



Study Manager
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Overview

Sarcomas contribute disproportionately to cancer burden in our community, because they affect the young, treatment is costly and prolonged, and morbidity and mortality is high. Genetic factors appear important in sarcomas, although they have not been well studied for the adult population. Early detection by identifying those at risk may lead to better prognoses.

National launch

During International Sarcoma Awareness Week (July 18-26, 2009), the Rainbows for Kate Australian Sarcoma Kindred (RFK ASK) Study was launched nationally at the Royal Prince Alfred Hospital by the NSW Minister Assisting the Minister for Health (Cancer), Jodi McKay. Marcus Boyson of the Rainbows for Kate Foundation and David Currow, CEO, Cancer Australia were also key speakers.

The Rainbows for Kate Australian Sarcoma Kindred Study is creating a vital research resource to enable further study into the genetic factors contributing to the hereditary risk of developing sarcoma.

Potential study participants are identified at key sarcoma clinics, asked to complete a questionnaire and provide biospecimens (blood and tissue). The biospecimens are stored indefinitely in a tissue bank to be utilised by researchers investigating genetic factors contributing to cancer. Information obtained from the questionnaire is used to ascertain the family history of cancer and other factors that may contribute to development of the disease. Participant recruitment began mid 2009 in Victoria and Queensland and slightly later in NSW. The ongoing nature of the project will enable continual provision of important practical information for clinicians and patients leading to more favourable outcomes.

Sites

Across Australia, five major sarcoma clinics are involved in the initial phase of the RFK ASK Study, namely the Peter MacCallum Cancer Centre in Melbourne, the Prince of Wales and Royal Prince Alfred Hospitals in Sydney and the Princess Alexandra and

Wesley Hospitals in Brisbane. The study also has the capacity to include willing participants in other locations.

Steering Committee

The RFK ASK Study Steering committee consists of key people from each of these sites as well as others with wide ranging expertise.

Steering Committee members

David Thomas, Medical Oncologist & Laboratory Head, PMCC, Melbourne
Gillian Mitchell, Director, PMCC Familial Cancer Centre, Melbourne
Heather Thorne, kConFab National Manager, PMCC, Melbourne
John Hopper, Director, Centre for MEGA Epidemiology, University of Melbourne
Jayesh Desai, Consultant Medical Oncologist, Royal Melbourne Hospital, Melbourne
Loane Skene, Professor and Program Director, Faculty of Law, University of Melbourne
Craig Lewis, Senior Oncologist, Prince of Wales Hospital, Sydney
Kathy Tucker, Head, Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney
Martin Tattersall, Head, Department of Medical Oncology, Royal Prince Alfred Hospital, Sydney
Sandro Porceddu, Senior Radiation Oncologist, Princess Alexandra Hospital, Brisbane
Michael Gattas, Clinical Geneticist, Genetic Health Queensland
Ian Dickinson, Orthopaedic Surgeon, The Wesley Hospital, Brisbane
Mary-Anne Young, Genetic Counsellor, PMCC Familial Cancer Centre, Melbourne
Maya Kansara, Post Doctoral Research Fellow, Sarcoma Genomics and Genetics Laboratory, PMCC
Kylie Gorringer, Senior Research Officer, Cancer Genetics Laboratory, PMCC, Melbourne

Eligibility for participation in the RFK ASK Study

All those diagnosed with sarcoma are eligible for recruitment to the study. Depending on the age at sarcoma diagnosis and the history of cancer in the family, further family members may be eligible for participation. We are also recruiting people with no cancer diagnosis to act as controls

Outcome

Researchers cannot promise that individuals will benefit from being a participant, but they do hope and expect that the outcomes of the research, made possible by the RFK ASK Study, will be of benefit to patients and their families affected by sarcoma in the future.