



**UNITED KINGDOM
CHILDREN'S CANCER
STUDY GROUP**

AN INTRODUCTION

Revised April 2004

Childhood cancer

Cancer, although a common problem in adults, is relatively rare in children. Only about 1 in 650 children under 15 years of age develops a cancer; about one-third of these are leukaemias. Approximately 1,700 children each year in the U.K. are affected. Of all cancers only 1 in 200 affects a child.

The proportion of children aged 0 - 15 years with cancer, who are treated by Group members has increased to some 90% of all children with cancer, and of these a high proportion are entered into clinical trials. Since 1977 when the UKCCSG was created there has been a progressive trend of increased survival for children treated in UKCCSG centres, showing particularly a benefit for children treated in UKCCSG Centres compared with those treated elsewhere. Studies of different tumour types and the multi-disciplinary nature of the UKCCSG have contributed greatly to the encouraging trends for children with cancer in the U.K.

Background

The United Kingdom Children's Cancer Study Group began in 1977 when a number of paediatricians who had been treating children with cancer joined together to form a group with the aims of improving the management of children with cancer and to advance the knowledge and study of childhood malignancy. From that small start, the Group has steadily expanded and now has over 500 members, working in 22 Paediatric Oncology Centres throughout the British Isles, and including about 60 corresponding members from other countries around the world. Membership of the Group is multidisciplinary and includes clinicians, pathologists, and representatives of other disciplines, epidemiologists and basic scientists. The Group's Constitution gives details of the various categories of membership.

Activities of the Group

The Group is active in a wide range of areas. These include the registration of all cases of childhood cancer (including leukaemia) seen by members of the Group. In 1977 this represented some 43% of all childhood cancers in the UK. In 2004 this is now nearer to 95%. The UKCCSG has close links with the Childhood Cancer Research Group, University of Oxford, which carries out epidemiological studies of childhood cancer and which is responsible for the National Registry of Childhood Tumours; the majority of these tumours are now registered through the UKCCSG Data Centre.

The main area of activity of the UKCCSG is the organisation and running of clinical trials. The Group is responsible for a range of Phase I, II and III studies in all areas of childhood cancer, except leukaemia. Virtually all trials are now run on an international basis, mainly in collaboration with colleagues in Europe. Members of the Group have been the principal coordinators and organisers of a number of major clinical trials, as well as playing a leading role in fostering and expanding international collaboration.

The UKCCSG has an active New Agents Working Group, now working closely with colleagues in Europe, to bring forward new agents and new therapies through collaborative Phase I trials. This work is enhanced by the creation of a dedicated Pharmacology facility, based at the University of Newcastle upon Tyne.

It is generally accepted that the next major advances in childhood cancer will be as a result of gaining a greater understanding of the biology of the disease. An area of increasing importance for the UKCCSG is, therefore, biological studies. In order to facilitate these a national Tumour Bank has been established in the UK. This operates on a system of central registration, with tumour material being stored at centres throughout the UK. Coordinated by the UKCCSG Biological Studies and Pathology Groups, the aim behind the creation of the Tumour Bank is the facilitation of basic scientific research.

As more and more children (currently around 75%) are cured of their disease, so increasing importance is being placed on investigations of the late effects of treatment, and the long term effects of the disease. Quality of life and psychosocial issues for survivors, as well as children and young people undergoing treatment, are also receiving greater attention.

The UKCCSG is also involved in improving the services and welfare of children and young people with cancer, and their families. In addition, the Group is increasingly becoming recognised as the official national policy group for paediatric oncology services. As the Group's activities and success have increased so its members have inevitably had to become involved in what might be considered more political activities: highlighting the problems of providing such services throughout the country in a uniform way and obtaining appropriate funding and staffing for the centres. A number of reports have been produced over recent years concerning the appropriate provision of cancer services and for manpower purposes, and the Group is now increasingly consulted on all childhood cancer matters by a range of organisations. In December 1997 a joint UKCCSG and SBNS (Society of British Neurological Surgeons) document 'Guidance for Services for Children and Young People with Brain and Spinal Tumours' was published.

The UKCCSG Parents Guide to Children's Cancers, produced in collaboration with CancerBACUP, is available through the Data Centre. The booklet is issued free of charge to all centres, patients and their families.

In December 1998 the UKCCSG launched *Contact*, a new national magazine for childhood cancer families. This magazine, which is produced quarterly, is now a collaborative venture with the National Alliance of Childhood Cancer Parents Organisations (NACCPO). The aims of *Contact* are to provide information and to help reduce the sense of isolation felt by many patients and their families. In a short space of time the magazine has achieved considerable success, helping to reinforce the strong links which exist between professionals and parents/parent and other support organisations.

In 2003 a Siblings Project Group was formed, initially producing information for siblings but now with an expanded remit.

Organisation of the Group

UKCCSG Centres

The network of specialised centres is the backbone of the organisation of the UKCCSG. There are now 22 UKCCSG Centres. These are:

Aberdeen	St. Bartholomew's/London	Belfast	Birmingham
Bristol	Cambridge	Cardiff	Dublin
Edinburgh	Glasgow	Great Ormond Street	Leeds
Leicester	Liverpool	Manchester	Middlesex
Newcastle	Nottingham	Oxford	
Royal Marsden	Sheffield	Southampton	

The majority of individual UK members of the UKCCSG are either based in, or affiliated to, one of the 22 centres. It is in these centres that the majority of children with cancer are treated. To assist in the dissemination of information from the Data Centre to the Centres, there is now a designated Clinician/Centre Co-ordinator at each centre. Collection of data from patients treated in the centres is carried out by the centrally funded centre data managers.

To aid the prompt completion and return of forms relating to the various trials, part-time data managers have, since about May 1990, been employed in the various UKCCSG Centres.

Management

Management of the UKCCSG is based on an Executive Group, elected from among the membership. There are three Officers (Chairman, Secretary and Treasurer), as well as 4 other elected members. Members of the Group serve for a maximum term of 3 years, on a rolling programme, so that they do not all relinquish office at the same time. The Executive Director of the UKCCSG Data Centre is *ex officio* a member of the Executive Group, and the only permanent member of the Executive. Management of the Data Centre is the responsibility of the Executive Director.

Working Groups

The development of clinical trials for each tumour type is devolved to individual working groups which meet two or three times a year and report back to the twice yearly national meetings. The Group operates clinical trials in almost all areas of childhood malignancy, except leukaemia, which is covered by the UK Childhood Leukaemia Working Party. There are now 30 Working Groups, including also discipline groups in radiotherapy, radiology, pathology and surgery. The activities of the working groups are fully documented in the UKCCSG Annual Scientific Report, produced in December each year.

National Meetings

The Group holds two national business/review meetings each year – in January and June - at which all studies, protocols and activities are reviewed.

Separate Scientific meetings are also held – either as stand-alone UKCCSG meetings or in collaboration with other organisations.

Once a year, usually in May, an “Up Data” meeting is organised. These meetings provide an opportunity for all the data managers from the Centres to meet each other, and the staff of the Data Centre, and are an extremely valuable training event. They are held in a different centre each year and provide an opportunity to combine a visit to the local children’s hospital. The meetings play a vital role in maintaining and strengthening the ‘networking’ between centres and the Data Centre, and also between centres. Two additional one-day training events are now held in the Autumn and Spring each year. A monthly Newsletter, ‘Up Data’ is circulated to all data managers in the centres.

The UKCCSG Data Centre

The central Office of the Group moved to Leicester University from Manchester in 1988. In 1994 the title of the Central Office was changed to UKCCSG Data Centre, to reflect more accurately the complexity of the work. In December 2000, having outgrown the University accommodation, the Data Centre moved to its new expanded commercial premises. These are providing the facilities, particularly a range of meeting rooms, needed by the UKCCSG to function fully as a national group. The number of staff employed in the Data Centre has increased over the years to a total of 28 (20 full-time and 8 part-time).

All the activities of the Group are coordinated within the Leicester Data Centre. The work of the Data Centre and its staff are managed by the Executive Director.

In 2003, the Data Centre became one of just six Trials Units accredited through the National Cancer Research Institute.

Financial Support

Since 1981 The Cancer Research Campaign (now Cancer Research UK) has provided a significant amount of the funding for the day to day activities of the group. Funding from the CR UK is on the basis of a five year grant, which meets many of the running costs of the UKCCSG Data Centre, part-time data manager support in all centres, and other miscellaneous expenses associated with running the Group. Additional funding is provided from a number of project grants linked to individual trials or projects, both from CR UK and other grant-awarding bodies; donations from parents and friends of patients, together with support from pharmaceutical companies. A centre levy is paid by each UKCCSG Centre, with corresponding members paying an individual subscription. Donations and covenants are encouraged, and a publicity leaflet is available from the UKCCSG Data Centre. In 1982 the UKCCSG was registered as a charity, No. 286669. From January 2003 the UKCCSG has been recognised with network status and has

received some financial support through the government-funded National Cancer Research Network.

Communication

The UKCCSG has its own Web Site (www.ukccsg.org). (We are grateful to Chugai Pharma for support of this facility). The site has a members password protected area, as well as a site for members of the public. A monthly newsletter for members – WatchDoc – is circulated via the web site.

UKCCSG 25th Anniversary

In 2002 the UKCCSG celebrated its 25th Anniversary. The occasion was marked in a variety of ways – celebration of scientific achievement through a series of high-profile invited lectures; a Public Lecture, bringing together professionals and families; as well as fun events in each of the treatment centres. The final event of the year was the launch of the commemorative history, ‘Quest for Cure: The UK Children’s Cancer Study Group – The First 25 Years’, which is available through the Data Centre.