





ANNUAL REPORT TO THE HCC

2019-2020

The Hawkesbury Canoe Classic (HCC)

- Arrow's major supporter

In November 2019, the HCC in its 43rd year donated \$73,000 to Arrow. Since 1994 the HCC has contributed almost \$4.223 million in donations to fund Arrow's medical research programs.



About the **Arrow Bone Marrow Transplant Foundation (Arrow)**

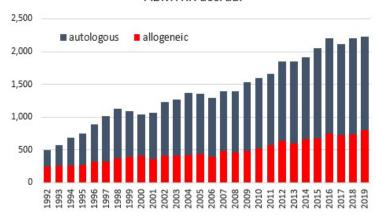
Arrow is a charitable organisation with a mission to: Improve the survival and quality of life for patients with blood diseases treatable by bone marrow and blood stem cell transplants and provide support for their carers in Australia

- by funding research projects
- by providing vital support to patients, their carers and families
- by improving patient care through specialised education and skills development for nurses and other health staff

What is a **bone marrow transplant?**

Haemopoietic stem cell transplants (HSCT) are used to treat a range of both haematological and non-haematological malignancies and other serious conditions. These stem cells may come from bone marrow, peripheral blood or cord blood. Transplants can be allogeneic, using stem cells from a donor, or autologous, where the patient's own stem cells are harvested and then returned, usually after high-dose conditioning chemotherapy (depending on the disease). HSCT are used as treatment for many indications including acute and chronic leukaemias, lymphoma, multiple myeloma, some solid tumours and other haematological conditions such as myelodysplasia, aplastic anaemia, thalassemia and immune disorders.

ABMTRR accrual





to become experts in the transplant field and ensuring clinicians have access to vital transplant data.

VISIT WWW.ARROW.ORG.AU



WHAT YOUR PADDLING HAS HELPED US ACHIEVE

Arrow/HCC Research Scientist



The Arrow/HCC Research Scientist grant in 2019 enabled Dr Tim Molloy to contribute to the exciting new research in the Department of Haematology's Blood, Stem Cell and Cancer Research Program at the St Vincent's Centre for Applied Medical Research of St Vincent's Hospital Sydney. Anaemia (insufficient red blood cells) is a prevalent disorder, affecting more than 10% of adults over 65, and >15% over age 75. Anaemic patients are at risk of impaired cognitive and physical functions, cardiovascular disease, hospitalisation, and high mortality, therefore represents a major health and economic burden in Australia. Strikingly, the causes of anaemia are unknown in up to one third of patients. The diagnosis of unexplained anaemia (UA) is made after protracted investigations and they are also difficult to treat effectively. Actionable tests and effective drugs for UA are therefore urgently needed. We postulated that most cases of UA could be explained by the acquisition of aging associated gene mutations in blood cells similar to myelodysplasia (MDS).

Our research study of over 200 patients attending the two local outpatient clinics was amongst the first to address this hypothesis by applying ultra-sensitive "deep next-generation sequencing" technology. Gene mutations identified in the blood cells of each patient were then correlated to the incidence of cytopenia, including UA. We observed that the prevalence of blood gene mutations were increasing with advancing age. Importantly, patients with unexplained anaemia have more recurring mutations than non-anaemic patients which supports our initial hypothesis that specific blood mutations may be driving this disorder. These exciting discoveries are a strong indication that these aging associated genetic changes may be key factors leading to UA. Our plan is to undertake further investigations using advanced pre-clinical laboratory models to uncover how these mutations may alter the bone marrow stem cell functions resulting in anaemia. The goal is to develop new diagnostic test and to create new drugs to patients with unexplained anaemia. These new discoveries may also help the management of BM transplant patients.

Dr Tim Molloy, a conjoint Senior Lecturer at the University of New South Wales, has continued his commitment to mentoring young scientists, supervising an honours student in 2019 and a new PhD student, Halla Eyjolfsdottir from Iceland who has joined our research program in mid-2019.

Volunteers from **Arrow**

An Arrow representative attends all landcrew and paddler information sessions and speaks on current research initiatives. An Arrow representative also attends the HCC Committee monthly meetings.

On average, Arrow is able to provide 25 volunteers to assist on event day and 10 attendees at each presentation dinner. In recent years Arrow has taken up responsibility for the management of the sales and sponsorship tents on event day.



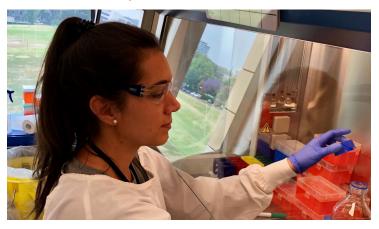


ABMTRR

The Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) was established in 1992 to record details of all stem cells transplants performed in Australia. New Zealand began contributing in 1998. Currently the database holds information on over 40,000 transplants from 52 centres around Australia and New Zealand. Accrual has been above 2,000 transplants per year since 2015. Data are used for clinical, research and administrative purposes.

Arrow has supported the registry since it was first established, and has continued its support each year by contributing towards the production and distribution costs of the Annual Data Summary. This document is distributed to more than 500 clinicians and researchers from Australia and New Zealand.

Scholarships for PhD students



Natalia Pinello

My research has progressed well in accordance with the original plans and objectives outlined in my proposal. Initially I planned to study the role of a specific chemical modification to human genes during normal blood cells development and in leukaemia. Interestingly, data I generated during this first year of my PhD candidature has revealed an additional chemical modification as a key regulator of white blood cells function. In light of these results, I have decided to extend my original aims and explore both modifications in parallel, aiming to develop a more comprehensive understanding of chemical modifications in both normal blood cells development and in cancer.

By establishing the techniques required to detect, quantify and profile chemical modifications in genes at The Epigenetics and RNA Biology Program at the Centenary Institute, led by Dr. Justin Wong; this year, I made substantial progress towards completing the first main aim of my PhD. I have created a map detailing the location of the two chemical modifications of our interest in different stages of white blood cells development. This map allows us to identify specific genes that are regulated by these modifications and to explore the effect of altered modification patterns on blood cells function. Our preliminary results suggest an active role of chemical modifications in the regulation of specific genes during white blood cells differentiation and immune functions. These are very exciting results as they opened up previously unexplored research avenues into the role of aberrant chemical modifications patterns in leukaemia, I will be exploring these further during the remainder of my PhD, ultimately aiming to contribute to the development of new treatments for blood cancer in the future.

ARROW RECEIVES NO GOVERNMENT FUNDING



THE ARROW HCC PARTNERSHIP

Arrow's participation in the HCC

Over the years, Arrow has had many board members, past patients and friends participate in the HCC – either as paddlers, volunteers, or landcrew. Arrow Chairman, Mark O'Hara, competed in his 20th HCC in 2018. He has paddled with many other Arrow supporters that have been affected by leukaemia including;

- Neil Pennock current Arrow Vice Chairman, who lost his partner to GVHD related complications post-transplant
- Heidi Fisse past Arrow
 President whose son, Stephen,
 passed away after a bone
 marrow donor could not be
 found
- Darren Williams former transplant patient and former Arrow board member

and Anthony Hodsdon – whose sister-in-law passed away suddenly after being diagnosed with leukaemia.



Bronwyn (Lisa) Cuthbertson

Lisa has over 15 years experience working in marketing and communications, primarily in the Arts sector. Lisa is 30 years post bone marrow transplant.

Philip Hartog

Philip holds a Masters Degree in Corporate Economics from Erasmus University, Rotterdam, Holland, and a Masters Degree in Business Administration (MBA) from Harvard Business School, Boston, USA.

Michael Quigley

Mike is a retired telecommunications engineer who was the CEO of NBN Co for its first four years.

Having undergone a bone marrow transplant for Chronic Myeloid Leukaemia in 1991, Mike served on the Arrow board until he took up responsibilities for Alcatel in the US in the late 1990s. Following a stem cell transplant for Acute Lymphoblastic Leukaemia in early 2018, Mike rejoined the Arrow board in late 2018.

Dr Keith Fay

Dr Fay is a Consultant Senior Staff Haematologist at the Kinghorn Cancer Centre in Sydney.

Dr Tim Molloy

Dr Tim Molloy is a senior research scientist in the Blood Stem Cell and Cancer Research Group at the St Vincent's Hospital Centre for Applied Medical Research. He also holds a Conjoint Senior Lecturer position with the St Vincent's Clinical School in the Faculty of Medicine, University of New South Wales.

Greg Arandt

Greg holds a B.Com(Hons) University of Melbourne (1990) / MA Economics (Distinction) University of London (1994)

Amanda McLaughlin

Amanda's transplant career began in 1994 at The Royal Melbourne Hospital caring for inpatient BMT patients, she has a Bachelor of Science (Nursing) and Post Graduate qualifications in Cancer Nursing and Apheresis.

Since moving to Sydney in 2005, Amanda has worked at St Vincent's as a Clinical Nurse Consultant in Apheresis. Amanda is very involved with the Haematology team and their education program and association with developing countries. The program has supported Myanmar, Sri Lanka and The Philippines. Amanda is inspired by her work and her motto is to - "make a difference to my patient's day."

Arrow Board of Directors

Mark O'Hara - Chairman

Mark has paddled in the HCC every year since 1999. He is currently the Facility Manager at Neuroscience Research Australia.

Vice Chairman – Neil Pennock

Neil is a Finance Consultant, specialising in project finance. He paddled the HCC with Mark O'Hara in 2018.

David Eden – Treasurer

David Eden was diagnosed with Chronic Myeloid Leukaemia in 1994. He had a bone marrow transplant in June 2000. David was awarded the Order of Australia in 2018 for his community service volunteer roles over many decades.

Assoc. Professor Anthony Dodds - Director

Associate Professor Anthony Dodds is a former Director of Haematology and Bone Marrow Transplantation at St Vincent's Hospital, Sydney. He is also Associate Professor of Medicine at the University of NSW.

Leonie Wilcox – Director

Leonie is currently the Manager of the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR).

Colleena Presnell - Director

Colleena was diagnosed with Acute Myeloid Leukaemia in 2001 and subsequently received two bone marrow transplants. Colleena was a corporate trainer in business communication for 22 years travelling throughout Australia, NZ and SE Asia.



If you would like further information about the Foundation and its activities, please contact the CEO (Robyn Flood) on 02 8382 2698 or email rflood@arrow.org.au.

Information is also available on our website at www.arrow.org.au.

ARROW BONE MARROW TRANSPLANT FOUNDATION