

# TRANSPLANT TALK



## The history of the Hawkesbury Canoe Classic (HCC) and Arrow partnership uncovered

As relatively new staff members, we've often wondered how and when the tremendous partnership between the HCC and Arrow began. And last week, whilst looking through some old files, we were lucky enough to unearth some solid evidence. The HCC first paddled for Arrow (then named The Australian Bone

Marrow Transplant Foundation) in 1993, to raise funds for a charity 'where the funds would be used for medical research,' according to an announcement published in the HCC's 1993 brochure for paddlers. In a message of thanks to the Hawkesbury Canoe Classic Association within the brochure, past

Arrow President (Barbara Crouch) wrote: "To you the paddlers, thank you for supporting us this year - our first as recipients of money raised from the Hawkesbury Classic Paddle. The money you and your friends contribute will go directly towards helping save lives."

## Vale Harold Smart (2/6/1933-29/3/2019)

Long term good friend to Arrow, Harold Smart, passed away recently. Harold would often call the office for a chat and would talk about how he introduced Arrow to the HCC.

Harold was diagnosed with Acute Myeloid Leukaemia in February 1991 and received bone marrow transplant at St Vincent's Hospital, Sydney under the care of Professor Kerry Atkinson in January 1992. Harold designed and sold aluminium canoes in New Zealand and continued to do so when he came to live in Sydney in 1986. Through his canoe making, he was in contact with Alison Bailey (whose father had passed

away from leukaemia) who was the secretary of the HCC at the time. After Harold's transplant, he joined the Australian Bone Marrow Transplant Foundation at Professor Atkinson's suggestion. Harold mentioned to Alison that the HCC should consider supporting Arrow. Alison put it to the HCC committee and after a visit to the event by Arrow representatives and the promise of some Arrow volunteers, they agreed! Harold never paddled in the HCC but he was very proud of his involvement in linking Arrow with the HCC and the partnership that eventuated.



Harold Smart

**We will be forever grateful to Harold for our relationship with the HCC.**

## Donations in memoriam

We gratefully acknowledge donations received in memory of:

- Katherine Robertson
- Harold Smart
- Roger Walker

## Events

- 100 reasons to celebrate our nurses  
12th October, 5.30 - 9.30pm  
18 Footers - 77 Bay Street, Double Bay
- Hawkesbury Canoe Classic  
26th - 27th October
- Arrow Annual General Meeting  
15th November 2019  
Kinghorn Cancer Centre

## The Allan Frenkel Foundation supports patients and carers with \$42,000 donation

The Allan Frenkel Foundation has brought comfort to patients and their carers in their time of need by funding vital support services for over two decades. Over the past 21 years, the Foundation has supported a clinical trial for PUVA wands to alleviate pain from mouth ulceration, contributed to the new bone marrow transplant ward

at St Vincent's Hospital, Sydney, and helped with emergency living expenses for patients and carers throughout treatment.

This year, the Allan Frenkel Foundation presented Arrow with \$42,000! Arrow CEO, Robyn Flood, said: "The generous gift will fund our patient support services



program enabling us to provide patients with grocery cards, petrol cards and payment of their utility bills. This program assists patients and carers experiencing severe financial difficulty as a result of loss of income during the transplant process. We are sincerely grateful to the Allan Frenkel

Foundation for their tremendous support of patients and their carers over many years."

To hear from one of our social workers how important this support is for patients and carers, visit: [arrow.org.au/how-we-help](http://arrow.org.au/how-we-help)

MAKE A DONATION TODAY!

VISIT [WWW.ARROW.ORG.AU](http://WWW.ARROW.ORG.AU)

OR COMPLETE THE FORM OVERLEAF

## NURSING SCHOLARSHIP UPDATES

### Why blood cancer **related gene abnormalities increase with age**

Professor David Ma and his team at the Blood Stem Cell and Cancer Research Unit at St Vincent's Hospital, Sydney, will receive a \$300,000 grant from Arrow's recently established Professor Ma/Quigley Innovation Fund. This grant will be used to identify the role of acquired myeloid gene mutations in the development of haematological cancers in the general population.

### The role of acquired myeloid gene mutations in the development of haematological cancers **in the general population - project outline by Professor David Ma**



Prof David Ma and team

Recent studies have found that abnormalities (mutations) in genes associated with blood cancers increase with age from less than 1% for people aged less than 40 to over 10% for those above 80 years of age. These individuals are 10 times more likely to develop blood cancers such as myelodysplasia or leukaemia.

The contribution of these mutations toward the development of malignancy depends on the individual mutations and the interactions with other factors in an individual. Some of these mutations may be the key factor initiating the transformation of normal bone marrow cells to become pre-cancerous and then cancerous, while others promote survival or expansion of these abnormal cells. The precise role of these abnormal genes in disease evolution from normal aging stem and progenitor cells to pre-cancer and then cancer cells remains to be determined. Recent advances in technological capabilities have made this determination possible,

and this is the goal of the current project.

Professor David Ma and his team will study acquired myeloid gene mutations in the blood of several hundred Australians from the general population over time using state-of-the-art Next Generation Sequencing techniques to identify altered and malignant blood cell development such as anaemia, cytopenia, myelodysplasia and other blood cancers. They will then determine which mutations may be predictive of disease development and may therefore be targets for closer monitoring of patients, or potential drug targets to prevent or treat disease progression.

### Meet the new **Arrow/HCC PhD Scholarship student**



Natalia Pinello

This year, Natalia Pinello 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.

Project outline by Natalia Pinello:

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.

The DNA in all of the cells in our body control 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.

Watch the video: [arrow.org.au/medical-research/arrow-hcc-phd-scholarships](http://arrow.org.au/medical-research/arrow-hcc-phd-scholarships)

### A heart-warming donation

When seven year old Isabella heard from her 'yaiya' (grandmother), and long-time Arrow supporter, Helen Psarakis, that children with leukaemia and other diseases often spend months in hospital for a bone marrow transplant she wanted to help. Isabella collected all her coins and visited the Arrow office to donate the \$20 that she had saved. Thank you Isabella! It's truly heart-warming to receive such a thoughtful donation.



ARROW RECEIVES NO GOVERNMENT FUNDING

PERSONAL STORY

## Create a beautiful wedding day memory

Generosity runs in the Psarakis family with Isabella's yaiya also donating a wedding dress drycleaning prize for auction to the highest bidder.

Bids are now open for the Deluxe Bridal Service valued at \$900. The service includes the cleaning and boxing of a bridal gown and veil by Impress – the preferred dry-cleaning professionals for Steven Khalil, Vera Wang, The Bridal Atelier Double Bay and J Andreatta Paddington. Impress has also

worked on fabric testing with Alex Perry; and cleaned and boxed Erica Packer's \$250,000 Christian Dior Bridal Gown in conjunction with The Powerhouse Museum.

The Impress bridal voucher is now open for bidding and will close at 10pm on 12th October at our 100 reasons to celebrate our nurses event.

To bid email Gloria Vincent at [gvincent@arrow.org.au](mailto:gvincent@arrow.org.au)



### Liverpool Catholic Club supports transplant patients

We thank the Liverpool Catholic Club for donating \$30,000 in support of Arrow's patient support services.

### Help fight fatigue after transplant

Do you suffer from cancer-related fatigue? Untire gives cancer patients and survivors the tools to reduce fatigue.

For more information visit: [untire.me](http://untire.me)



### Woolworths reaffirms commitment to transplant patients

Due to the rigours of a bone marrow transplant, many patients are unable to work during treatment and often for many months after. Subsequently, their carers may also need to work reduced hours or take time off in order to care for their loved ones. This reduction in incomes makes it difficult to manage everyday living costs such as doing the weekly grocery shop.

Woolworths have come to the rescue again with another donation of \$10,000 in grocery cards available for our most needy patients. The support provided by Woolworths allows us to provide practical support to families during an emotionally and financially distressing time for patients and those who care for them.

## 100 reasons to celebrate our nurses

Over the past 30 years, Arrow is proud to have enriched the education of one hundred transplant nurses through scholarships – and with your help we look forward to funding hundreds more!

We invite you to join us in recognising and thanking our transplant nurses on Saturday 12th October from 5.30 – 9.30 pm at the 18 Footers Yacht Club in Double Bay. The ticket price of \$95 per person includes canapes, beverages and covers the cost of a nurse to attend!

To book visit: <https://www.trybooking.com/540579>

If you are unable to attend but would like to make a donation in support of Arrow's nursing scholarships, please visit: [www.givenow.com.au/crowdraiser/public/celebratingournurses](http://www.givenow.com.au/crowdraiser/public/celebratingournurses)

The following scholarships were awarded this year with funding from our generous supporters:

#### Professor Geoffrey Driscoll Nursing Scholarship for Haematology and Related Nursing

Thank you to Mrs Jan Driscoll and family, for their ongoing commitment to supporting transplant nurses wishing to enhance their nursing skills through further education.

The following transplant nurses have been awarded scholarships to study transplant related subjects via the Australian College of Nursing:

**Dimity Ryan** from the Riverina Cancer Care Centre was awarded \$2500 to study Chemotherapy and Other Systemic Treatments in Cancer Care.

**Kellie Symes** from University Hospital Geelong received a \$2500 scholarship to study Blood and Marrow Transplantation.

**Tara Hutton** from Royal Brisbane and Women's Hospital was awarded a \$5000 scholarship to study Chemotherapy and Other Systemic Treatments in Cancer Care and Blood and Marrow Transplantation.

**Bernadette Crisp** from Gold Coast University Hospital was also awarded \$5000 to study Chemotherapy and Other Systemic Treatments in Cancer Care and Haematology Nursing.

**Emma Butler** from the Riverina Cancer Care Centre was awarded \$2500 to study Chemotherapy and Other Systemic Treatments in Cancer Care.

**Kate McKibbin** and **Tamara Casey** from the Riverina Cancer Care Centre also received scholarships of \$2500 each to expand their education in Haematology Nursing.

**Geetha Augustine**, a clinical nurse at Royal Perth Hospital received a \$2500 scholarship to study Blood and Marrow Transplantation. She writes: "I am grateful to Arrow and the Driscoll family for selecting me for this scholarship.

Currently, I am a clinical nurse working at the haematology and outpatient chemotherapy unit at Royal Perth Hospital. Previously, I worked at the transplant unit at Fiona Stanley Hospital. I am passionate about bone marrow transplantation, and this study is helping me understand the transplant process and increase my skills in haematology nursing. My long-term goal is to become a haematology nurse practitioner. This qualification will allow me to provide quality care and will help to increase my knowledge about the impact of transplants on patients and their families."

## Ide furthers her **transplant education at the University of Sydney**

Ide Irwin, a registered nurse on the Haematology ward at St Vincent's Hospital, Sydney recently received the Trace Richey Scholarship through the Arrow Bone Marrow Transplant Foundation and said that studying the Master of Cancer and Haematology Nursing at the University of Sydney will give her the nursing skills that will enable her to have a direct impact on every patient that she comes in contact with, and each transplant colleague she works with.



"I am delighted and honoured to receive this scholarship. It means so much to me. Studying a Masters is going to be so good for my professional development. Increasing my knowledge will have a direct impact on my patients and colleagues. I am so, so grateful. Thank you to everyone involved."



Nabin and Jacqueline

## Nabin and Jacqueline **upskill in Switzerland**

Nabin Karki and Jaqueline Nipperess both received a Shaun Rosen Nurses' Education and Training Scholarship to attend The Haematology Nurses & Healthcare Professionals Group (HNHCP) Educational Conference in Zurich, Switzerland in February this year. The conference was nursing-specific and offered a range of educational programs aimed at developing nurses' skills and knowledge in managing some of the common, but very challenging, issues such as

informed patient consent, haemophilia, thrombotic thrombocytopenic purpura, neutropenic sepsis, tumour-lysis syndrome, patient transfer of care in ICU and central venous access devices.

Other recently awarded Shaun Rosen Scholarship recipients include Ide Irwin and Mary Hayes who will each receive funding to attend the annual Blood conference in Perth from 20-23 October.

## Annabel attends **conference in Spain**



understanding of hematopoietic cell transplantations and cellular therapies at the 4th European Bone Marrow Transplant conference held in Spain from 6th to the 8th of September.

The trip was made possible by funds from the Shaun Rosen Scholarship which was established with a \$25,000 donation from Shaun Rosen in 2016.

Annabel wrote: Some great insights from European colleagues on various topics including HLA matching, treatments for Myeloma, management of GvHD and CAR T cell therapy. An interesting and informative meeting in a beautiful city.

Bone Marrow Transplant Coordinator, Annabel Horne, was given the opportunity to meet transplant experts from around the globe while advancing her

## Calling all past **nursing scholarship recipients**

We are excited to celebrate Arrow's milestone of funding 100 nursing scholarships and would like to invite past nursing scholarship recipients to attend our 100 reasons to celebrate our nurses special event as our guests. The event will be held from 5.30 - 9.30 pm on 12 October at the 18 Footers in Double Bay.

If you are a past nursing scholarship recipient please email Robyn Flood at [rflood@arrow.org.au](mailto:rflood@arrow.org.au) before 30 September to register your interest.

## Support the work of **ARROW**

**YES..** I would like to become a Member (**\$30**)  **Please send me information on how to leave a gift in my will.**

**YES..** I would like to donate  **\$75**  **\$50**  **\$100**  **Other amount \$** \_\_\_\_\_ Donations of \$2 and over are tax deductible

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PLEASE COMPLETE AND RETURN TO: **ARROW BONE MARROW TRANSPLANT FOUNDATION. 16 Leichhardt Street, DARLINGHURST NSW 2010.**

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