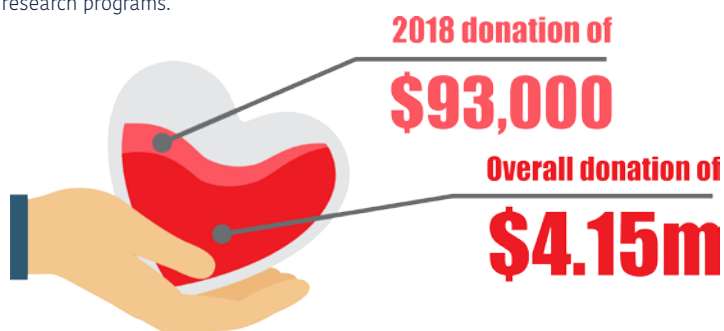


HCC ANNUAL REPORT

2018-2019

The Hawkesbury Canoe Classic (HCC) - Arrow's major supporter

In November 2018, the HCC, in its 42nd year, donated \$93,000 to Arrow. Since 1994 the HCC has contributed almost \$4.15 million in donations to fund Arrow's medical research programs.



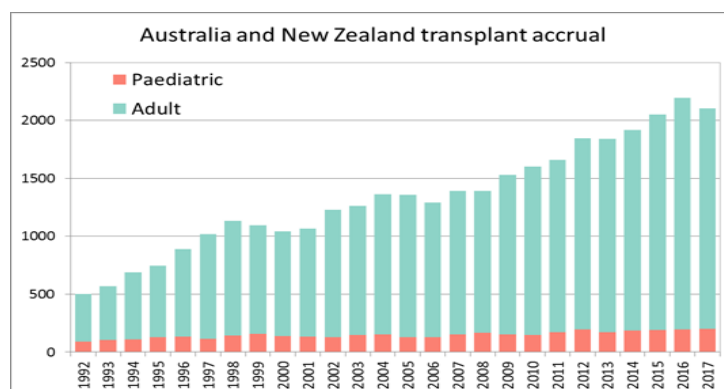
About the Arrow Bone Marrow Transplant Foundation (Arrow)

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.



Source ABMTRR Annual Data Summary 2017

PADDLING WITH A PURPOSE



Together we have improved the outcomes for thousands of patients who have needed a bone marrow transplant to survive disease. We've done this through funding ground breaking research, providing vital resources for researchers, educating health practitioners to become experts in the transplant field and ensuring clinicians have access to vital transplant data.

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PAST AND PRESENT PROJECTS SUPPORTED BY THE HCC

Grant funding for **medical research**



For research on graft versus host disease (GVHD), a major cause of death in post transplant patients, gene profiling of leukaemia and lymphoma and the clinical potentials of adult stem cells.

Purchase of **medical research equipment**

Including

- A dissecting microscope
- 2. Minus 80° freezer
- 3. Refrigerated bench top centrifuges
- 4. Cytospin centrifuges
- 5. Low O2 incubator



Arrow/HCC **Research Scientist**

In 2018 the Arrow/HCC Research Scientist, Dr Tim Molloy, continued to co-lead a major research project with Professor David Ma, Department of Haematology and BM Transplantation at the St Vincent's Centre for Applied Medical Research of St Vincent's Hospital Sydney. This project examined the potential of a gene known as "microRNA-10a" as a new drug target and predictive test for the treatment of acute myeloid leukaemia (AML). AML has the highest mortality rate of any blood cancer in adults. There is a dire need to discover new therapies and in particular to develop treatments better tailored to the genetics of individual leukaemias that can be used in conjunction with bone marrow transplantation to improve cure rates. One new strategy currently in clinical trials worldwide referred to as "MDM2/4 inhibition" has shown significant promise. Our work was the first to demonstrate that measuring microRNA-10a in leukaemic cells may be able to predict which AML patients will respond to this treatment, potentially allowing doctors to select the correct patients to treat. Excitingly, we demonstrated that inhibiting microRNA-10a significantly increases the action of the anti-MDM2/4 drug. This opens the possibility of applying our research results in future clinical trials.

Tim recognises the need to build capacity for future bone marrow disease research and as such in 2018 continued to mentor young scientists in the field. He co-supervised Kevin Hendrawan in his PhD studies investigating the use of bone marrow transplantation for the treatment of autoimmune disorders such as multiple sclerosis (MS). Tim was also promoted to conjoint Senior Lecturer at the University of New South Wales, and was awarded the UNSW Sydney High Quality Research Paper Award – a reward scheme that recognises researchers in publishing high quality research work.

Scholarships for **PhD students**



Natalia Pinello – the 2019 Arrow/HCC PhD Scholarship recipient

Natalia has had a long-standing passion for RNA biology. After completing her undergraduate studies at the University of the Republic in Montevideo, Uruguay, she joined the Genetics Department at the Clemente Estable Biological Research Institute where she studied microRNA synthesis pathways in cancer. Since then, she has been fascinated by the complexity of transcriptional regulation. In 2012 she joined the Gene and Stem Cell Therapy Program at the Centenary Institute, Sydney, led by Professor John Rasko. There she worked as a research assistant for Dr. Justin Wong, where she contributed to seminal work on alternative splicing and gene expression regulation, published in numerous prestigious scientific journals including Cell, Nature Communications, Nucleic Acids Research and Genome Biology. This year, she started her PhD studies under the supervision of Dr. Wong at the Epigenetics and RNA Biology Program at the Centenary Institute. Her PhD aims to characterise the role of RNA modifications in haemopoiesis and leukaemia.

Natalia's research

The DNA in all of the cells in our body controls what each cell looks like and all of its specific functions. This is because DNA provides the genetic blueprint for the production of RNA, which is like the instruction manual for the manufacture of proteins, or the physical components of our cells. This process is called "gene expression". Chemical decorations on our cell's DNA play a key role in regulating gene expression through changing which RNA gets produced, and therefore which proteins are manufactured. Previous studies have reported mechanisms and roles of some of these DNA decorations in controlling gene expression in both normal development and disease. This has led to the development of drugs to treat diseases in which the patterns of these DNA decorations are abnormal. Recently, chemical decorations have also been found in RNA, but their functions and how they might affect gene expression are yet unknown. My PhD project focuses on understanding the role of RNA decorations in normal blood cell development and cancer, so that this understanding can help contribute to the discovery of new treatments for blood cancers.

Hear what Natalia says about her research <https://youtu.be/vBSKfikPwVo>

Telehealth Clinical **trial**

In 2014, Arrow granted \$80,000 to a new telehealth clinical trial investigating the home delivery of health services to improve outcomes for transplant survivors.

Hospital **infrastructure**

In 2016, Arrow allocated \$50,000 of the HCC donation towards a \$300,000 grant for the new Haematology and Bone Marrow Transplant Ward at St Vincent's Hospital, Sydney. The overall cost of the project was \$5.5m and Arrow contributed \$300,000 to the project which is the cost of providing one single patient room.

celebrating a 25 year partnership

ARROW RECEIVES NO GOVERNMENT FUNDING



EDUCATION AND PATIENT SUPPORT

Workshops at Blood 2018

With the 2018 HCC donation, Arrow supported the ABMTRR Workshops at Blood 2018 in Brisbane in October. These workshops allowed data managers to come together to learn about the importance of data quality in order to maximise the benefits to research and patient care, and how enhancements to the ASTRO database can assist with streamlining data collection, study management and analysis. It was also a networking opportunity, as many data managers have no regular contact with others in similar roles.

Past HCC donations have been used:

- for the Cancer After Stem cell Transplantation (CAST) study undertaken by the Children's Cancer Institute Australia (CCIA) in collaboration with the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR).
- for a research project which aims to cure severe degenerative intervertebral disc disease, a major cause of back pain.
- for a research project titled, **'Defining defective genes in leukaemia in children with trisomy 21 using induced pluripotent stem cells'**



Patient and carer support

The renovation of premises in Darlinghurst NSW, fondly known as 'Arrow House'. The Arrow office is located upstairs and the remainder of the terraces are used as patient and carer accommodation for those travelling from regional areas and interstate to receive bone marrow transplant or to care for their loved ones.



Transplant Data

The Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) was established in 1992 to record details of all Haemopoietic Stem Cell Transplant. The ABMTRR operates under the auspices of the Bone Marrow Transplant Society of Australia and New Zealand. Contributing centres provide registrations of new transplants to the ABMTRR and also information on the progress of previous transplant patients. Currently the database holds information on over 36,000 HSCT from 52 centres around Australia and New Zealand. Accrual has been above 2,000 transplants per year since 2015.

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. Data are provided for research projects and ad hoc requests from clinicians, researchers and government officials. The information may be used for publications in peer reviewed journals, presented at conferences (both local and international) and used by hospital and government departments for administrative, quality and planning purposes.

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.

Mark also undertakes all his paddles in memory of his good friend, Greg Neate, who achieved the amazing feat of paddling the Classic only 111 days post bone marrow transplant. In 2016, Mark's son Matt and Greg's son Chris paddled for the first time also in memory of Chris' father Greg. They completed the 111km in under 12 hours and raised \$4310.

Former St Vincent's Hospital Haematologist, Dr John Kwan, paddled the HCC in 2009 to support research which aims to help the patients he treats. John said, "111km of overnight paddling seems nothing in comparison to what our patients are able to endure - the multiple treatments, hospitalisations not to mention the emotional ups and downs. Being at the coalface of what they can endure is truly inspirational - it certainly provided mental ammunition to spur me on to the finish! The raising of vital funds to support Arrow's research and practical assistance can only help to find a cure and improve our patients' lives - to be a part of that and support them by completing the HCC is truly a great privilege and one that I will do again!"



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.

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PROMOTING THE HCC

OUR PEOPLE

Arrow's promotion of the HCC

The HCC is promoted by Arrow through the following channels:

- in Arrow newsletters (March and October)
- on our website – always an item on the 'home' page, 'events' page and 'latest news' (www.arrow.org.au),
- in all Arrow brochures as our 'Major Supporter' (1000 per year produced). Brochures are available to the general public, sent to hospitals, donors, transplant patients, and available at fundraising events,
- on a plaque within Arrow House – this is a large plaque placed near the front door of Arrow House thanking the HCC for their contribution to the renovation of Arrow House,
- on a plaque within the newly built Research Precinct on the St Vincent's Hospital campus at Darlinghurst – this is a large wall plaque on the ground floor reception area where contributors to research are acknowledged,
- plaques acknowledging the HCC's contribution have been placed on all medical research equipment purchased with HCC donations,
- Facebook.

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.

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)



Contact information

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

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