

2015/16 Project Funding

In 2015/16, we committed \$2.2 million for 9 additional projects. As a result we are currently funding 27 projects over the next 5 years.



Clinical Trials: Transplantation Research Nurse for leukaemia immunotherapy

Institute: The Royal Children's Hospital **Funding**: \$97,041 over 1 year (2015-16)

Salary and training for a Transplantation Research Nurse to develop expertise in complex targeted immunotherapies. The key outcome is the Australian-first opening of the flagship immunotherapy CAR T cell clinical trial for children with acute lymphoblastic leukaemia in 2016. This trial — using the patient's own genetically engineered immune cells — offers new hope to children with relapsed leukaemia.



Family: Family Resource Coordinator (0.87 EFT)

Institute: The Royal Children's Hospital

Funding Partner: Portland House Foundation (\$40,000 in 2015)

Funding: \$208,929 over 3 years (2015-18). Renewal – funded since 2006 Salary funding for a non-medical staff member providing practical and emotional support services for children and their families across inpatients, outpatients and day oncology. The Family Resource Coordinator facilitates discussion between staff and families, and provides day-to-day support services through play, social activities and respite.



Research: Clinical Research Fellow

Institute: Hudson Institute of Medical Research, with Murdoch Childrens Research

Institute, Monash University **Recipient**: Dr Sara Khan

Funding Partner: Australian Lions Childhood Cancer Research Foundation (100%)

Funding: \$450,000 over 3 years (2016-19)

Clinical research training and laboratory consumables for a paediatric oncologist to investigate new therapeutic options for two of the most prevalent and aggressive paediatric brain tumours, medulloblastoma and Diffuse Intrinsic Pontine Glioma (DIPG). Key outcomes will be the development of a rapid and cost-effective clinical tool to determine the medulloblastoma molecular subtype; new DIPG gene targets for potential therapeutic intervention; and preclinical validation of potential pharmacological epigenetic modifiers of DIPG.



Research: Understanding the genetic basis of chemotherapy-induced heart disease **Institute**: The Royal Children's Hospital, with Murdoch Childrens Research Institute, Monash Children's Hospital, British Columbia Children's Hospital (Canada)

Recipient: Dr Rachel Conyers Funding Partner: My Room (100%) Funding: \$214,830 over 3 years (2015-18)

Research project to investigate why 20-30% of childhood cancer patients are susceptible to chemotherapy-induced heart disease. Genetic profiling of over 300 childhood cancer survivors and development of stem cell technology to investigate cardiac toxicity will determine why some patients are sensitive and others resistant. The key outcome will be the development of a rapid, clinical tool to predict patient sensitivity to chemotherapy.





Research: Developing molecular diagnostic testing

Institute: Murdoch Childrens Research Institute, with Peter MacCallum Cancer

Centre

Recipient: A/Prof. Paul Ekert

Funding: \$125,000 over 2 years (2015-17)

Research project to identify key genetic mutations and gene regulation abnormalities in cancers such as low grade glioma and leukaemia to map the best potential treatment for each individual cancer patient. The key outcome is the development of genetic/epigenetic profiling capacity to deliver molecular

diagnostic testing for clinical use.



Research: Personalised childhood cancer care partnership between The Royal

Children's Hospital and Sydney Children's Hospital

Institute: Murdoch Childrens Research Institute, with Children's Cancer Institute

Recipient: A/Prof. Paul Ekert

Funding Partner: Steven Walter Children's Cancer Foundation (100%)

Funding: \$225,000 over 3 years (2015-18)

Research project to advance personalised medicine as standard of care based on an understanding of the gene mutations that cause cancer. Expertise and analysis developed at The Royal Children's Hospital will be shared with Sydney Children's Hospital through this collaborative project. The key outcome is the development of tools and processes to make individual analysis of paediatric cancers available to Australian families.



 $\textbf{Clinical Trials:} \ \textbf{Bright light therapy to measure the impact on children with acute}$

lymphoblastic leukaemia

Institute: The Ritchie Centre, Hudson Institute of Medical Research, Monash

University

Recipient: Dr Lisa Walter

Funding: \$18,428 over 1 year (2016-17)

Research clinical trial to investigate the effects of light therapy on the quality of sleep, fatigue and overall quality of life of children with acute lymphoblastic leukaemia. Light therapy is a low cost, portable and effective treatment currently used to treat depression in adult cancer patients by resetting the circadian rhythms. The key outcome from this pilot evaluation is to determine whether bright light therapy can improve sleep-associated symptoms experienced by children with cancer.



Clinical Care: Music Therapist (0.6 EFT) **Institute:** The Royal Children's Hospital

Funding Partner: Portland House Foundation (\$40,000 in 2016)

Funding: \$172,600 over 3 years (2016-19). Renewal – funded since 2007 Salary funding for a Music Therapist to provide clinical music therapy services to children under treatment within the Children's Cancer Centre. Music therapy enables children and adolescents to use music to express their experiences of illness that are difficult to communicate with words alone. Therapeutic music intervention allows a trained Music Therapist to support vulnerable children and promote positive coping skills.





Research: Genomics of brain and solid tumours of childhood

Institute: Murdoch Childrens Research Institute, with Victorian Comprehensive

Cancer Centre and University of Melbourne **Recipient**: Dr Dong-Ahn Khuong-Quang **Funding**: \$271,833 over 2 years (2016-18)

Research project to increase the understanding of childhood cancers. There are two key outcomes: to develop and improve the classification of solid tumours, including brain tumours on the basis of epigenetic signatures using RNA sequencing (focus on medulloblastoma and high grade gliomas); and to develop a methodology and testing platform to identify the genomic profiles of paediatric solid tumours in blood using advanced sequencing techniques (with a focus on neuroblastoma and lymphoma). This has the capacity to provide a "frontline" test to identify the presence of a tumour and track the response to treatment.



Research: Clinical implementation of transcriptome sequencing for precision

cancer medicine

Institute: Murdoch Childrens Research Institute **Recipient**: A/Prof. Paul Ekert and Dr Alicia Oshlack **Funding**: \$284,249 over 2 years (2016-18)

Research discovery project using advanced techniques to read genetic code in cancer cells and identify the changes in those cells that cause cancer. This information can then be used in clinical trials that test new treatments that directly target the specific genes causing that cancer. The key outcome is to develop the sequencing and analytic platforms for clinical reporting, and to develop a tool that

can aid in the identification of standard, high and very high risk patients.



Family: Family Gym Memberships Institute: The Royal Children's Hospital Funding: \$1,658 over 1 year (2016-17)

Funding for two 12-month gym memberships at the independent gym based at The Royal Children's Hospital for parents of inpatients of the Children's Cancer Centre. The key outcome is to provide support to improve wellbeing for parents of children who are hospital-based for prolonged periods while caring for their children.



Clinical Trials: Clinical Trial Manager (1.0 EFT)

Institute: Monash Children's Hospital Funding: \$380,507 over 5 years (2016-21)

Salary funding for a Clinical Trials Manager to lead the clinical trials unit. The key outcome is to increase the portfolio of trials open, and the number of children enrolled in clinical trials and accessing new treatments.



Research: Head of Molecular Diagnostics (0.4 EFT)

Institute: The Royal Children's Hospital, with Murdoch Childrens Research Institute

Recipient: A/Prof. Paul Ekert

Funding Partner: Steven Walter Children's Cancer Foundation (100%)

Funding: \$600,000 over 5 years (2014-19)

Salary funding for a leadership position with protected clinical research time to develop new molecular diagnostic tools and build expertise and research capacity. The key outcome will be evidence of the changes that occur in the genes of cancer cells, and how those changes can be used in cancer diagnosis and the selection of appropriate treatments.





Family: Family and Community Resource Liaison Officer (0.4 EFT)

Institute: Monash Children's Hospital

Funding: \$36,150 over 3 years (2014-17). Renewal – funded since 2007 Salary funding for a non-medical staff member providing practical and emotional support services for children and their families. The Family Resource Coordinator facilitates discussion between staff and families, and provides day-to-day support services through play, recreation, social activities and respite.



Clinical Trials: Clinical Research Associate – Early Phase Clinical Trials (1.0 EFT) Institute: The Royal Children's Hospital, with Murdoch Childrens Research Institute

Funding: \$257,063 over 3 years (2014-17)

Salary funding to build a portfolio of trials to offer children new treatment options, supporting our goal of achieving 75% of all patients to be enrolled in a clinical trial. The Clinical Research Associate coordinates research clinical trials (phase I and II) focusing on new drugs to treat cancer, potentially providing better clinical outcomes for children and adolescents.



Family: The Beaded Journey

Institute: The Royal Children's Hospital, Monash Children's Hospital, Peter

MacCallum Cancer Centre



Funding: \$29,000 over 3 years (2014-17). Renewal – funded since 2008
The Beaded Journey, a therapeutic program that gives children the opportunity to tell their personal cancer story by marking key medical and non-medical events throughout their treatment. Each event is represented by a bead placed on a string to symbolise the child's tenacity and bravery.



Clinical Care: Psychologist (0.8 EFT)
Institute: Monash Children's Hospital

Funding: \$104,987 over 3 years (2014-17). Renewal – funded since 2008 Salary funding to provide mental health services to children and their families to improve their psychological adjustment to cancer diagnosis and treatment. The role also provides support and psychosocial education to Children's Cancer Centre staff.



Clinical Care: Music Therapist (0.8 EFT) Institute: Monash Children's Hospital

Funding Partner: The Pratt Foundation (\$40,000 in 2015)

Funding: \$263,417 over 3 years (2014-17). Renewal – funded since 2009 Salary funding to provide clinical music therapy services (song-writing, active music making, therapeutic music lessons, improvisation, relaxation) to children to improve their psychological adjustment to cancer diagnosis and treatment. Therapy sessions also provide support during procedures and for pain and anxiety management.



Clinical Care: Neuropsychologist (0.2 EFT) Institute: Monash Children's Hospital Funding: \$27,187 over 3 years (2014-17)

Salary funding to provide neuropsychology assessments to children with cancer at risk of long-term neurocognitive impact due to the effects of their disease or treatment. This new role addresses a service gap for children, providing assessments at key time points: initial assessment, treatment phase, post-treatment surveillance, and long term follow up.





Research: Head of Solid Tumours and Neuro-oncology (0.4 EFT)

Institute: The Royal Children's Hospital, with Murdoch Childrens Research Institute

Recipient: A/Prof. Michael Sullivan

Funding Partner: Australian Lions Childhood Cancer Research Foundation (100%)

Funding: \$258,085 over 2 years (2013-15)

Salary funding for a leadership position with protected clinical research time to develop a portfolio of research clinical trials and build research capacity. Focussing on liver cancer and low grade gliomas, the key outcome will be evidence of the biology and genetics of these diseases to reduce the toxicity of treatments and offer new treatment options.



Clinical Care: Procedural Pain and Play Therapist (1.0 EFT)

Institute: Monash Children's Hospital

Funding: \$32,761 (2014/15). Renewal – funded since 2007

Salary funding for a Procedural Pain and Play Therapist to provide positive coping strategies and manage the distress and anxiety commonly associated with cancer treatment. The therapist also manages The Beaded Journey, available to all children receiving treatment within the Children's Cancer Centre.



Clinical Trials: Clinical Trial Associate (1.0 EFT)

Institute: Monash Children's Hospital

Funding Partner: Steven Walter Children's Cancer Foundation (100%)

Funding: \$222,667 over 5 years (2013-18)

Salary funding for a Clinical Trial Associate to increase the number of clinical trials available to children under treatment for cancer, providing additional treatment options.



Clinical Care: Neuropsychologist (0.2 EFT)

Institute: The Royal Children's Hospital

Funding: \$115,800 over 3 years (2014-17). Renewal – funded since 2007 Salary funding to provide neuropsychology assessments to children with cancer at risk of long-term neurocognitive impact due to the effects of their disease or treatment. This role addresses a service gap for children who do not have access to a government-funded service in the critical post-treatment monitoring period (3-5 years).



Clinical Care: Art Therapist (1.0 EFT)
Institute: The Royal Children's Hospital

Funding Partner: Hopscotch Heroes (\$10,000 in 2016)

Funding: \$256,012 over 3 years (2014-17). Renewal – funded since 2010 Salary funding to provide art therapy services enabling children under treatment for cancer to process their emotions such as anxiety, depression, hopes and fears. Through non-verbal and safe mannered individual and group sessions, children can use creative avenues whilst socialising with other children sharing similar cancer

experiences.





Clinical Care: Medical Consultant Sessions (1.2 EFT)

Institute: Monash Children's Hospital Funding: \$718,314 over 5 years (2011-16)

Salary funding for Paediatric Haematology and Oncology sessions (12 sessions/week) with a medical consultant to provide clinical care and treatment to

children with cancer. Clinical care is provided in both the outpatient day

oncology/clinic setting and the paediatric inpatient units.

Project Pending



Clinical Care:

Family: Counselling for parents

Funding Partner: The Pratt Foundation (\$40,000 in 2016)

Funding: (up to) \$100,000 over 1 year (2016-17)

At its June 2016 meeting, the board of the Children's Cancer Foundation will ratify funding a new project which will make available to parents of children with cancer face-to-face counselling with a psychologist. Recent research has confirmed both the unmet demand for and benefit of such a service. It is anticipated that the project will become recurrent after completion of a 12 month pilot phase.