Childhood cancer survivors follow-up study

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

'What is the purpose of this study?'

The purpose of this study is to investigate the support and information needs of long term survivors of childhood cancer. The ultimate purpose of this study is to find better ways to support survivors by improving long term follow-up services.

'Why have I been invited to participate in this study?'

You are eligible to participate in this study because your child previously received cancer treatment at a participating hospital.

'What if I don't want to take part in this study, or if I want to withdraw later?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment your child receives now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you or your child. If you wish to withdraw from the study once it has started, you can do so at any time without giving a reason.

'What does this study involve?'

If you agree to participate in this study, you will be asked to complete this questionnaire which will take approximately 25 minutes.

‘Are there risks to me in taking part in this study?’
It is possible that thinking about your health and the related emotions you have experienced may cause you to feel worried or upset. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling Dr Jordana McLoone on +612 9382 3114. Any questions or concerns that arise about your health can also be answered by your doctor.

‘Will I benefit from the study?’
This study aims to improve the services offered to families with a child affected by cancer. However, it will not directly benefit you.

‘Will taking part in this study cost me anything, and will I be paid?
Participation in this study will not cost you anything. You will not be paid for your participation.

How will my confidentiality be protected?’
Only the research staff directly involved in this study will know whether or not you are participating in this study and have access to your data. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Data will be held securely at Sydney Children’s Hospital.

‘What happens with the results?’
We plan to share the results of the study with the Human Research Ethics Committee (HREC) for ethical monitoring purposes and in peer-reviewed journals and at conferences or other professional forums for the promotion of knowledge in the health services. When published, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, via the Behavioural Sciences Unit newsletter.

‘How is this study being paid for?’
The study is being supported by the Kids Cancer Centre, Sydney Children’s Hospital.

‘What should I do if I want to discuss this study further before I decide?’

When you have read this information, the researcher Dr Jordana McLoone will discuss it with you and answer any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on her direct line: (02) 9382 3114.

‘Do I have to sign a separate consent form?’

No. By completing this questionnaire you are providing consent for your information to be included in this research study.

‘Who should I contact if I have concerns about the conduct of this study?’

This study has been approved by the Human Research Ethics Committee of the South Eastern Sydney Local Health District – Northern Sector. Any person with concerns or complaints about the conduct of this study should contact the Research Ethics Secretariat, Human Research Ethics Committee of the South Eastern Sydney Local Health District – Northern Sector, Prince of Wales Hospital, Randwick NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email ethicsnhn@sesiahs.health.nsw.gov.au). Please quote the study reference number: 12/173 (HREC/12/POWH/345).

You may have a right to take legal action to obtain compensation if you require treatment or suffer loss resulting from the study. This is particularly the case if the need for treatment or loss is a result of the negligence of any of the parties involved in the study; the cost of your treatment would have to be paid out of such compensation.

Thank you for taking the time to consider this study. If you wish to take part in it, please complete the questionnaire.

Survivors' needs come first as we build a new plan for the future.

Study co-ordinator
Dr Jordana McLoone

Any questions?

PARTICIPATING HOSPITALS AND LONG TERM FOLLOW-UP CLINICS

KIDS CANCER CENTRE
haematology · oncology · transplant
SYDNEY CHILDREN'S HOSPITAL RANDWICK

The Royal Children's Hospital Melbourne

Monash Children's
Southern Health

Royal children's Hospital and Health Services

John Hunter Children's Hospital
Kaleidoscope - The Children's Health Network

Starship
CHILDREN'S HEALTH

the children's hospital at Westmead

Women's and Children's Hospital
ADELAIDE

NSW Cancer Survivors Centre
renewing life

The Wellington Hospital

Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service

Canterbury
District Health Board
Te Poari Hauora ō Waitaha