



THE UNIVERSITY OF BIRMINGHAM

LONG TERM FOLLOW UP STUDY NEWSLETTER

DID YOU KNOW?

In Britain

- Currently 70% of people diagnosed with childhood cancer, leukaemia, tumour or similar illnesses are cured.
- Each year there are 800 to 900 people who survive childhood cancer, leukaemia, tumour or similar illnesses.

INSIDE THIS ISSUE:

| | |
|---|---|
| Preliminary Study | 1 |
| The Study Expands | 1 |
| What will the study achieve? | 2 |
| What sort of information will the study find? | 2 |
| Why is the study important? | 2 |
| Thank you for your help | 2 |
| How to contact us | 2 |
| Progress with Full-scale Study | 2 |

Preliminary Study

In 1997 we wrote to about 400 people who had been treated for cancer, leukaemia, tumour or similar illness in one of three areas of Britain:- Birmingham, Manchester and Newcastle. This was a Preliminary Study and if successful the aim was to carry out a Full-scale Study involving all survivors of childhood cancer, leukaemia, tumour or similar illnesses throughout Britain. The Preliminary

Study was funded by two national charities, Cancer Research UK (was Cancer Research Campaign) and the Kay Kendall Leukaemia Fund. Approval was obtained from 53 Local Research Ethics Committees. Questionnaires were sent, through GPs, to a selected group of people who had been treated for cancer, leukaemia, tumour or similar illnesses.

GPs and survivors

were very helpful and in the end we received a completed questionnaire from about 80% of the people selected for the study. In general, the questions included in the questionnaire worked well. Therefore there was a strong case for seeking funds to carry out a nationwide Full-scale Study.

The Study Expands

After the success of the Preliminary Study we again approached Cancer Research UK (was Cancer Research Campaign) and the Kay Kendall Leukaemia Fund for the resources for a Full-scale Study that would involve sending a questionnaire to all survivors of childhood cancer, leukaemia, tumour or similar illness diagnosed

in Britain between 1940 and 1991. Additional funds were sought to obtain details of the treatments which the survivors had received to treat their childhood illnesses. Again these charities agreed to fund the Full-scale Study. Every Local Research Ethics Committee in Britain was contacted, 212 in all, and they all approved the study.

There are about 14000 individuals aged at least 16 who were treated for a relevant illness somewhere in Britain between 1940 and 1991. You received a study questionnaire as you are one of these 14000 individuals.

“This study should benefit both existing survivors and future survivors of childhood cancer, leukaemia, tumour or similar illnesses.”

THE KAY RENDALL LEUKAEMIA FUND

What will the study achieve?

As in the Preliminary Study a wide range of issues is explored in the study questionnaire. The principal aim of the Full-scale Study is to estimate the risks of any long-term complications ('side-effects') resulting from the illnesses and treatments. We hope this will benefit both existing survivors and those diagnosed with such childhood illnesses in the future.

Existing survivors

should benefit from the reassurance which a large study is likely to bring in relation to many possible side-effects of disease or treatment. Should groups of survivors be identified who seem to be at an increased risk of some side-effects then such survivors would probably benefit from the possibility of closer medical contact.

Future survivors should

benefit from the information produced from the study which is relevant to the design of future treatment protocols.

The overall aim being to further improve survival and reduce the side-effects experienced following treatment for childhood cancer.

What sort of information will the study find?

An example of the reassurance that may come from such large investigations concerns the health of children of survivors. Previous studies of the children

produced by survivors of childhood cancer, leukaemia, tumour or similar illnesses suggest that the risk of cancer and birth defects in the children of survivors is

broadly similar to that of the general population. Such information is obviously very helpful to survivors thinking of starting a family of their own.

Why is the study important?

Currently about 70% of those diagnosed with childhood cancer, leukaemia, tumour or similar illnesses are cured. As a consequence there are an additional 800-900 such survivors each year in Britain. This emphasises the need for the Full-scale Study.

Thank you for your help

All those at the Study Co-ordinating Centre would like to take this opportunity to say a big

'THANK YOU'

for your help with the study. These national studies are critical so that the treatment of children diagnosed with cancer, leukaemia, tumour or similar illnesses in Britain may continue to be among the best in the world.

How to contact us

Should you have any questions or issues which you would like to discuss, please call us on our free telephone helpline and one of the study team would be happy to talk with you.



CANCER RESEARCH UK



Progress with Full-scale Study

The Study Co-ordinating Centre is sending out 2 batches of questionnaires every week. At the time of

going to press 13000 questionnaire packages had been sent out.