

TRANSPLANT TALK



ISSUE 1.

2020

CEO Report



Richelle Koller, CEO outside of Arrow House

Welcome to the 2020 edition of Arrow's Transplant Talk, and what a year it has been! With COVID-19 impacting so much around the world, it has been a difficult year for charities which have continued to work tirelessly raising funds and awareness for their valuable causes.

Here at Arrow, it is no exception. In this edition we talk about the numerous projects that Arrow has supported over the past year, and how we have also adapted to the ever-changing landscape.

From the frontline: life on a bone marrow transplant ward during COVID-19



Amanda McLaughlin

Amanda McLaughlin is a Clinical Nurse Consultant in the Apheresis Department of Haematology and Bone Marrow Transplant at the Kinghorn Cancer Centre. Amanda's aim is to "make a difference to her patient's day" and she has continued that dedication through her volunteer role as a Board member at Arrow. With over 15 years experience working with bone marrow transplant patients, Amanda has faced many challenging situations, however none like COVID-19.

Here she reflects on the unique situation of COVID-19 and the impact it has had on patients, treatment and nursing staff.

"The impact of COVID-19 has been enormous," says Amanda. "Increased infection risks for patients has seen the implementation of strict infection control procedures; extra testing, self-isolation pre-transplant, closer monitoring of symptoms, and extra cycles of chemotherapy to keep patients in remission. We take every measure to keep patients safe. I am required to undertake a strict health assessment pre-work. Anyone with a fever is sent for testing and required to self-isolate until he or she swabs negative for COVID-19. All meetings are online instead of face-to-face to reduce infection risks. Nursing teams are split into teams A and B to reduce infection risks. We are encouraged to drive rather than take public transport to work to reduce the risk of infection. Reduced socialisation at work with colleagues and a 1.5 metre rule is requested. Reduced socialising with others outside the home may also be requested."

For Amanda, the risk of infection is a very scary prospect. Amanda says: "As a clinical nurse consultant and frontline worker, I was very concerned

Whilst COVID-19 loomed, patients in hospitals across Australia continued to be diagnosed with life threatening illnesses and undergo vital bone marrow transplants. A difficult time for all involved with additional health and safety measures implemented at the hospital, restricted hospital visitation hours, and additional uncertainty for patients during an already uncertain time.

We take our hats off to the patients who have braved their way through treatment during these times, and the heroes of the hospital who have gone above and beyond to take care of their patients.

I personally would also like to thank everyone for their warm welcome since joining the Arrow Bone Marrow Transplant Foundation as CEO in September. Arrow has a terrific community of passionate and dedicated individuals, and I look forward to being a part of growing the charity into the future and continuing the important work of helping bone marrow transplant patients.

about asymptotically being responsible for the spread of COVID-19 inadvertently. I was very concerned for my patient population, colleagues and my family." Another significant challenge has been the shortage of blood products and stem cell donations impacting the availability of bone marrow transplant treatment. "Cells are frozen in a central European location and then transported," explains Amanda. "Couriers are met at the airport rather than hospitals for cell handover to reduce infection risks. It has been a massive logistical challenge."

Despite these challenges, the clinical teams have worked around the clock, ensuring patient care and treatment have remained uninterrupted.

As to what you can do to help? Amanda says it is important that the greater and wider community appreciates the work all those on the frontline are doing and to continue to exercise social distancing precautions. With patients undergoing bone marrow transplants being highly immune deficient, it is important that

Hello's and Goodbye's

After 15 years leading Arrow, our CEO Robyn Flood, has chosen to retire. Robyn has been a fantastic ambassador for Arrow creating and maintaining relationships that are invaluable to Arrow's programs. To have such a calm, capable and committed person at the helm of Arrow has enabled us to set a course of growth and expansion while maintaining our high ethical standards in everything we do. Congratulations Robyn on a fabulous career, enjoy your well-deserved retirement and all the best for the future!



Robyn Flood

We welcome Richelle Koller our new Chief Executive Officer and Company Secretary who has taken over the reigns from Robyn. Richelle comes to Arrow with a wealth of charitable and financial experience and we look forward to Richelle leading the team as we strive to grow and create opportunities for supporting research, education, patients and carers into the future.

We also say goodbye to Gloria Vincent, our Communications Manager. After more than 10 years of creative and innovative communication with the Arrow community, Gloria has chosen to move on to another role. We thank Gloria for her commitment and dedication to the Arrow mission over many years.

all of us in the community are doing our part to ensure we keep patients safe.



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PATIENT SUPPORT



Care, warmth and love

“Care, warmth, and love” are three words that come to mind when young bone marrow transplant recipient Frank Li describes the sponsorship of Arrow’s grocery card initiative by Independent Grocers of Australia (IGA).

And that is exactly what IGA is all about – taking care of locals. With a network of 1,400 independently owned stores across Australia, IGA actively participates in the community, doing whatever it can to help local charities, putting well over \$60 million back into communities across the country. With a generous donation of \$20,000 in grocery cards to Arrow for distribution to bone marrow transplant patients, IGA’s support is greatly valued.

Bright Li, Frank’s father, says that receiving a grocery card from Arrow during the challenges the family faced during his son’s illness was very helpful. He used the card to buy daily food shopping items for the family such as vegetables.

“This support is very important; not only financially but more importantly, mentally,” said Bright. “With this support, we know we are not alone and we are not forgotten. It’s a big challenge for us but we know there is someone caring about us. It has made our life a bit easier. I am sure we will give something back once we can.”



Thanks to the APS Foundation, \$3,000 of petrol cards have been donated to offer vital support to transplant patients struggling to meet the costs of travel during their treatment.

Rosemary says: “Transplant patients and their carers really appreciate assistance in the form of petrol cards. These cards are used by patients from the country or outer urban areas who need to travel distances to get to and from their medical appointments. Patients are always greatly appreciative of this assistance”.

We are so glad to be able to help patients when they need us most!

Travel support for bone marrow transplant patients

For patients undergoing bone marrow transplants the costs associated with travel can be significant.

Rosemary, a social worker on the frontline with patients, explains that “by the time they (patients) get to having a transplant, after a lengthy and usually complex medical history, they have already incurred significant additional travel costs in addition to other expenses”.

Arrow helps relieve this burden by offering petrol cards for patients and their carer for their many journeys to and from their treatment centres.

Tracey Scone Wig Library



Cheryl Edmonds and Roslyn Zahra, The Individual Wig

Arrow’s Tracey Scone Wig Library was established in 2000 and has helped hundreds of patients who have suffered hair loss due to chemotherapy. The loan of a wig has provided patients with a much needed boost to their confidence and self esteem.

As with many programs this year, the Tracey Scone Wig Library was impacted by COVID-19. With the need for additional hygiene and safety measures we chose to

reinvent the way we deliver our wig service, partnering with wig supplier, The Individual Wig at Darlinghurst.

The team at The Individual Wig has kindly looked after our patients, helping to fit and supply them with a brand new wig. Thanks to the financial support of Tour de Cure we have gifted over 50 new wigs to cancer patients since COVID-19 helping patients to feel as much of their normal self as possible during treatment.

Our sincere thanks to the **Tour de Cure** fundraising team which held its Spring lunch in November. Despite the challenges faced during COVID-19 with social distancing requirements, the team delivered an exceptional fundraising event raising an amazing \$1,000,000. We thank them very much for their long term support of the Tracey Scone Wig Library and also give thanks to The Individual Wig for their help during COVID-19 ensuring we kept this important service going.

Gifts of Friendship



Arrow’s Gifts of Friendship program provides comfort and support by visiting patients with life threatening illness in hospital. With COVID-19 limiting patient visitors this year, Colleena Presnell, Kerry Moran and Jenny Joseph from the Gifts of Friendship team established a podcast bringing their visits to patients virtually!

Listen to our podcast series to learn from patients who have experienced a transplant as well as information from doctors, nurses and clinicians and many other interesting stories and tips. Our podcasts are available on most podcast platforms including Spotify and Apple Podcast.

If you are a past patient we would love to hear from you. We welcome news from past patients and would love to share your story and interview you on the Gift of Friendship program. If you are interested please contact Colleena on 0419 424 353 or maxco2@bigpond.com.

Leaving MS behind



Kevin Hendrawan

He's a keen runner, practises one of the oldest surviving Japanese martial arts—Katori Shinto Ryu—and is driven by his curiosity for the immune system.

That drive has gained Kevin Hendrawan—a PhD candidate at St Vincent's Centre for Applied

Medical Research (AMR)—a grant of \$14,000 from the Arrow Foundation Special Grants fund.

Kevin will use his grant to purchase cytokine detection kits. These kits are used in his investigation into how autologous haematopoietic stem cell transplantation (AH SCT) improves clinical outcomes in patients with Multiple Sclerosis (MS), an autoimmune disease of the brain and spinal cord. AH SCT eradicates the patient's defective immune system using high-dose chemotherapy and replaces it by transplanting the patient's own adult bone marrow stem cells. Put simply, it "re-boots" a patient's immune system. "While our immune system is important for eliminating harmful

foreign molecules and/or microbes (like the virus causing COVID-19), it is equally important that it does not attack our own cells and organs," explains Kevin. "This balance is in-part maintained by immune-suppressive cells known as T regulatory cells (or Tregs). In autoimmune diseases, this balance is disturbed due to the impaired function of Tregs, which results in our immune system turning against our own cells."

The cytokine kits donated by Arrow will allow Kevin to quantify cytokine's in a patient's blood following AH SCT. Cytokines are signaling molecules that are secreted by immune cells to coordinate immune responses.

"Following AH SCT, we hypothesise that these inflammatory cytokines are suppressed, which may coincide with an increase in

anti-inflammatory cytokines. This anti-inflammatory shift may allow Tregs to regain their important suppressive functions and contribute to clinical improvement following AH SCT. "I am very thankful that the Arrow Bone Marrow Transplant Foundation was able to support this important and interesting work.

"And the importance cannot be underestimated. Tregs are a possible candidate for future cell therapy which could reduce the need for high-dose chemotherapy, which is not ideal for patients due to the side-effects associated with its toxicity."

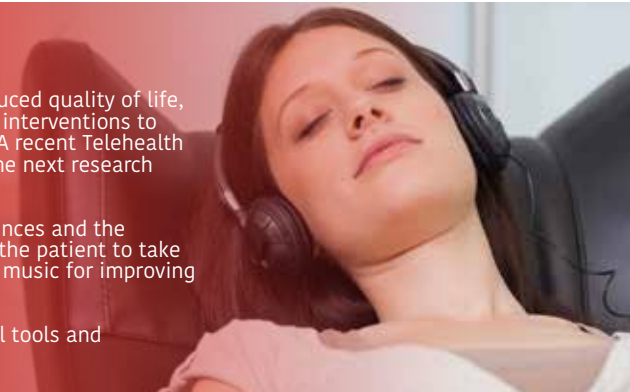
How we would all love to see a treatment that not only reduces the painful side effects of chemotherapy but also sees us leaving multiple sclerosis behind.

Music to patients' ears

It is well known that significant numbers of post bone marrow transplants patients have reduced quality of life, such as tiredness from anxiety/stress, depression and insomnia. A number of non-drug based interventions to improve transplant patient's well-being has been evaluated with varying degrees of success. A recent Telehealth trial on exercise and mindfulness training has seen significantly positive results, leading to the next research project to be conducted at St Vincent's Hospital, Sydney, as funded by Arrow.

Music listening is universal, adaptable to suit all ages, cultural backgrounds, personal preferences and the emotional status of individuals. Selection and use of different types of music also empowers the patient to take back control of their life. The aim of this planned pilot study is to identify the key features of music for improving the wellbeing of bone marrow transplant patients.

Arrow has made a grant of \$14,600 to this Musical Therapy clinical study to purchase essential tools and equipment. We look forward to updating you on the results of the study.



Haematopoietic Stem Cell Transplant Research



Arrow recently made a grant of \$70,630 to Dr Tim Molloy, an outstanding researcher, who is working with Professor David Ma at the Blood, Stem Cell and Cancer Research Program on a project that aims to improve haematopoietic stem cell transplant (HSCT).

The project uses the latest technology of next generation sequencing to identify and develop genetic biomarkers with the goal of the better selection of patients for HSCT to improve post-transplant outcomes. HSCT is a standard-of-care treatment for a range of diseases including

haematological cancers, leukaemia, myelodysplasia, myeloma and lymphoma as well as autoimmune diseases such as severe systemic sclerosis.

This important contribution to research was only made possible thanks to the generosity of **Liverpool Catholic Club** and the **Orgill Family Foundation** which donated \$60,000 and \$10,000 respectively.

Our partners' continued support enables us to keep on funding medical research that will one day change lives.

Temperature checks on the rise

In this current COVID-19 environment, we have all become very familiar with regular temperature checks, however for bone marrow transplant patients it is particularly essential.

Patients undergoing transplants and cancer treatment are immune compromised and particularly susceptible to infection. A spike in temperature can be a sign of infection, therefore regular temperature checks are essential.

Amanda McLaughlin, Clinical Nurse Consultant at the Kinghorn Cancer Centre explains: "Temperature management is a significant component of hospital care –

especially for our haematology/oncology patients".

To ensure there is enough equipment on hand, Arrow has made a grant of \$2,500 to the Kinghorn Cancer Centre for the purchase of 15 state-of-the-art ThermoScan thermometers. The grant was made possible by the generous support of **The Chestnut Tree Foundation in memory of Sylvia Hartog**.

Amanda says: "With the grant from Arrow and the Hartog family in memory of Sylvia, our front line nursing staff can undertake appropriate, quick and easy assessments of all our patients."



