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Paul's and Jean's first school photographs



Annual Report & Accounts 2005



Registered Charity No. 298405. Inaugurated in 1988 by Diana, Princess of Wales in memory of Jean and Paul O'Gorman





About CHILDREN with LEUKAEMIA

Foreword by the Chairman

NCESS OF WALES s plaque to inaugurate pened the Garden nempry of Paul d of leukaemia ry 1987 aged 14 Vests



Leukaemia is cancer of the blood. It is the most common childhood cancer and, despite enormous advances in treatment, it remains a devastating disease, killing one in every four children who are diagnosed. The number of new cases is rising every year and we don't know why.

Paul O'Gorman was 14 years old when he was diagnosed with leukaemia. He died only three months later - in February 1987.

Paul had made his parents promise to help other children with leukaemia and in November 1987 they held their first fundraising ball. Their most dedicated fundraiser, Paul's sister Jean, insisted

on attending even though she herself was critically ill with cancer and was to die only two days later.

Shortly after Jean's death, Eddie and Marion O'Gorman met Diana, Princess of Wales. Deeply moved by their double tragedy, she personally helped start this charity which she inaugurated in January 1988.

What began as a small memorial charity is now Britain's leading charity dedicated to the conquest of childhood leukaemia through pioneering research, new treatment and support of leukaemic children and their families. The indomitable spirit of Paul and Jean continues to inspire our work.



I am pleased to record that, despite our 2005 fundraising being severely affected by the Tsunami appeal, we sustained our annual income at over £10 million.

The continued increase in the number of children surviving leukaemia is a great testament to the skill and dedication of the scientists and doctors who continually strive to improve treatments and care - and to years of investment in leukaemia research. The minimal residual disease project - funded in partnership between CHILDREN with LEUKAEMIA and the Leukaemia Research Fund - is the single most important development in leukaemia treatment since the development of combination therapies in the 1960s. I am delighted that we will now be funding this work through to its completion in 2009.

Despite these encouraging developments in treatment, the growth in the number of children developing the disease every year is of enormous concern. We are determined to get to the bottom of this increasing incidence and have sustained our focus on causes throughout 2005. In May we awarded 12 grants for new projects focused on causes. These outstanding projects hold real promise of advancing our knowledge and may help us to reverse the increasing incidence. We have already started the application process for a further round of grants for causes projects in 2006 and expect to announce the awards towards the end of the year.

We continue to invest substantially in welfare projects - to ease the strain on family life. We have now completed our commitment to Great Ormond Street Hospital for the new patient hotel which is providing such wonderful facilities to families travelling to London for treatment. And we have embarked on a new partnership with the team at GOSH to help fund the expansion of their inpatient cancer facilities.

We are making progress in our campaign for better protection against the dangers of exposure to





electric and magnetic fields, a well-established risk factor for childhood leukaemia. As well as participating in SAGE, the stakeholder advisory group established by the Department of Health, we have been carrying out a range of other activities designed to draw attention to the issue and encourage the implementation of protective measures against this very real risk to health.

We continue to develop and improve the governance of the charity. The death of Lord Mark Carlisle in 2005 was an enormous blow to us all. Mark became a trustee in 1991 and made a tremendous contribution during his 14 years in office. We have strengthened the trustee board with the recruitment of four new trustees - Professor Denis Henshaw, Sandra Mileham, Baroness Morgan of Drefelin and Linda Robson - each of whom brings new and important skills and talents to the Board.

We have also strengthened the staff team, with the introduction of two new posts. Dr Adrienne Morgan joined us as Staff Scientist in February 2006 and Peter Reynolds joined us as Deputy Chief Executive in June 2006. Both of these posts will substantially enhance our ability to meet our charitable objectives and I am delighted to welcome Adrienne and Peter to the team.

As ever, we are indebted to our friends, staff, volunteers and supporters whose continuing dedication has made possible the vital work described in this report. On behalf of the trustees I would like to record our gratitude for their hard work. I hope that we can continue to count on their support in the years ahead. There is much still to do.

holdie O' Gurman

Eddie O'Gorman **Chairman of Trustees** 4th July 2006





Our aims and objectives

CHILDREN with LEUKAEMIA around Britain

Our aims

We aim to conquer childhood leukaemia. We want all children diagnosed with leukaemia to be cured and for the cure to be effected with minimum disruption to their lives. Further we want to understand what causes children to develop leukaemia so that the rising incidence can be halted and reversed.



Our objectives

1. We will fund high quality research aimed at developing treatments which are not only more effective but are also less debilitating and disruptive to children's lives.



2. We will fund high quality research aimed at improving our knowledge about the causes of childhood leukaemia.



3. We will provide capital funding to encourage the development of centres of excellence in childhood leukaemia research.



4. We will take forward the results of relevant research so that the knowledge gained can be used to best effect.



5. We will raise public awareness about issues of concern and seek to influence the development of policy to promote the best interests of children with leukaemia or at risk of leukaemia.



6. We will support welfare initiatives to minimise the difficulties and disruptions caused by treatment.

KEY • Research facilities Research projects • Welfare projects

1 Paul O'Gorman Leukaemia Research Centre, University of Glasgow (due to open in 2007).

2 Minimal residual disease study, Royal Hospital for Sick Children, Glasgow.

3 Young Oncology Unit, Christie Hospital, Manchester.

4 Paul O'Gorman Blood Laboratory, Wolfson Molecular Imaging Centre, University of Manchester.

5 Paul O'Gorman Molecular Diagnostic Laboratory, The Paterson Institute, Christie Hospital, Manchester (due to open in 2006).

6 DNA sequencer, Cancer Immunogenetics Laboratory, University of Manchester.

7 Dr Ketal Patel, MRC Laboratory of Molecular Biology, Cambridge. Identification and characterisation of novel genes that function in the Fanconi anaemia tumour suppressor pathway.

8 Alasdair Philips, Cambridge. An exploration of the possible causes of childhood leukaemia and other cancers.

9 Paul O'Gorman Laboratory, Coghill Research Laboratories, Gwent.

10 Professor Nick Priest, University of Middlesex. Environmental radioactivity as a cause of leukaemia in a high radiation area within central Asia: feasibility study.

11 Paul O'Gorman Building, Bristol Royal Hospital for Children.

12 Professor Denis Henshaw, Human Radiation Effects Group, University of Bristol. Programme funding studies into environmental risk factors for childhood leukaemia.

13 Minimal residual disease study, University of Bristol/ Bristol Royal Hospital for Children.

14 Dr Craig Donaldson, University of the West of England. A study of human NKT cells in stem cell transplant recipients.

15 Professor Alan Preece, Bristol Haematology and Oncology Centre. Programme funding studies of the association between childhood leukaemia and proximity to power lines.

16 Community children's nurses in Cornwall and Tyne and Wear.

17 CHASE Hospice, Surrey. To support the provision of services for children with leukaemia

B Sussex Snowdrop Trust. To support the provision of services for children with leukaemia

¹⁹ Paul O'Gorman Respite Centre, Angmering on Sea.



20 Professor Eric Wright, University of Dundee Medical School. Investigations of microenvironmentally-mediated damage as a promotional factor in childhood leukaemia

(2) Northern Institute of Cancer Research, Paul O'Gorman Building, University of Newcastle.

22 Dr Tevfik Dorak, University of Newcastle. Genes influencing body iron content and childhood leukaemia risk.

23 Dr Richard Feltbower, University of Leeds. Does population mixing measure infectious exposure at the community level?

24 Minimal residual disease study, Sheffield Children's Hospital.

Paul O'Gorman Patient Hotel, Great Ormond Street Hospital for Children, London.

26 Paul O'Gorman Leukaemia Research Centre, Institute of Child Health, London.

27 Institute of Cancer Sciences, Paul O'Gorman Building, University College London (due to open in 2006).

(23) Expansion of Haematology and Oncology Services, Great Ormond Street Hospital, London.

29 Paul O'Gorman House. Parental accommodation facility at the Royal Free Hospital, London.

30 Laboratory of Cellular Therapeutics, Paul O'Gorman Childhood Leukaemia Centre, Royal Free Hospital, London.

> **31** Dr Hugh Brady. Paul O'Gorman Leukaemia Research Centre, Institute of Child Health, London. The role of MLL in the molecular pathogenesis of infant and childhood leukaemia.

32 Dr Paul Veys & Dr Persis Amrolia. Great Ormond Street Hospital, London. Anti CD34 immunotoxin study.

⁶³ Minimal residual disease study, Hammersmith Hospital, London.

34 Home from Home, Middlesex Hospital, London (due to open summer 2007).

Professor Mel Greaves, Institute of Cancer **35** Research, London. Collateral DNA damage as an indicator of prior aetiological exposures in infant leukaemia.

Dr Mike Murphy, Childhood Cancer ³⁶ Research Group, University of Oxford. Programme funding - studies into risk factors for childhood leukaemia.

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Objective 1. We will fund high quality research aimed at developing treatments which are not only more effective but are also less debilitating and disruptive to children's lives.

Three out of four children diagnosed with leukaemia now survive. This is incredible progress considering that only 50 years ago a diagnosis of leukaemia was tantamount to a death sentence for every child who was diagnosed. However it is not progress enough for the one child in four who does not survive and we will continue to fund research aimed at developing treatments for those forms of childhood leukaemia which still elude successful treatment.

As well as developing treatments which are more effective, we are working towards the development of treatments which are less disruptive to children's lives. Children diagnosed with leukaemia are initially given high doses of toxic drugs to rid their bodies of the deadly cancer cells. This is followed by further bursts of intensive therapy to ensure that all leukaemia cells have been destroyed and then lower dose maintenance therapy to prevent the disease from returning. This entails frequent trips to hospital, with the child often admitted for weeks at a time. Some children will also require a stem cell (bone marrow) transplant to help them recover.

Our achievements in 2005:

• Dr Nicholas Goulden, Bristol Royal Hospital for Children. Stratification of chemotherapy based on levels of minimal residual disease. Funding of £392,228 was granted in support of year four of this ground-breaking project, taking our total funding of this work to £1.83 million. See page 8 for further details of Dr Goulden's project.

• Dr Craig Donaldson, University of the West of England. Dr Donaldson and colleagues are studying an important cell in our immune system called the Natural Killer T-cell (NKT-cell). This cell is involved in an important and beneficial side-effect called Graft vs Leukaemia in which stem cells transplanted from a donor help to kill the leukaemia cells remaining in the patient's bone marrow. The team are trying to find out more about how the NKT-cells work and, in particular, how to encourage the rapid recovery of the cells post-transplant. We made a grant of £94,140 to enable the team to continue this work for a further two years.

• Dr Paul Veys and Dr Persis Amrolia, Great Ormond Street Hospital for Children. This

team is trying to develop a new, less toxic method of preparing children for stem cell transplantation. At the moment, powerful chemotherapy or radiotherapy must be used to destroy the patient's own bone marrow and create space for the donated marrow cells. Unfortunately these treatments can damage the patient's other organs, causing life-threatening side-effects. Drs Veys and Amrolia are developing a new way of destroying the patient's marrow, by using an antibody that recognises bone marrow cells and linking it to a toxin which will kill them. Because this "immunotoxin" binds only to marrow cells it should kill them specifically, without causing damage to other tissues. We made a grant of £17,000 to pay for the laboratory consumables required for this work.

Our plans for 2006:

• The plans for years four to six of the minimal residual disease study (led by Dr Nicholas Goulden in Bristol) have now been approved by the Leukaemia Research Fund scientific board. We have undertaken to raise the £1.7 million necessary to meet the cost of this work. We paid the first instalment of £619,267 in March 2006.

• We are in discussion with the London Cord Blood Consortium about a possible collaboration to help take forward their work to improve umbilical cord stem cell transplantation.

• We will work with the scientists we fund, our scientific advisory panel and others working in the





field - especially the Leukaemia Research Fund, with whom we have enjoyed a close collaboration for 18 years now - to identify new areas of work which could lead to benefits in the treatment and care of children with leukaemia. We will look at ways of improving the effectiveness of our grantmaking in this field.

• We will continue to monitor all of the treatmentrelated work funded by us including the projects mentioned on the facing page and the infant leukaemia programme which we fund at the Institute of Child Health (under Dr Hugh Brady). At the time of writing, we have already begun a programme of visiting funded projects.



Objective 1. We will fund high quality research aimed at developing treatments which are not only more effective but are also less debilitating and disruptive to children's lives.

Case Study

Stratification of chemotherapy based on levels of minimal residual disease Dr Nicholas Goulden, Bristol Royal Hospital for Children

Every child will have some leukaemia cells remaining in their bone marrow when they achieve remission (the point at which their disease is considered to have been brought under control). These remaining cells are known as minimal residual disease (MRD). Previous studies indicate that the precise level of MRD is a reliable predictor of relapse risk, however the number of cells is so small – often less than one leukaemia cell in 10,000 normal cells – that it is not possible to detect them under the microscope.

Dr Goulden likens the bone marrow to a factory which produces blood cells. In leukaemia, one of the production lines is malfunctioning and is producing faulty cells in such huge numbers that the whole factory is overwhelmed and the other production lines can't continue making normal blood cells. Chemotherapy is used to shut down the faulty production line. This destroys most of the leukaemia cells and allows the bone marrow to start producing normal blood cells again. But some of the leukaemia cells are hiding around the factory and every so often they may jump out and start causing havoc again. These cells are the MRD. There may be just one or two cells hiding in the cupboards, in which case the child is at low risk of relapse. Or there may be hundreds of them, in which case the child is at high risk of relapse and needs more intensive treatment to get rid of all these cells and prevent them from taking over the factory again.

This national study is using a new molecular technique which enables scientists to find and measure the remaining leukaemia cells – the equivalent of going looking in the cupboards. The technique involves the development of unique molecular markers for each child's leukaemia cells from bone marrow samples taken at the time of diagnosis. These markers are then used to screen subsequent samples taken from that child.

The team aims to establish whether relapse can be avoided in children found to have a high level of MRD at day 28 by intensifying their treatment at this early stage; and whether children found to have a low level of MRD at day 28 can receive lower doses of chemotherapy, minimising their risk of treatment-related side-effects without compromising their chance of a cure.

More than 800 children have so far commenced treatment under the trial, which is now in its fourth year. Even at clinical trial stage, it is likely that this technique has already saved young lives. We are confident that within the next three years, this technique will become part of standard NHS practice.

CHILDREN with LEUKAEMIA has so far contributed £2.45 million to the project and we have undertaken to raise a further £1 million to take it through to completion.



Objective 2. We will fund high quality research aimed at improving our knowledge about the causes of childhood leukaemia.

Although improvements in the treatment of childhood leukaemia are one of the great medical success stories of the 20th century we still know very little about what causes children to develop leukaemia in the first place.

Over the same period during which the proportion of childhood leukaemia cases resulting in death has been decreasing, the number of new cases has been steadily increasing, making it imperative that we prioritise efforts to understand the causes of the disease.

Our achievements in 2005:

During our successful 2004 international conference on the causes of childhood leukaemia we announced new funding of £1 million for projects investigating causes. In May 2005 our grants panel awarded funding to 12 projects - out of the 43 applications submitted - at a total cost of £1.05 million.

The funded projects are those which were felt to offer the best hope of advancing our knowledge of the causes of childhood leukaemia. The projects cover a diverse range of factors purported to be linked to childhood leukaemia including environmental and lifestyle factors such as radiation, electricity, diet and infection as well as studies of the genetic mutations which are involved in leukaemia development. The 12 projects are described on the following pages.

This was the first time we have run such a grant round ourselves and we put a great deal of effort into ensuring that we had rigorous procedures in place for scrutinising the applications received. Our acceptance into the Association of Medical Research Charities (AMRC) in 2005 shows that we achieved this aim. The AMRC lays down minimum standards of good practice to which member charities must adhere, including policies on peer review and other aspects of grant-making. To be eligible for membership, charities must be able to demonstrate that they meet these criteria.

New grants for research into the causes of childhood leukaemia

Dr Vladimir Binhi, Russian Academy of Science. "Theoretical study of the role of magnetic nano-particles in the transduction of weak alternating and slow variable magnetic fields to the level of biochemical reactions"

We awarded £20,490 to Dr Binhi to investigate the possible role that the tiny magnetic particles in our brains play in mediating a biological reaction to magnetic field exposure.

Although exposure to magnetic fields has been shown to increase the risk of childhood leukaemia. there is so far no well-established biological mechanism to explain this increased risk. It has been shown, however, that the human brain contains tiny magnetic particles which respond to magnetic fields. These may play a role in mediating the interaction of magnetic fields with the human body.

Dr Binhi will carry out an analysis of the literature and conduct an original theoretical study to attempt to clarify the role of these particles in relation to their ability to change the rates of certain biochemical reactions which regulate the immune system. He will use this information to create a theoretical model to advance our understanding of whether external magnetic fields can alter immune function and induce leukaemic changes. This model will provide a template upon which to base laboratory research efforts and will help us to identify which characteristics of magnetic fields should be measured in future epidemiological studies.

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Professor Gladys Block, University of California, Berkeley. "Effect of maternal and child diet and folate metabolism gene variants on childhood leukaemia risk" We awarded £133,022 to Professor Block for this project looking at the interplay between diet and genetic factors.

Diet has been linked to childhood leukaemia in a number of studies although maternal diet and early childhood diet have never been comprehensively examined. In this study Professor Block will carry out a detailed analysis using data from the Northern California Childhood Leukemia Study (NCCLS). She will focus on folate, known to be important in the development and maintenance of healthy cells, building upon existing data from the NCCLS to examine the role of genes involved in the metabolism of folate.

Professor Patricia Buffler, University of California, Berkeley. "Individual genetic susceptibility and environmental exposures in the aetiology of childhood leukaemia" Professor Buffler was awarded £110,106 to look at the effect of genetic make-up on a child's vulnerability to certain environmental carcinogens. Many studies have looked for associations between childhood leukaemia and exposure to environmental factors such as parental smoking, vehicle emissions and pesticides and the literature is generally supportive of a link.

Professor Buffler proposes that some children are more vulnerable to the effects of environmental carcinogens because of their genetic make-up, something that few studies have so far taken into account. Using new molecular genetic techniques, Professor Buffler will use data from the NCCLS to examine whether variation in the expression of genes known to be involved in the metabolism of environmental carcinogens - in both the mother and the child - are associated with childhood leukaemia. She will go on to examine whether variation in these genes modifies the association between exposure to these environmental carcinogens and childhood leukaemia.



Dr M Tevfik Dorak, Paul O'Gorman Building, University of Newcastle upon Tyne. "Genes influencing body iron content and childhood leukaemia risk"

Dr Dorak was granted £93,532 to investigate the association between childhood leukaemia risk and a genetic mutation (HFE-C282Y) known to affect body iron content.

Whilst the connection between increased body iron content and cancer risk has been repeatedly demonstrated in adults, no study has examined whether the same risk applies to children. However, an association has been found between the HFE mutation, which increases body iron levels, and childhood acute lymphoblastic leukaemia (ALL). It is also known that leukaemic children have higher levels of blood iron and this sometimes persists after treatment.

Dr Dorak suggests that genetic variation passed on by the mother can increase iron levels in the developing foetus, increasing the risk of childhood ALL. At least one in 10 people in the UK are carriers of the HFE mutation and it is important that we understand more about any association with ALL.

Dr Dorak will study the effects of this mutation on iron levels in the blood of healthy newborns and their mothers. He will look for associations between childhood ALL and other genes related to iron regulation and, for comparison, he will examine the role played by other genes in iron regulation in the development of ALL in patients from Turkey where the HFE mutation is virtually non-existent.

Dr Richard Feltbower, University of Leeds. "Does population mixing measure infectious exposure at the community level?"

We awarded £69,052 to enable Dr Feltbower to examine the validity of using population mixing measures as proxies for exposure to infection.

Several studies have identified associations between population mixing and childhood leukaemia, inferring that leukaemia may be directly caused by exposure to infection. The 'hygiene hypothesis' suggests that because today's children are not exposed to the same level and range of infections as their counterparts of 50 years ago, their immune systems are not fully developed and this may increase their risk of leukaemia.

Dr Feltbower will compare the validity of different population variables and quantify the strength of their association with infectious diseases. He will then develop new census-based measures of population mixing and community characteristics to more accurately reflect the load and diversity of infectious diseases.

If Dr Feltbower succeeds in developing reliable measures, these will be made available for use in future epidemiological studies, enabling the influence of infections in childhood leukaemia development to be more precisely determined.



Dr Tevfik Dorak, shown here with Research Associate Rachel MacKay, is based in the new Paul O'Gorman Building at the University of Newcastle upon Tyne. The fantastic facilities in this new research centre (see page 19) will help them make best progress in their research.

Dr Leeka Kheifets, University of California, Los Angeles. "Updated pooled analysis of childhood leukaemia and magnetic fields"

We provided £110,106 for Dr Kheifets' update of the previous pooled analyses of studies investigating the link between magnetic fields and childhood leukaemia.

For various reasons, it is difficult to establish the association between magnetic fields and leukaemia in a single study. Combining results in a 'pooled analysis' overcomes some of the difficulties and the results of such analyses have shown that long-term exposure to high intensity magnetic fields is associated with a doubling of leukaemia risk in children.

Dr Kheifets will update previous analyses using six recently published studies. By pooling the data she will be able to measure the association with much greater precision. She will also be able to examine the dose-response relationship at high exposure levels, not possible in smaller studies due to the relatively few cases in the high exposure category, and explore whether risk differs across subgroups. This work will give a greater insight into the relationship between magnetic fields and leukaemia risk and will contribute to the development of muchneeded precautionary policies.



Professor Sam Milham, Washington DC. "Studies of the relationship between environmental EMF exposure and childhood leukaemia"

Professor Milham was granted £16,555 for further studies of the relationship between electricity and childhood leukaemia.

In Great Britain a new peak in childhood leukaemia mortality between the ages of two and four years emerged in the 1920s and leukaemia mortality increased almost 5% per year in children under 10 years of age in the 50 years starting in 1911. A similar pattern was apparent in the United States and other countries and it has been shown that the United States peak emerged and spread with a striking correlation to residential electrification.

> Professor Milham, who led the US study looking at the spread of electrification, will be carrying out a series of further studies to explore the relationship between electricity and childhood leukaemia. In the main part of his study he will attempt to replicate his US finding by tracking the spread of the childhood peak of leukaemia with the spread of electrification in the province of Manitoba, Canada, where the date of electrification of all 523 cities and towns is

> > known.



Dr Ketan J Patel, MRC Laboratory of Molecular Biology, Cambridge. "Identification and characterisation of novel genes that function in the Fanconi anaemia tumour suppressor pathway"

Dr Patel was awarded £111,000 to study the genetic pathway of Fanconi Anaemia (FA), a genetic condition which leads to an enormous propensity to develop leukaemia.

Most cases of childhood leukaemia result from some kind of chromosome abnormality leading to loss or dysregulation of genes. All of our cells possess proteins that prevent or repair such damage to our genetic information but sometimes these do not work effectively.

A group of proteins have been identified which are essential to carry out this genetic repair. Loss of any one of the ten proteins in the group leads to FA. These ten proteins do not seem to work in isolation but rather constitute parts of a pathway. Although FA is very rare, the genetics of the condition provide a unique opportunity to explore the pathways by which leukaemia develops.

Using our funding, Dr Patel will identify and study new components of the FA pathway, with the aim of establishing a complete molecular understanding of how it works to protect our cells from leukaemiacausing genetic alterations. Identifying the function of Fanconi genes will give an important insight into what prevents all of our cells from accruing the genetic changes that lead to leukaemia.

Professor Nicholas Priest, Middlesex University. "Environmental radioactivity as a cause of leukaemia in a high radiation area within central Asia: feasibility study"

Professor Priest was awarded £15,000 to assess the feasibility of a full-scale investigation into the association between environmental radioactivity and childhood leukaemia.

Acute exposure to high dose radiation is a known cause of childhood leukaemia. It is thought that protracted exposure to low dose environmental radiation could also be a cause of childhood leukaemia but methodological problems have caused contradictory results in the studies which have so far been undertaken.

The main problems encountered in such studies are the low resolving power – a consequence of the relative rarity of the disease - and the low variation in radiation dose between cases and controls. Radiation exposures in the 'uranium provinces' of south-eastern Kazakhstan and Kyrgyzstan appear to be both more variable and much higher than in the UK and most other western nations and, as such, these areas may be suitable locations for an investigation into childhood leukaemia. Professor Priest has designed a pilot study to confirm the variability in radiation exposures and to assess the reliability of childhood cancer diagnoses in the region.

This study will help Professor Priest to shape a fullscale investigation into the association between environmental radiation and childhood leukaemia so that it has the best chance of delivering valid and reliable results. If a positive association is found, it should be possible to take steps to protect children living in areas of high natural background radiation.

Professor Russel Reiter, University of Texas. "Light-at-night, melatonin and experimental leukaemia progression"

Professor Reiter was awarded £72,436 for a study investigating the role of exposure to light-at-night in the development of leukaemia.

Melatonin is a hormone which is produced naturally by our bodies during the hours of darkness and has been shown to have anti-carcinogenic properties. Exposure to light during the hours of darkness interrupts production of melatonin and there is evidence that this may increase our risk of cancer. The increasing use of artificial light-at-night may be contributing to the rising incidence of childhood leukaemia (as well as other cancers).

Although there is already a growing body of evidence concerning the damaging effects of lightat-night, there is little experimental data. Professor Reiter, the world's leading authority on melatonin, will directly test whether exposure to light-at-night influences the growth of leukaemia cells in rats. This work will take forward our understanding of the damaging effects of exposure to light-at-night and the beneficial effects of melatonin.

Professor Eric Wright, University of Dundee. "Investigations of microenvironmentallymediated damage as a promotional factor in childhood leukaemia"

Professor Wright was awarded £138,493 to further his investigations into whether some people may have genetic susceptibility to radiation damage, making them more vulnerable to its effects.

Exposure to ionising radiation increases the risk of leukaemia in both children and adults and it is generally assumed that the disease develops as a direct result of DNA damage at the time of exposure. However we know that the chromosome abnormalities linked with the development of leukaemia can be present at birth and that only a small proportion of children born with these abnormalities actually go on to develop leukaemia.

A number of recent research findings have challenged conventional beliefs about the effects of radiation. Taking into account these findings, **Professor Wright hypothesises** that - since radiation exposures could not produce such specific translocations in such large numbers of individuals - exposure to radiation is not responsible for initiating leukaemia, but rather for promoting the disease development at a later stage. Specifically he proposes that the radiation-induced tissue injury is genetically determined and that the chromosome abnormalities which have been linked with leukaemia may affect the body's ability to cope with radiation damage.

Professor Wright, who has spear-headed many of the advances in our understanding of the effects associated with exposure to ionising radiation, will analyse tissue samples from irradiated mice at different time points to examine the immediate and delayed effects of radiation.





Objective 2. We will fund high quality research aimed at improving our knowledge about the causes of childhood leukaemia.

Dr Joseph Wiemels, University of California, San Francisco. "Aetiology of t(1;19) E2A-PBX1+ leukaemia: an integrative research project"

Dr Wiemels was awarded £161,110 to investigate the genetic events which lead to a particular chromosome abnormality associated with a form of childhood leukaemia.

One of the problems hampering our understanding of the aetiology of childhood leukaemia is that it is often treated as one disease when, in reality, it is a collection of diseases that may have different causes. These different diseases are characterised by genetic abnormalities evident at diagnosis.

Dr Wiemels is focusing on a common genetic mutation in childhood leukaemia, a translocation between chromosomes 1 and 19. He hypothesises that this translocation is induced by a combination of enzymes produced by the cells and external factors that may be infectious or environmental in origin.

Dr Wiemels will perform molecular analyses of the genes, enzymes and DNA structures involved in the chromosome translocation to uncover the underlying mechanisms. And he will collaborate with colleagues on the Northern California Childhood Leukemia Study to identify epidemiological factors which are common among leukaemic children with the t(1;19) translocation.

By breaking down the disease sub-groups in this way Dr Wiemels may be able to produce more definitive answers about the environmental factors that play a role in the development of childhood leukaemia as well as advancing our understanding of the mechanisms involved in the development of the disease.





Our plans for 2006:

• In February 2006 we launched a further grants round to encourage the development of high quality projects investigating the causes of childhood leukaemia. Professor Victor Hoffbrand is chairing the scientific panel for this new grants round, the focus of which is biological mechanisms rather than epidemiology. We expect to announce the awards in November.

 At the time of writing we have already made an agreement in principle to fund a programme of work by the world-renowned Childhood Cancer Research Group (CCRG) at the University of Oxford. The CCRG holds the largest and best national, population-based childhood cancer registry in the world. It encompasses childhood cancer registrations across the whole of the UK and is considered virtually complete from 1962 to the early years of the 21st century. As a major part of the programme funded by CHILDREN with LEUKAEMIA the team there will be carrying out further investigatons to clarify some of the findings

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of the Draper Report, their study into the assocation between proximity to power lines and childhood leukaemia risk which was published in 2005 (see page 22).

 As our knowledge about the causes of childhood leukaemia improves, and the gaps in knowledge become more apparent, we will be looking into the feasibility of developing a pro-active, targeted funding programme, through which we may seek to commission research into areas of particular interest.

• We will continue to work to improve our monitoring procedures for all funded projects and programmes including those listed on the preceding pages and our ongoing programme of funding at the University of Bristol (Professor Denis Henshaw) and will work with all funded scientists to ensure maximum dissemination of research findings

(see also Objective 4).

Objective 3. We will provide capital funding to encourage the development of centres of excellence in childhood leukaemia research.

As a new charity back in 1988, our first goal was to raise £2 million for a new research centre at London's Great Ormond Street Hospital. It took seven years for us to achieve this goal, but the Paul O'Gorman Childhood Leukaemia Research Centre there now houses one of the UK's leading research teams in the field.

Since then we have also contributed funding to assist the development of other childhood leukaemia research centres around the UK. There are now Paul O'Gorman Childhood Leukaemia Research Centres in Bristol, London, Manchester and Newcastle. Two further centres will soon be opening - at the Institute of Cancer Sciences, University College London (UCL) and the new Paul O'Gorman Leukaemia Research Centre at the University of Glasgow.

Our achievements in 2005:

 In 2005 we made a payment of £1 million to UCL towards the costs of building and equipping the Paul O'Gorman Building housing the new Institute of Cancer Sciences, due to open in autumn 2006, taking our total contribution to £1.5 million. The Institute will co-ordinate all of UCL's cancer research, providing a focus for excellent basic science and translational studies across the College's different sites. The Institute will ultimately house over 200 scientists.

 On a smaller scale we were pleased to be able to respond positively to a request from the Cancer Immunogenetics Laboratory at the University of Manchester to fund a DNA sequencer to facilitate their research into the causes of childhood leukaemia. The grant of £64,591 was made in memory of Lord Carlisle of Bucklow, a trustee of CHILDREN with LEUKAEMIA who died in 2005. The grant was partly funded by the many generous donations made by Lord Carlisle's friends and family and a legacy which Lord Carlisle had generously included in his will.

Our plans for 2006:

In March 2006 we made a payment of £200,000 to complete our £500,000 pledge to the University of Glasgow for the new Paul O'Gorman Leukaemia Research Centre there. This new Centre will bring together Glasgow's existing leukaemia expertise, which is currently scattered around a number of different sites making collaboration more difficult than it might otherwise be. The new Centre will provide a much-needed translational research facility that will give both clinicians and researchers access to the most advanced facilities and equipment.

We also plan to complete our commitment to UCL in 2006 by raising a further £500,000 towards the Institute of Cancer Sciences.

In recent years, our focus has shifted slightly away from the development of research facilities so that we have more funding available to support research projects and programmes. As such, we are unlikely to take on further major commitments for building projects.

At the time of writing we have begun a programme of visits to monitor the work being carried out in the existing Centres and encourage collaboration between them.

-Zerren Miller



Paul O'Gorman Building

The Paul O'Gorman Building, housing the Northern Institute of Cancer Research at the University of Newcastle upon Tyne, was officially opened by Sir Bobby Robson in February 2005. Childhood leukaemia is one of four major research themes at the Institute where more than 100 scientists benefit from the facilities available in the new Building.

As well as directly funding research into both the causes of and treatment for childhood leukaemia we have a key role in disseminating the results of this research so that information is shared by researchers around the world, enabling best progress to be made. Although two of the three conferences described below are taking place in 2006, the funding was granted in 2005, hence their inclusion in this section.

Our achievements in 2005:

European Radiation Research (ERR)

Meeting, Leicester. We made a grant of £6,739 to enable the organisers of this important meeting to invite keynote speakers for relevant sessions (including those on non-ionising radiation, genomic instability, radiation carcinogenesis, DNA damage and stem cells). Two hundred scientists from across Europe as well as America, China, Japan and India attended the meeting in September 2005, during which more than 100 oral presentations were made. Meetings like this are critical in ensuring that current research findings are disseminated and discussed and in fostering communication and collaboration between those working in the field to ensure that optimal progress is made.

The Molecular Basis of Childhood Leukaemia, Institute of Child Health, London. We awarded £10,000 to the Institute of Child

Health to support their 2006 Haematology-Oncology Symposium. As for the ERR meeting above, our funding was given to enable the organisers to invite keynote speakers. Many of the leading experts in this field are from the US, meaning that the travel and accommodation costs are high.

 International workshop on non-targeted and non-linear effects of ionising radiation, Edinburgh. The aim of this three day workshop, organised by Professor Eric Wright of the University of Dundee, is to provide a forum to discuss the wider relevance of some recent

developments in radiation biology which are concerned with effects that are not readily explained in terms of the current paradigm of radiation action. Professor Wright aims to bring together some of the people who have identified these phenomena with those who have insight from other areas of biomedical research. We have made a grant of £29,000 to help support the costs of this ground-breaking event which will help us to better understand the role of ionising radiation in leukaemia development. The workshop will take place in August 2006.

• Also in line with this objective in 2005 we commissioned a review of the scientific evidence relating to electric and magnetic fields and their role in the causation of childhood leukaemia. The resulting document 'Do electric and magnetic fields cause childhood leukaemia? A review of the scientific evidence' will be used to inform the ongoing debate about precaution.

 We were delighted that work funded by CHILDREN with LEUKAEMIA at the University of Bristol has resulted in the introduction of a practical measure which may help to save the lives of children with leukaemia. Disposable plastic aprons have been used by nurses for a number of years now since their cotton uniforms were implicated in the spread of bacteria. However plastic acquires a static electric charge which can attract bacteria from the surrounding air. Dr Janet Allen tested a number of different types of apron, made either from ordinary or anti-static plastic to see whether anti-static plastic is a more effective barrier. One anti-static apron from five types tested resulted in a 38% reduction in bacteria attracted onto its surface compared with the standard aprons currently used. The use of the anti-static aprons - which have now been included in the NHS catalogue as a direct result of Dr Allen's work may help to reduce the spread of hospital infections, particularly in isolation wards such as those in bone marrow transplant units where immuno-compromised patients are more susceptible to infection.



Our plans for 2006:

• We will develop plans for an annual CHILDREN with LEUKAEMIA grant holders' conference. The aim of such a conference would be to bring together those working in the field of childhood leukaemia to share research findings and latest knowledge and encourage collaboration between the different groups we are funding.

· We will also look at other ways of ensuring widespread dissemination of the findings of research that we fund. This includes plans to develop our website to include better information about funded projects.

• We will develop plans for a further conference on the causes of childhood leukaemia - to take place in 2008.





Objective 5. We will raise public awareness about issues of concern and seek to influence the development of policy to promote the best interests of children with leukaemia or at risk of leukaemia.



One of our fundamental aims is to advance There is little protection against this risk for children in this country. Current guidelines set an knowledge of the causes of childhood leukaemia exposure limit 250 times higher than the level at and to understand the reasons for its increasing which a doubling of childhood leukaemia risk has incidence. There are some areas of research where the outcomes may have practical implications for been found. In 2004 the Department of Health the prevention of leukaemia. One such area is the (DoH) established a stakeholder advisory group now established link between electricity and (known as SAGE) to consider the case for revising these guidelines downwards. SAGE is jointly childhood leukaemia. The association with funded by DoH, CHILDREN with LEUKAEMIA and exposure to electric and magnetic fields was first suggested by a 1979 study which reported a National Grid. Forty organisations (including disproportionately high number of childhood statutory, voluntary and commercial) are cancer deaths in families living close to electricity represented on SAGE and are working towards transmission equipment. making recommendations to Government for practical precautionary measures. It is a complex area but, as a first step, we are pushing for an immediate moratorium on the building of new homes and schools near to existing high voltage lines and on the construction of new lines near to existing homes and schools.

Many other studies have investigated this link between electricity and childhood leukaemia, with mixed results, but the largest and most recent study (the Draper Report, published in June 2005) reported a significantly increased risk of leukaemia in children in England and Wales living within 600 metres of a high voltage overhead power line.





Objective 5. We will raise public awareness about issues of concern and seek to influence the development of policy to promote the best interests of children with leukaemia or at risk of leukaemia.

Our achievements in 2005:

 In June 2005 we used the opportunity presented by the publication of the Draper Report to raise awareness of the dangers of electric and magnetic fields (EMF), with resulting coverage on all four breakfast news shows plus many of the broadsheets and tabloids. We were pleased that the media covered the issue responsibly, raising public concern without causing alarm.

• We carried out a range of activities to raise awareness of the issue amongst politicians and pave the way for effective implementation of the recommendations of SAGE. Through our contacts with MPs we ran a programme of parliamentary questions during the year. We received very helpful responses from Caroline Flint, the Parliamentary Undersecretary of State for Public Health and Yvette Cooper, Minister of State for Housing and Planning. In addition, Dr Howard Stoate MP tabled an Early Day Motion (EDM) on our behalf. The EDM called for Government to take immediate action to protect children from the damaging effects of high voltage overhead power lines and supported our call for a moratorium on the building of new schools and homes in proximity of these lines. We had 101 signatures from back bench MPs by year end. This has since increased to 170.

We commissioned law firm Bircham Dyson Bell

to look at the legal aspects of EMF exposure and determine the extent to which the potential effects of EMF on human health is a matter recognised by law in the determination of planning and other development consents, with a particular focus on power lines and electricity sub-stations. The resulting report 'Electric and magnetic fields and public health: legal requirements, responsibilities and shortcomings' has been used to inform our campaign for improved protection from EMF exposure.

• We commissioned Opinion Leader Research to establish the public's perspective concerning the power line/childhood leukaemia issue and their views on what constitutes appropriate precautionary action. Although most participants were initially unaware of the association between power lines and childhood leukaemia, once informed of the current evidence, most felt that something needed to be done to address the issue. Burying the power lines was the preferred option amongst participants. The expense of this was recognised and participants accepted that, as consumers, at least a proportion of the cost would be shouldered by them. There was also a strong feeling amongst participants that they should have more opportunity to have a say on where new power lines are sited.

 In December we held a one-day meeting in London for members of SAGE to learn about the experiences of countries which have already introduced precautionary measures to protect against the potentially damaging effects of EMF. We heard from speakers from Australia, the Netherlands, Sweden and Switzerland, just four of the countries which have already introduced precautionary measures. This highly targeted event was well attended with representatives from organisations such as the Department of Health, the Health Protection Agency, Office of the Deputy Prime Minister, Ofgem, National Grid and a range of academic institutions, professional Cancer risk 'up to Topc higher near power lines' bodies and interest

Our plans for 2006:

• In January 2006 we extended the qualitative public opinion research carried out for us by Opinion Leader Research by commissioning Taylor Nelson Sofres to carry out a larger scale public opinion poll. We were surprised at the level of concern expressed by the 965 people surveyed by TNS. Sixty per cent of respondents expressed concern about the link between childhood leukaemia and EMF and half of these people were so concerned that they said they would be prepared to pay extra on their electricity bills to help fund measures to reduce exposure. This information will now be used to support our call for precautionary measures.

 Dr Howard Stoate MP, with the support of CHILDREN with LEUKAEMIA, has established a cross-party Parliamentary Commission to examine the scientific evidence on the links between EMF and childhood leukaemia, review planning guidelines on the proximity of housing to power lines and consider the public's views on the

Power cables linked to cancel





appropriateness of the Government taking precautionary action to reduce exposure to EMF. The first meeting was held in May and a series of further meetings will take place over the summer. Joining Dr Stoate on the Commission are Dr Ian Gibson MP, Michael Connarty MP, Sandra Gidley MP and Nick Hurd MP.

• We will maintain our involvement with SAGE to represent the interests of children potentially affected by exposure to EMF. The report on power lines is due to be published this year and we will work to ensure that the scientific evidence and associated public opinion on this issue are fully reflected in the final version.

· Whilst the debate continues about the appropriate level of precaution to be adopted, we continue to fund research to help us understand the link between electricity and leukaemia.

 We will continue to represent the interests of children with leukaemia and children at risk of leukaemia by providing a voice on other relevant issues. Issues

Leukaemia risk for children born close to power lines

currently on the agenda include: the regulation of donor lymphocyte infusion (a curative treatment for chronic myeloid leukaemia) to ensure that it is allowed to continue under the new European Union Blood Directive; the future of the **Health Protection Agency's Radiation Research** Programme (the only Government funding programme covering the causes of childhood leukaemia), which was frozen in 2005; and the future of funding for specialist tertiary treatment centres which are currently suffering from a funding shortfall as a result of new Department of Health funding

arrangements.



A diagnosis of leukaemia is a devastating blow which sends families reeling. The child will immediately be referred to their regional treatment centre, often many miles from home, for further tests. Treatment will begin straight away.

This involves great upheaval for the whole family, with the child and a parent often absent for long periods especially during the initial stage of intensive treatment.

We always allocate a significant proportion of our funds to welfare projects designed to help children and families cope with the trauma of leukaemia diagnosis and treatment. Our first such welfare project was our respite facility, the Paul O'Gorman Respite and Recuperation Centre, in West Sussex - a place for the family to relax and spend time together during their breaks in treatment. We have also provided funding to help improve the facilities at various hospitals such as the Christie Hospital in Manchester where we helped the team to develop specialised facilities for their teenage cancer patients.

Our achievements in 2005:

• We reached our target of £2 million for the new Patient Hotel at Great Ormond Street Hospital, The team at Great Ormond Street treat children from all over the UK, seeing one in every 10 children with cancer. Children and parents face a long return journey to London and back for their regular outpatient treatment and often the distances involved prove too much and children end up being readmitted unnecessarily, causing upheaval for them and taking up valuable in-patient beds. The Paul O'Gorman Patient Hotel supports the Hospital's day care facilities by providing somewhere for parents and children to stay before and after treatment. It means that they can travel to London the afternoon before treatment and travel home the day afterwards, safe in the knowledge that they have somewhere comfortable and convenient to stay. It also helps to ensure that inpatient beds are available for those who really need them.

• We continued our partnership with the Paul O'Gorman Lifeline Charity (or Lifeline), a partnership which began in 1996 when we contributed to the cost of bone marrow transplants at Hammersmith Hospital for two teenage leukaemia sufferers from St Petersburg. Over the years, Lifeline's work has widened to include children from other countries where children do not have access to life-saving leukaemia treatment, including Georgia, Kyrgyzstan and Ukraine.

In 2005 we provided funding of £755,267 to Lifeline. The medical costs for a single child may be as much as £85,000. The costs of travel and accommodation can push this up to well over £90,000. Lifeline works with a variety of other organisations which help support these costs. They receive substantial support for Georgian patients from a local charity which pays for travel, subsistence and some medical expenses. In Italy, where many of the patients are now treated, regional government authorities provided grant aid for 16 patients in 2005, representing about €1.6 million.

The children that Lifeline helps really represent the tip of the iceberg. As the work of Lifeline becomes better known, the demands on their resources continue to grow. In 2005 the charity received 95 new referrals, in addition to the 34 patients still under treatment from the previous year. They have never yet had to turn a child away on the grounds of cost but as the number of referrals continues to grow, it makes Lifeline's primary aim - to improve the medical facilities in the countries where they work - more and more important. They are making considerable progress but it is a slow and expensive process.

• We made our annual grant of £60,000 to The Variety Club of Great Britain to fund two nurses – in Cornwall and Tyne & Wear - to provide support and care for children in the community.



 We were pleased to provide a further grant of £50,000 to CHASE Hospice Care in Guildford to help them continue to provide services for the families of children whose leukaemia treatment has failed. They offer care and support in the family home and at St Christopher's, their hospice in Guildford.

• And we made a grant of £20,000 to the Sussex Snowdrop Trust to support the costs of providing nursing care and other support to children with leukaemia and their families.

• On a lighter note, every year we organise the We will also continue to work with the Paul most enormous party for children suffering from O'Gorman Lifeline Charity to support their work in leukaemia. Some bring brothers and sisters. And to caring for children with leukaemia from the former make sure it really is an enormous party, we invite Soviet Union. thousands of other disadvantaged children as well. The 18th Amazing Great Children's Party, held in • We will review the use and operation of our respite Battersea Park in July, proved to be a fantastic day facility at Green Hedges in West Sussex and the out for thousands of smiling children. We are provision of parental accommodation facilities at the grateful for the generosity of all the companies and Royal Free Hospital in north London to ensure that individuals who donate their time, talents and these continue to meet the needs of affected products, without which this party for so many children and families and that they continue to deserving children would not take place. represent best use of our funds.

Our plans for 2006:

 In 2006 we are continuing our partnership with Great Ormond Street Hospital by raising funds to support a much needed expansion of their cancer wards to help them cope with the increasing number of patients that they are treating. We have pledged to raise £1.7 million towards the cost of this expansion and made our first payment of £500,000 on 7th April 2006, marking what would have been Paul O'Gorman's 34th birthday. We expect to achieve our £1.7 million target within four years.



Raising the funds to support our charitable activities

All of the work described on the preceding pages is underpinned by our fundraising - we receive amazing support from individuals and groups around the UK who go to incredible lengths to raise vital funds for our work. We are entirely reliant on this voluntary support as we receive no government funding.



Soak those spong

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Just some of our achievements in 2005:

Celebrity appeals

Almost 50 per cent of our income comes from our postal appeals which simply would not be possible without the continued support of our many celebrity friends. In 2005 our Summer and Christmas raffle appeals were fronted by Linda Robson and Gary Lineker and our Spring and Children's Party appeals were spear-headed by Dame Judi Dench and Jeremy Beadle. This programme of appeals raised £4.3 million during the year. We are focusing increasingly on encouraging people to commit to regular gifts and our success is reflected in the fact that our committed giving income (standing orders and payroll giving) increased by 25 per cent in 2005 and now contributes in excess of £0.5 million per annum.

Children's fundraising

Children's fundraising is an important part of our programme. Not only does it raise significant funds to support our work but it helps to educate children about leukaemia. Our first children's fundraiser, the Children's Marathon Challenge, was launched in 2002. Since then, over 400,000 children have raised an astonishing £6 million for their schools, guide units, scout sections, clubs, groups and CHILDREN with LEUKAEMIA.

In April 2005, in response to requests from teachers and group leaders for something suitable for older children, we piloted a new challenge - the Cheeky Monkey's Marathon Challenge. Just like the

Children's Marathon Challenge, children can do any activity based on the number 26. Almost 13,000 children took part in this new activity in 2005, raising funds of £236,000, £146,000 of which was remitted to CHILDREN with LEUKAEMIA (they are allowed to keep half the money raised for their school/group). By the end of the project (31st March 2006), 20,175 children had taken part, with the total funds raised standing at £370,000 (with £227,000 remitted to CHILDREN with LEUKAEMIA). We are grateful to Carlton Cards for allowing us to use the fantastic Bubblegum characters which make this Challenge so distinctive.



The Flora London Marathon was our single most important fundraiser in 2005. Once again we fielded a team of over 1,100 runners who between them raised a staggering £1.9 million, a record for us and indeed a record for the event. Distinctive in their Mr Men and Little Miss vests, our runners always create a major presence for CHILDREN with LEUKAEMIA on race day. We are grateful to Chorion plc who have made CHILDREN with LEUKAEMIA the official charity of the Mr Men and Little Miss characters, enabling us to continue to use these wonderful images free of charge for both our running events and the Children's Marathon Challenge.

We continued to build our participation in other running events and in 2005 we fielded our largest ever team in the Great North Run. 806 runners endured unseasonably hot weather to complete the 13.1 miles from Newcastle to South Shields as part of our Mr Men and Little Miss team.



We were delighted to be chosen to benefit from Run for the Children, a national family fitness programme launched in 2005 which encourages children and parents to start making healthy lifestyle choices. As a part of this, families take part in a 3 km run in a local park and are asked to raise sponsorship for CHILDREN with LEUKAEMIA.



Running events



Raising the funds to support our charitable activities

Special thanks go to...



And some of our plans for 2006:

 We will continue to build on the success of our running events - to encourage more people to run on our behalf and to raise the maximum amount of sponsorship in doing so. We have been made the official UK charity of the 2006 ING New York City Marathon and Half Marathon which will help us to increase our profile at these major events and to boost the income generated from them. At the time of writing, the Flora London Marathon has already taken place and once again our Mr Men and Little Miss Team boasted more than 1,100 runners. In addition to the funds raised by our fantastic team of runners, CHILDREN with LEUKAEMIA is also one of the charities set to benefit from the efforts of Sir Steve Redgrave who set out to raise the highest ever amount achieved by an individual fundraiser in this event. He has already smashed the existing record by more than £0.5 million, raising £1.8 million.

Sir Steve was assisted in his endeavour by Lloyd Scott who took part in this year's Marathon - which took place on St George's Day - wearing a full suit of armour and dragging a 200lb dragon. Lloyd completed the route in a mere eight days.

We will continue to encourage our donors to commit

to making regular donations as this gives us a secure income stream, helping us to plan our charitable work with greater confidence. In March Sir Steve Redgrave headed up our first ever direct debit appeal. At the time of writing, this has already resulted in over 300 new direct debits and more than £400,000 in cash donations. In April we began our first ever telephone fundraising campaign: telephoning new donors recruited from the Gary Lineker's Christmas raffle appeal to ask them to consider giving to us regularly by direct debit. Staff and trustees will be monitoring this carefully - not only to measure financial efficiency but also to keep an eye on any donor dissatisfaction.

 Following the successful piloting of the Cheeky Monkey's Marathon Challenge we will be rolling out the scheme nationally in 2006.

• We will be taking steps to develop new partnerships with both companies and trusts in 2006. We already have a small number of valuable corporate and trust partnerships, but the income from these sources makes up only a small proportion of our total income. This has been identified as an important area of potential development and we have already stepped up our activity in this area.

CHILDREN with LEUKAEMIA is grateful to the very many individuals and organisations who donate vast amounts of time and effort either directly in support of our charitable objectives or by raising vital funds to enable us to progress our objectives.

• As usual, the largest area of volunteer assistance in 2005 was the Amazing Great Children's Party in July when more than 1,000 volunteers helped us to ensure that the children had a day to remember. We are especially grateful to Hugo Amaya-Torres for continuing as Chairman of the Party committee.

• All of our scientific advisors and members of our grants panels give their time voluntarily. We are grateful to our 2004/5 grants panel, made up of: Professor Denis Henshaw (Chair), Professor Michel Coleman, Dr Thomas Erren, Professor Dudley Goodhead, Professor Victor Hoffbrand and Professor Nicholas Priest. Professor Victor Hoffbrand has undertaken to Chair the 2006 grants panel.

• The charity benefits from volunteer assistance in the office, estimated at 0.4 full-time equivalent staff during the year and we are grateful to those who support our staff team in this way.

 We are fortunate to have many celebrity friends who support our work in various ways. Special thanks go to Jeremy Beadle who devotes an enormous amount of time to the charity. As well as hosting his annual Quiz Party and acting as compére at the Paul O'Gorman Banquet & Ball, on Christmas Eve he took part on Celebrity Who Wants to be a Millionaire? with Sir Alan Sugar and raised £16,000 for CHILDREN with LEUKAEMIA and Great Ormond Street Hospital. We are also indebted to Linda Robson who gives us a substantial amount of her time. Linda became a trustee in 2005.

 Voluntary committees contribute a huge amount of time to ensure the success of our special events such as the Opera at Syon, the Captains' Cup and Jeremy Beadle's Quiz Party. These events raised almost £500,000 in 2005. We are particularly grateful to Margrete Hargreaves Allen and Julia Craig Harvey for continuing to co-chair the Opera committee; to Nick Hill for chairing the 2005 Quiz committee and to Holly Bellingham for taking over as Quiz chair in 2006.

• In 1993, rather than continue to give to charity on an ad hoc basis, ICAP decided to do something on a larger and more innovative scale. So Charity Day was born, a day on which both the company's revenues and the brokers' commissions are all given away to just a few charities. The idea has proved hugely successful and we are very grateful to ICAP customers and staff whose enthusiastic and generous support made possible their fabulous donation of £150,000 in 2005.



- Our great friend Caroline Randerson raised over £60,000 for us at her annual ball in 2005. In the 18 years that Caroline has been raising money for us she has donated more than £400,000.
- In 2005 CHILDREN with LEUKAEMIA benefited from Club Triumph's 2,000 mile, 48-hour run from Enfield to John O'Groats to Lands End and back to Enfield. The tenacity and tremendous fundraising efforts shown by the 200 navigators raised almost £54,000.
- Our thanks go to Vince O'Brien, Chairman of the BVCA, who nominated CHILDREN with LEUKAEMIA to receive the £13,000 proceeds from the Real Deals Private Equity Awards Dinner in April 2005 and a further £28,000 from the sports and movies memorabilia auction at the annual BVCA dinner in November.
- We are delighted that RBS Insurance Services who took over Churchill Insurance in 2004 – has chosen to continue Churchill's longstanding support of CHILDREN with LEUKAEMIA, making us one of their two corporate charities. In 2005 their staff raised almost £20,000 towards our vital work and, with a number of exciting activities planned for the year ahead, they look set to raise at least twice this amount in 2006.
- Clare Fogarty organised the Friends of Notre Dame Winter Ball which raised £15,000 for our work. Clare's son, Emmett, who is currently undergoing treatment for leukaemia, provided us with a drawing which has been sent as a 'thank you' to many of our supporters in 2006.
- Huge thanks go to Debbie and Wendy Westwood who continue to raise money for CHILDREN with LEUKAEMIA through the Hollie O'Brien Leukaemia Research Appeal, which they set up in memory of Debbie's daughter and Wendy's granddaughter, Hollie, who tragically died from leukaemia at the age of four years. Throughout 2005 their various fundraising activities raised a staggering £13,000.
- Thanks also to Anne Ferguson who organises an annual St Trinians Sponsored Walk in aid of CHILDREN with LEUKAEMIA. Dressed in gym skirts, fishnet stockings and ponytails, Anne and more than 70 'classmates' raised a fantastic £12,000 for us in 2005.
- For the second consecutive year, members and executives of Associazone Parmigiani Valtaro have most kindly chosen to support CHILDREN with LEUKAEMIA at their 2005 Charity Gala Ball. Our special thanks go to Piero Zanelli for all his hard work organising the event, which raised £10,000.
- There are many, many others who have given invaluable support in 2005. Space does not allow an exhaustive list but to each and every person who has contributed to our work in 2005 we extend an enormous thank you.



Governing documents

The dormant holding charity, the Foundation for Children with Leukaemia operates under its Trust Deed (dated 4th January 1988) and Variation of Trust Deed (dated 10th December 2003). The operating company, Children with Leukaemia, operates under its Memorandum and Articles of Association dated 11th November 2003 as amended by special resolution, dated 30th November 2004.

Board of Trustees

The governing body of the operating company is the Board of Trustees, which has been built up during 2005 to a current total of seven members. It meets at least three times a year together with the Chief Executive.

Trustee appointment and induction

A number of new trustees were appointed in 2005. The policy with respect to the size and make-up of the Trustee Board is to keep the size of the Board small whilst ensuring that the founding family remains in a minority. Selection of trustees is made based on vacancies arising, sympathy with the objects of the Charity and the additional skills and experience that potential new trustees are able to afford – for example one of the new trustees is a specialist in scientific research and one in voluntary sector communication. Under the Articles of Association, trustees are appointed by a majority vote of the members (who are all the current trustees) by ordinary resolution.

Each new trustee receives the Charity Commission publication 'The Essential Trustee: What you need to know' as well as the most recent published annual report. The Chief Executive offers an induction day to all trustees which provides full information about the operations of the Charity.

Management

The Trustees exercise executive responsibility for the governance of the Charity and through the Chairman supervise the management of the Charity by the Chief Executive and the staff team. The Chairman and Chief Executive also task the Board with decision-making on some strategic management issues as appropriate.

The staff are expected to call upon the expertise of a panel of scientific advisers before making recommendations to Trustees.

It is the Trustees' policy to work with other relevant charities and during the course of 2005, the Charity worked closely with the Leukaemia Research Fund, the Great Ormond Street Hospital Children's Charity, Paul O'Gorman Lifeline and the Venik Trust.

Risk and internal control

The Trustees have overall responsibility for ensuring that the Charity has an appropriate system of controls, financial and otherwise. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities and to provide reassurance that:

- its assets are safeguarded against unauthorised use or disposition;

- proper records are maintained and financial information used within the Charity or for publication is reliable; and

- the Charity complies with relevant laws and regulations.

As part of the Charity's risk management process the Trustees acknowledge their responsibility for the Charity's system of internal control and reviewing its effectiveness. It is also recognised by the Trustees that such a system is designed to manage rather than eliminate the risk of failure to achieve the Charity's objectives and can only provide reasonable, not absolute, reassurance against material misstatement or loss.

The Trustees keep under regular review the major risks that could affect their achievement of the Charity's objectives. It is the Trustees' policy that a substantive annual risk assessment takes place and that wherever possible, different experts examine the issues each year. It is anticipated that this will usually entail the use of one firm from the Charity's roster of professional advisers whether legal or accountancy and that the fresh perspectives brought each year will add considerable value in identifying potential exposure not previously apparent to the staff and trustees.

In 2004, a risk review was carried out by the Charity's internal auditors, Sayer Vincent. Risk management strategies were implemented during 2005 to control against these identified risks. During 2005, the Charity's new auditors, Deloitte prepared a risk management document. Following this guidance from Deloitte, in 2006 it is intended to compile an ongoing risk register to identify potential risks which could have a critical impact to enable further risk management to be introduced.

Reserves

The Trustees have adopted a reserves policy which they consider appropriate to ensure the continued ability of the Charity to meet its objectives. The Trustees have recently reviewed their reserves policy. Their aim was to find a balance between maximising charitable work and the need for preparation for contingencies. Consideration was given to assessing the risk, probability and likely impact on the Charity's ability to meet its financial obligations and reduce expenditure following any short-term decline in income. The Charity has a very low ongoing cost base and a fixed asset base of zero. The Trustees feel it is sufficient to maintain an unrestricted reserve of a minimum of two months and up to a maximum of four months of the annual total expenditure with an aim to be in the middle of the range. Free reserves at 31 December 2005 amounted to $\pounds 2.1m$ (2004: $\pounds 2.0m$), which represents 11 weeks of unrestricted resources expended during 2005 and therefore meets the policy requirement.

Investments

The Memorandum of Association allows the Charity to deposit or invest funds in any manner but to invest only after obtaining such advice from a financial expert as the Trustees consider necessary and having regard to the suitability of investments and the need for diversification.

The Charity recognises that it must have enough resources to carry out its present and future activities effectively. Therefore the Trustees have agreed to hold sufficient cash levels, invested only on short term deposit, to meet fluctuating needs. It is felt that this amount of cash should be in line with the level of reserves.

Cash balances generally are increasing over time since more funds are being kept available to meet longer term grant commitments. The Trustees are keen to ensure that these funds are not exposed to any risk since this cash value has already been promised to grant holders. They would like to maximise real returns so resources in excess of the level of reserves may be invested as cash for such fixed terms as are deemed optimal from time to time in relation to cash flow requirement and short and medium interest rates prevailing at the time.

Grant making policy

It is the Trustees' policy to maximise the proportion of its charitable output that is achieved through grant making.

Welfare grants

Over recent years, the Charity has granted its welfare establishments to other charities and under standing agreements has provision to fund the work of these facilities. New welfare facilities are now initiated only through third parties under grant funding. There is no open application process for welfare grants and no welfare grants are given to individuals. The staff of the Charity proactively work with the Trustees to determine which organisations should be supported.

Research grants

An increasing proportion of the Charity's output is achieved through medical research. Capital funding for scientific institutions is now being decreased as a proportion of the Charity's total output in favour of revenue funding for scientific and medical research.

Project funding in these areas is directed in two ways:



1. Research into treatment

The Charity works in partnership with the Leukaemia Research Fund, the Great Ormond Street Hospital Children's Charity, University College London and other institutions giving grants in support of the parts of their programmes which are relevant to the Charity's objects.

2. Research into prevention and causes

In 2005, the Charity was accepted as a member of the AMRC and advertises worldwide for project applications which are then subject to peer review and assessment by the Charity's expert research grants committee before the Trustees determine which projects to support. It is also the Trustees' policy to keep a number of directly funded programmes of long-term research supported at UK institutions in areas which are of wide-ranging importance in relation to childhood leukaemia.

Statement of Trustees' responsibilities for the financial statements

UK company and charity law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the Charity's incoming resources and application of resources during the year and of its state of affairs at the end of the year. In preparing those financial statements the Trustees are required to

select suitable accounting policies and then apply them consistently;

 make judgements and estimates that are reasonable and prudent;

• state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and

• prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper records which disclose with reasonable accuracy the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 1993. They are also responsible for safeguarding the Charity's assets and hence taking reasonable steps for the prevention and detection of fraud and breaches of law and regulations.

Approved by the Board and signed on its behalf on 4th July 2006 by

Eddie O Gurman

Eddie O'Gorman Chairman of Trustees



Information about the Charity

Independent auditors' report to the trustees of the Foundation for Children with Leukaemia

CHILDREN with LEUKAEMIA is the registered working name of the Foundation for Children with Leukaemia (formerly the Paul O'Gorman Foundation for Children with Leukaemia) which was constituted as a charity under a Trust Deed dated 4 January 1988, in memory of Paul O'Gorman who died on 6 February 1987 and his sister Jean, who died on 3 November 1987. The Charity was inaugurated by Diana, Princess of Wales on 12 January 1988 at Mill Hill County High School where Paul had been a pupil.

On 1 January 2005, the Foundation for Children with Leukaemia transferred its assets and operations to Children with Leukaemia, a company limited by guarantee with Company number 4960054. The registered charity number for this new company remains the same as for the Foundation.

Details of the Charity's activities are available from the principal office of the Charity: 51 Great Ormond Street, London WC1N 3JQ Tel: 020 7404 0808 Fax: 020 7404 3666 Email: info@leukaemia.org www.leukaemia.org

Trustees

Trustees of the operating charity, CHILDREN with LEUKAEMIA, who served during the year were:

Eddie O'Gorman (Chairman) The Earl Cadogan DL The Lord Carlisle of Bucklow, PC, QC, DL (died in office, 14 July 2005) **Professor Denis Henshaw** (appointed 21 June 2005) Sandra Mileham (appointed 21 June 2005) **Baroness Morgan of Drefelin** (appointed 5 November 2005) Marion O'Gorman Linda Robson (appointed 21 June 2005)

Chief Executive

Edward Copisarow

Registered Charity Number 298405

Solicitors

Nabarro Nathanson Lacon House, Theobald's Road, London WC1X 8RW

Auditors

Deloitte & Touche LLP Hill House, 1 Little New Street, London EC4A 3TR

Bankers

National Westminster Bank plc 30 North Audley Street, London **W1A 4UQ**

SCIENTIFIC ADVISERS Prof. A. V. Hoffbrand, DM, FRCP,

- FRCPath, DSc (Chairman)
- Prof. M. Coleman, BM, BCh, MSc, MFPhm
- Prof. N. E. Day, MA, PhD, MRCPath Prof. J. Golding, MA, PhD, FSS, DSc
- Prof. J. M. Goldman, DM, FRCP, FRCPath
- Prof. I. M. Hann, MD, FRCP, FRCPath, FRCPCH, FRCPI FRCPCH, DRCOG
- Prof. I. A. G. Roberts, MD, FRCP, FRCPath, FRCPCH, DRCOG

AMAZING GREAT CHILDREN'S PARTY Hugo Amaya-Torres (Chairman)

CELEBRITY FRIENDS

Jeremy Beadle (Chairman) Russ Abbot • Debbie Arnold • Jane Asher Colin Baker • Floella Benjamin • David Berglas Rodney Bewes • Christopher Biggins Cilla Black • Brenda Blethyn • Patricia Brake Sir Richard Branson • Johnny Briggs Tim Brooke-Taylor • Faith Brown • June Brown Frank Bruno • Max Bygraves • Sir Michael Caine Brian Cant • Jasper Carrott • Frank Carson Christopher Cazenove

George Cole Graham Cole • Joan Collins • Phil Collins Jess Conrad • John Conteh • Ronnie Corbett Bernard Cribbins • Roger Daltrey • Paul Daniels Jim Davidson • Dickie Davies • Sharron Davies Roger de Courcey • Dame Judi Dench Declan Donnelly • Jason Donovan Glynn Edwards • Bruce Forsyth • Peter Gilmore Reg Gutteridge • Haruhisa Handa Ainsley Harriott • Barry Hearn • Bob Holness Bob Hoskins • Jane How • Michael Howe Nerys Hughes • Gareth Hunt • David Janson Sir David Jason • Gorden Kaye • Kevin Keegan Diane Keen • Henry Kelly • Felicity Kendal Sarah Kennedy • Eddie Kidd • Burt Kwouk Bonnie Langford • Eddie Large • George Layton Rosemary Leach • Rula Lenska • Lennox Lewis Gary Lineker • Joanna Lumley • Linda Lusardi Sandy Lyle • Sir Paul McCartney • Debbie McGee Anthony McPartlin • Philip Madoc • Ruth Madoc Ron Moody • Garfield Morgan • Patrick Mower Tom O'Connor • Bill Oddie • Richard O'Sullivan Nick Owen • Nicholas Parsons • Su Pollard Robert Powell • Pauline Quirke • Claire Rayner Sir Steve Redgrave • Angharad Rees Anneka Rice • Tessa Sanderson • Gerald Scarfe Phillip Schofield • Lloyd Scott • Pat Sharp Ivor Spencer • Michaela Strachan • Eric Sykes Chris Tarrant • Angela Thorne • David Vine Dennis Waterman • Kevin Whately June Whitfield . Simon Williams . Gary Wilmot Frank Windsor • Terry Wogan • Susannah York Paul Young

CHILDREN with LEUKAEMIA 51 Great Ormond Street London WC1N 3JQ Tel: 020 7404 0808 Fax: 020 7404 3666 Email: info@leukaemia.org www.leukaemia.org

We have audited the financial statements of Children with Leukaemia for the year ended 31 December 2005 which comprise the consolidated statement of financial activities, the consolidated balance sheet, the consolidated cash flow statement and the related notes 1 to 18. These financial statements have been prepared under the accounting policies set out therein.

This report is made solely to the charity's trustees, as a body, in accordance with Regulation 7 of the Charities (Accounts and Reports) Regulations 2005. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report 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 and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

As described in the statement of trustees' responsibilities, you are responsible as trustees for the preparation of the financial statements, which are required to be prepared in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

We have been appointed as auditors under s43 of the Charities Act 1993 and report in accordance with regulations made under s44 of that Act. Our responsibility is to audit the financial statements in accordance with relevant United Kingdom legal and regulatory requirements and International Standards on Auditing (UK and Ireland).

We report to you our opinion as to whether the financial statements give a true and fair view in accordance with the relevant financial reporting framework and are properly prepared in accordance with the Charities Act 1993, Regulation 3 of the Charities (Accounts and Reports) Regulations 2005 and the trust deed.

We read the trustees' report and the other information contained in the annual report for the above year as described in the contents section and



consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the financial statements.

Basis of opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made in the preparation of the financial statements and of whether the accounting policies are appropriate to the charity's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion, we also evaluated the overall adequacy of the presentation of information in the financial statements.

Opinion

In our opinion:

• the financial statements give a true and fair view of the charity's and the group's state of affairs, in accordance with United Kingdom Generally Accepted Accounting Practice as at 31 December 2005 and of the group's incoming resources and application of resources in the year then ended;

 the financial statements have been properly prepared in accordance with the Charities Act 1993, Regulation 3 of the Charities (Accounts and Reports) Regulations 2005 and the trust deed.

Delittle & Tanke LLP

Deloitte & Touche LLP Chartered Accountants and Registered Auditors Hill House, 1 Little New Street London EC4A 3TR

6th July 2006



Consolidated statement of financial activities for the year ended 31 December 2005

Financial activities 2005

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2005

	Note	Total restricted funds £	Total unrestricted funds £	Total 2005 £	Total 2004 £
Incoming resources					
Incoming resources from generated funds Voluntary Income Appeals and associated donations Committed giving Schools and childrens groups fundraising Running events Community fundraising Corporate and trust donations Legacies Activities for generating funds Special events and trading	12	- - - 25,000 - - 25,000	4,258,932 596,997 903,477 2,336,520 535,518 393,415 <u>172,625</u> 9,197,484	4,258,932 596,997 903,477 2,336,520 535,518 418,415 <u>172,625</u> 9,222,484	4,322,815 475,279 1,218,967 1,862,539 447,017 451,827 <u>595,504</u> 9,373,948 612,410
Investment income			480,932 209,369	480,932 209,369	110,205
			209,309	209,309	
Incoming resources from charitable activities					19,079
Other incoming resources	2	-	149,111	149,111	2,300,000
Total incoming resources		25,000	10,036,896	10,061,896	12,415,642
Resources expended Costs of generating funds: Costs of generating voluntary income Charitable activities		-	1,429,363	1,429,363	1,855,798
Research into Prevention & Causes Research into Treatment Welfare Education		8,750 15,500 - -	2,011,813 2,191,466 3,755,144 549,682	2,020,563 2,206,966 3,755,144 549,682	2,760,002 2,710,676 5,352,030
Governance costs		-	40,582	40,582	54,252
Total resources expended	3	24,250	9,978,050	10,002,300	12,732,758
Net incoming / (outgoing) resources before transfers		750	58,846	59,596	(317,116)
Gross transfers between funds	12	(750)	750		
Net incoming / (outgoing) resources bef recognised gains and loses	ore other		59,596	59,596	(317,116)
Gain on revaluation of freehold property				<u> </u>	343,076
Net movement in funds		-	59,596	59,596	25,960
Funds at the start of the year		-	2,015,599	2,015,599	1,989,639
Funds at the end of the year			2,075,195	2,075,195	2,015,599

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 12 to the financial statements. The notes on pages 40 to 43 form part of these financial statements.



Registered Charity No. 298405. Inaugurated in 1988 by Diana, Princess of Wales in memory of Jean and Paul O'Gorman



CONSOLIDATED BALANCE SHEET AS AT 31 DECEMBER 2005

		Group	2005 Charity	Group	2004 Charity
	Note	£	3	3	3
Fixed assets Investments	6	100	-	100	100
Current assets Debtors and prepayments Cash at bank and in hand	8	732,220 4,672,238	1,000	442,357 4,280,704	442,357 4,280,704
Creditors: amounts falling due within one year	9	(1,310,795)	-	(1,072,591)	(1,072,591)
Net current assets		4,093,663	1,000	3,650,470	3,650,470
Total assets less current liab	ilities	4,093,763	1,000	3,650,570	3,650,570
Creditors: amounts falling du after more than one year	e 10	(2,018,568)	-	(1,634,971)	(1,634,971)
Net assets		2,075,195	1,000	2,015,599	2,015,599
Represented by: Unrestricted funds	11	2,075,195	1,000	2,015,599	2,015,599

The notes on pages 40 to 43 form part of the financial statements. Approved and signed on behalf of the Trustees on 4th July 2006

Ne	t cash inflow from operating activities	
Int	erest received	
Inc	crease in cash in the period	
No	tes to the Cash flow Statement	
a)	Reconciliation of changes in resources to net cash inflow from operating activiti Net incoming / (outgoing) resources before other recognised gains and losses Investment income Changes in debtors Changes in creditors Grant of tangible fixed asset	es
b)	Analysis of net funds	1 Ja
	Cash at bank and in hand	4,2
	Int Inc No a)	 to net cash inflow from operating activitien Net incoming / (outgoing) resources before other recognised gains and losses Investment income Changes in debtors Changes in creditors Grant of tangible fixed asset b) Analysis of net funds

The Earl Cadogan Trustee

Idie O Guman

Eddie O'Gorman Trustee



CONSOLIDATED CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2005

Note	2005 £
a)	182,165
	209,369
b)	391,534

2,952,367
110,205
3,062,572

2004

2	00	4

£ (317, 116)

(110, 205)109,627 1,959,690 1,310,371 2,952,367

2005 £ 59,596

(209, 369)(289, 863)621,801

182,165

31 December 2005 £ 4,672,238

Cashflow

£ 391,534



NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2005

1. Accounting policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the year and the preceding year.

(a) Accounting conventions

The financial statements are prepared in accordance with applicable accounting standards and the Statement of Recommended Practice (SORP): Accounting and Reporting by Charities, published in March 2005 in all material respects and are prepared under the historical cost convention, as modified by the revaluation of reehold property.

(b) Group status and basis of consolidation

The Foundation for Children with Leukaemia is the ultimate parent company and did not trade during 2005. The consolidated financial statements incorporate the results of the Foundation and Children with Leukaemia, the subsidiary charity using the line by line basis. The balance sheet for the subsidiary charity is shown in note 15. The operating charity owns the whole of the share capital of Helping Children with Leukaemia Limited, a company registered in England. The company was dormant throughout the current and previous years. In the opinion of the trustees, the company is not material in the context of the overall accounts and therefore, the consolidated financial statements have not been prepared.

(c) Fund accounting

Unrestricted funds comprise accumulated surpluses and deficits on general funds and are available for use at the discretion of the trustees in furtherance of the general objectives of the charity and have not been designated for other purposes Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The costs of raising and administering such funds are charged against the specific fund.

(d) Incoming resources

Income is recognised in the period in which the charity is entitled to receipt and the amount can be measured with reasonable certainty. In accordance with this policy, legacies are included when the charity is advised by

the personal representative of an estate that payment will be made or property transferred and the amount involved can be quantified. Voluntary income in the form of donations, proceeds of appeals and other fundraising activities are recognised upon receipt.

(e) Resources expended and basis of allocation of costs

All expenditure is accounted for on an accruals basis and the majority is directly attributable to specific activities. Other indirect costs are apportioned to activities in accordance with staff activity and an assessment of where the resources have been applied.

Grants to third parties are included in the SOFA when approved by the trustees when a constructive obligation exists, notwithstanding that they may be paid in future accounting periods.

Support costs include the direct expenditure and overhead costs relating to the appeals and fundraising functions. They also include the allocation of costs incurred to support and co-ordinate fundraising activities. These costs are allocated across the categories of charitable expenditure and the basis of this cost

allocation has been explained in note 4 to the accounts. Governance costs are the costs incurred to manage the charity in compliance with constitutional and statutory requirements.

(f) Taxation

Children with Leukaemia, as a registered charity, is exempt from taxation of income falling within Section 505 of the Taxes Act 1988 or section 256 of the Taxation of Chargeable Gains Act 1992 to the extent that this is applied to its charitable objectives. No tax charge has arisen in the year.

(g) Tangible fixed assets

Tangible fixed assets costing more than £10,000 are capitalised and included at cost including any incidental costs of acquisition. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows: Freehold property 4% straight line Fixtures and fittings 15% straight line

(h) Pension scheme

Permanent employees are entitled to join the Grouped Stakeholder Pension Plan provided by Bank of Scotland which was established on 14 September 2001. In 2005, the charity made a contribution of 10% of salary per month to any personal or stakeholder pension scheme selected by all permanent employees who elected to take advantage of this benefit. Contributions are taken to the SOFA as they become payable.

2. Other incoming resources	2005	2004
Reversal of grant for running costs of Paul O'Gorman House	105,000	
Repayment of University of Bristol grant Repayment of Lifeline Building grant	44,111	2,300,000
	149,111	2,300,000

3. Total resources expende	d	Research into					Costs of generating		
		Prevention &	Research into				voluntary		
	Note	Causes	Treatment	Welfare	Education	Governance	income	2005 Total	2004 Total
		£	£	£	£	£	£	£	£
Staff costs	13	87,299	64,439	200,557	141,406	-	170,458	664,159	479,502
Direct charitable spend		1,933,264	2,142,527	3,554,587	408,276		-	8,038,654	10,466,471
Printing, postage & stationery							695,004	695,004	899,025
Function and venue costs		100 and					554,940	554,940	825,338
Other expenditure					-		8,961	8,961	8,170
Audit fee				-		22,325	-	22,325	19,750
Other office costs					-	18,257		18,257	34,502
		2,020,563	2,206,966	3,755,144	549,682	40,582	1,429,363	10,002,300	12,732,758

4. Support costs

Support costs are allocated to activities as follows:

	generating voluntary income £	Research into Prevention & Causes £	Research into Treatment £	Welfare £	Education £	2005 Total £	2004 Total £
Central Services Operational management	24,425 16,580	17,828 15,544 	15,643 9,623	33,809 17,469	8,265 82,902	99,970 142,118	55,883 137,717
	41,005 =====	33,372	25,266 ======	51,278	91,167 ======	242,088	193,600

Central office overheads are allocated on a per person basis to staff in the office. The time spent by each staff member on every activity of the charity is allocated on a month by month basis throughout the year. Overheads and staff costs are then allocated to the various charitable activities based on this staff time basis

5. Costs of charitable activities

	Activities	Grant			
	undertaken	funding of	Support		
	directly	activities	costs	2005 Tota	I 2004 Total
	£	£	£	£	£
Research into					
Prevention & Causes	826,720	1,160,471	33,372	2,020,563	2,760,002
Research into Treatment	668,332	1,513,368	25,266	2,206,966	2,710,676
Welfare	1,813,215	1,890,651	51,278	3,755,144	5,352,030
Education	458,515		91,167	549,682	
			_		
	3,766,782	4,564,490	201,083	8,532,355	10,822,708

6. Investments

Long

CHILDREN with LEUKAEMIA holds 100% of the share capital of Helping Children with Leukaemia Limited. The net assets of the company as at the year end were £100 (2004: £100). The company did not trade during the year.

7. Trustees' emoluments

The Trustees received no remuneration or expenses during the year.

8. Debtors	2005	2004	
	3	£	
Trade debtors	41,299	53,270	
Other debtors	239,816	115,592	
Accrued income	144,202	273,495	
Prepayments	306,903		
	732,220	442,357	

Accrued income represents legacies, as the charity has been formally notified by the personal representative of the estates. The trustees are reasonably certain that amounts in respect of these legacies will be received after the year end.

9. Creditors: amounts falling due within one year

	2005	2004
	3	3
Trade creditors	611	637
Taxes and social security	17,781	28,357
Short term grants	859,914	403,349
Accruals and deferred income	432,489	640,248
	1,310,795	1,072,591

10. Creditors: amounts falling due after more than one year

	2005	2004
	£	3
term grants	2,018,568	1,634,971

11. Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds	Total funds
	2005	2005	2005	2004
	£	£	£	£
Fixed assets	100		100	100
Net current assets	4,093,663	-	4,093,663	3,650,470
Creditors falling due				
after more than one year	(2,018,568)		(2,018,568)	(1,634,971)
Net assets at the				
end of the year	2,075,195	-	2,075,195	2,015,599
		=======		



12. Statement of funds

	At the start	Incoming	Outgoing		At the end
	of the year	resources	resources	Transfers	of the year
	£	£	£	£	£
Restricted funds		25,000	(24,250)	(750)	
Unrestricted funds	2,015,599	10,036,896	(9,978,050)	750	2,075,195
Total funds	2,015,599	10,061,896	(10,002,300)	-	2,075,195

The restricted funds comprised donations given from Trust Funds to be spent on specific projects and these were all discharged during 2005, all on grants to third parties.

£750 was received in 2005 for the purpose of funding the 2004 grant made to Dr Hugh Brady. Since this grant was paid out in 2004 from unrestricted funds, £750 was transferred from restricted back to unrestricted funds during 2005.

13. Staff costs

	2005	2004
	3	3
Salaries and wages	549,187	433,180
National Insurance	59,558	46,322
Pension	55,414	-
	664,159	479,502

One employee earned between £100,000 and £110,000 during the year. (2004: one employee earned between £100,000 and £110,000.) No other employee had emoluments exceeding £60,000.

The average weekly number of employees during the year, as calculated on a full time equivalent basis, was as follows:

Number of	employees
2005	2004
17	' 14

All employees contributed to fundraising campaigns, projects and programmes and the management and administration of the charity.

14. Capital commitments

There were no capital commitments at 31 December 2005 (2004: Nil).

15. Investment in subsidiary

The subsidiary, Children with Leukaemia, is a company limited by guarantee and has no share capital. The liability of members is limited to the sum of £1 per member

The results of the subsidiary are exactly those shown in the Consolidated Statement of Financial Activities since the Foundation was dormant during the period.

The balance sheet for the subsidiary as at 31 December 2005 is as follows:

	2005
	3
Assets	5,403,558
Liabilities	3,329,363
Unrestricted funds	2,074,195

16. Control

There is no controlling party of the Foundation for Children with Leukaemia.

17. Related parties

Lord Cadogan is one of the trustees of the operating charity. He is also Chairman of the Board of Trustees for the Leukaemia Research Fund. The charity gave a grant of £392,228 via the Leukaemia Research Fund during 2005. Lord Cadogan did not take part in discussions concerning the decision to make this grant.

Professor Denis Henshaw is another of the trustees of the operating charity. He is also the holder of a grant made in 2004 for £1,056,948 which is being paid out to his institution (the University of Bristol) over the years 2005 to 2009. The balance at the end of 2005 was £792,711.

Professor Nicholas Priest was a member of the panel of scientific advisers who determined the allocation of a funding round during 2005. He received a project grant of £15,000 (to be paid to his institution, Middlesex University) but was not present for the discussions concerning his grant proposal.



& Notes to the Financial Statements continued



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