</b>	1,054,561

## Introduction

As part of the restructuring of CCLG, a number of areas of activity, previously coordinated by CCLG, have now been devolved to different organisations. These areas are: the network of treatment centres; national cancer registration; clinical study groups and clinical trials. In order to ensure that appropriate cross communication and strategic direction are achieved, the lead for each of these areas, as well as the CCLG Chair, meets monthly by conference call in what is known as the Children's Cancer and Leukaemia (CCL) Chairs Forum. The Forum also



provides the opportunity for discussion on more general points, such as the future of academic training and research in paediatric oncology; user representation in CCL matters, review of the Cancer Reform Strategy, and engagement with the Teenage and Young Adult (TYA) cancer community.

## Children's Cancer and Leukaemia Clinical Studies Group (CCL CSG)

This Group, under the auspices of the National Cancer Research Institute, came into existence on 1st April 2010, following the reappraisal and reconfiguration of the trials portfolio previously run by the Children's Cancer and Leukaemia Group. Dr Chris Mitchell, was appointed as the first Chair.

From the previous CCLG structure, it was agreed that there should be seven subgroups within the CCL CSG, but that some conditions should have their activities subsumed into existing CSGs. The CCL subgroups are: Leukaemia, Central Nervous System, Liver, Renal, Germ Cell, Neuroblastoma and Novel Agents. Rhabdomyosarcoma and Non-Hodgkin Lymphoma fall into the Sarcoma and Lymphoma CSGs.

The list of trials in the Group's portfolio includes 22 open trials and 21 in follow up. A total of 1,647 patients were recruited to studies in 2009-10. There are a number of trials in development. A key priority for the coming year is to ensure that new studies are incorporated into the portfolio so that there are no significant gaps in the coverage of paediatric

cancer. At the same time the CCL CSG is committed to working closely with the other CSGs which include paediatric trials in their portfolio: Lymphoma, Sarcoma and Teenagers and Young Adults.

## The Children's Cancer and Leukaemia Network

Responsibility for coordination of clinical governance of the network of treatment centres now rests with the National Cancer Research Network within the NIHR (National Institute for Health Research). Collaboration with the Medicines for Children Research Network (MCRN) will continue where appropriate, particularly in relation to new drug studies and industry interface. The role of NCRN includes responsibility for maintaining the infrastructure of the CCL centres in order to support clinical trial activity, and to ensure good practice in terms of patient recruitment, as well as quality and timeliness of patient data, which underpins the delivery of clinical trials across the network. Two key appointments – a part-time Associate Director, a clinical lead role, and a full-time senior manager – will be made early in the New Year 2011.

## The National Cancer Intelligence Network (NCIN)

The core objective of NCIN ([www.ncin.org.uk](http://www.ncin.org.uk)) is to promote the use of data to change clinical practice and improve outcomes for patients. The work of NCIN is guided by a number of Clinical Reference Groups (CRGs) which are organised on a 'site specific' basis for common adult cancers and by a separate CRG for Children, Teenage and Young Adult (CTYA) cancer. Membership of the CTYA CRG includes representatives from both registries involved in CTYA cancer (the Oxford based registry for children and Manchester for TYA), clinicians and a parent representative.

Over the past year a significant amount of work has been undertaken to finalise the CTYA content of the National Cancer Dataset for which NCIN has now assumed responsibility; it is expected that this will be implemented in England from September 2012.



## Clinical Trials

The former CCLG clinical trial portfolio is now managed across a number of different host institutions. The largest number – a total of 152 trials, including 116 closed trials with no on-going analysis, 15 closed trials with on-going analysis, 9 trials open to recruitment and 12 trials open in follow up only – were transferred to the Cancer Research UK Clinical Trials Unit, University of Birmingham, on 31st March. A new Children's Cancer Team has now been appointed. A lot of new trial activity has been undertaken by the Team in the last 16 months. This has culminated in 4 new trials planned to open in the next year, including one for which international sponsorship has been put in place. A further 10 trials are at an advanced stage of development.

The University of Birmingham is also host to two open studies of magnetic resonance spectroscopy of brain tumours, run by the Functional Imaging Group. The vision and overall research theme is to develop scans which improve our understanding of childhood tumours and help doctors with diagnosis, treatment selection and development of new drugs. A major CRUK/EPSRC/MRC/DOH 5-year programme grant underpins the infrastructure of the Group, with further funding from the Samantha Dickson Brain Tumour Research Trust.

The portfolio of pharmacology studies are now run from the University of Newcastle by the Newcastle Pharmacology Group. The Group currently has five open studies. A further nine have been completed and the findings published. A number of completed clinical studies have recently been published, including studies highlighting the benefits of individualised patient treatment. Based on their findings, the Group is now utilising a pharmacokinetic monitoring approach for 13-cis retinoic acid treatment of high risk neuroblastoma patients. The total number of patients recruited to the pharmacology studies has now passed 450. The Group is involved in a number of studies of the pharmacokinetics of new treatments for childhood cancer. An exciting new development is the successful collaboration with clinical centres in India.

**A**s a membership organisation for healthcare professionals, CCLG exists ultimately to benefit current and future patients, through treatment, support and care. There are many individuals who share the aims of improving outcomes for children and younger teenagers with leukaemia and cancer, or are otherwise interested in the work of CCLG. These include parents and other relatives or acquaintances of those affected, as well as survivors, and others with no direct link to childhood cancer.

**Neil Ranasinghe** – Neil's daughter, Anne, was diagnosed with ALL in January 2004. Now aged 9, she is doing very well – starring on the CCLG Publicity Leaflet and Banner, and taking fame in her stride. Neil was a founder member of the CCLG Patient Advocacy Committee, leading on the publication 'Getting the best from the Internet'. Sponsorship from a major triathlon and half-marathon allowed him to part sponsor an issue of *Contact* – a magazine he feels passionately about. He encouraged medical writers from Thomson Reuters to volunteer to write lay summaries of published scientific papers, which are accessible on the CCLG website. For this he was rewarded by his employer with a Community Champion Award. The prize funded salary costs of a member of CCLG staff for one year.

Neil is also an active member of the CCLG Website Working Party and has recently joined the Publications Committee.



**Anthea Martin** – is a survivor of childhood cancer, having been diagnosed with Ewing's sarcoma 20 years ago. Anthea joined the Editorial Board of *Contact* magazine in late 2005, since when she has provided unique insight as a survivor. She has been a regular contributor of articles, undertook the task of editing the International Issues, and is currently leading on production of 'Best of *Contact*' – a special publication to mark 50 issues of *Contact*. In January 2010 Anthea also joined the CCLG Publications Committee.



'Friends of CCLG', is a new group launched in late 2010 to bring together existing and new supporters under one umbrella, for mutual benefit.

CCLG is very fortunate in the friends it already has. There are many different ways in which support is provided. We hope that more people will be encouraged to support us by joining the Friends of CCLG. Here we focus on what some of our friends have contributed.



**Amanda Bailes** (pictured above, right, with CCLG Executive Director, Sue Ablett) – Amanda's younger daughter, Emily, was diagnosed with cancer at the age of five in March 2004, losing her battle with the disease in March 2008. In July 2008, on what would have been Emily's 10<sup>th</sup> birthday, her family set up the Emily Bailes Fund, with the specific purpose of raising money for CCLG. An ambitious target of £100,000 was set, in the hope of raising that sum by Emily's 21<sup>st</sup> birthday. Already, thanks to the incredible commitment of Amanda, her family, work colleagues and supporters, that target has now been reached. Funds raised so far have covered production of reprints of a range of information leaflets for siblings; an issue of *Contact*, and salary costs for a member of the CCLG Finance Team. Amanda's commitment to CCLG was honoured recently when she was awarded an Excellence Volunteering Award by her employer. She now has big plans for Emily's Big Walk – a major national sponsored event – to take place in 2012.

### ■ Multiprofessional membership:

To continue the expansion of CCLG to include also non-medical healthcare professionals

### ■ Academic paediatric oncology:

Completion of a formal national review of academic paediatric oncology in order to define future strategy

### ■ Clinical treatment guidelines:

Working with the tumour Interest Groups, to ensure that clinical treatment guidelines are available for patient management where no clinical trial exists

### ■ CCLG Tissue Bank:

To complete the move to a centralised national Tissue Bank in order to enhance the standard and quality of banking and to facilitate release of samples to support translational research

### ■ Parent/patient information:

To continue to provide free of charge a high quality range of information booklets for families, healthcare professionals and others

### ■ Friends of CCLG:

To take forward the Friends of CCLG as a means of uniting all supporters

### ■ Board of Trustees:

To complete appointments to the Board of Trustees

### ■ CCLG Website:

Development of a new website in order to enhance communication with the membership and the general public

### ■ Fundraising:

To continue a proactive approach to fundraising to secure the financial future for CCLG in order to be able to deliver all the above. The appointment of a number of Patrons will be integral to this.



## **Children's Cancer and Leukaemia Group**

*Caring for children – curing their cancer*

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