

# Transplant Voice

ISSUE 02  
2012

## Arrow supporters raise \$17,827 in the 2012 City2Surf!



Decked out in 'Walk 4 Whit' t-shirts and caps, twenty of Whitney Lane's closest friends and family braved the cold and windy conditions at this year's City2Surf to raise a huge \$14,487 for Arrow in Whitney's memory.

Whitney Lane was diagnosed with Aplastic Anaemia in 2004 when she was 11 years old, and in 2010 developed Paroxysmal Nocturnal Haemoglobinuria (PNH), a rare disease of the bone marrow. The fatiguing symptoms of Whitney's condition didn't stop her from actively collecting over 20,000 signatures in a petition, requesting that the Federal Government include Soliris®, the drug required for the treatment of

PNH, on the Pharmaceutical Benefits Scheme (PBS).

At just 19 years of age, Whitney successfully lobbied the Government and showed Australian's suffering from rare and life-threatening illnesses that it is possible to access the same life-saving treatments as those suffering from more common conditions. Whitney underwent a bone marrow transplant on the 18th of April this year, and due to complications with the process, very sadly passed away in May.

Ellena Winstanley, the 'Walk 4 Whit' team leader, said: "It has been an absolute pleasure to assemble the team and get behind Arrow. We are all incredibly fond of Whitney and very conscious of all that she fought for throughout her life in relation to various forms of blood diseases. When this opportunity presented itself it was clear that raising funds for Arrow would be a great way to assist others in Whit's position, and also to support the research of blood related diseases. Masses of people began to join our cause and got us far beyond anyone's expectations. To witness friends and family coming together so generously with their time and money was an incredibly heartwarming experience, and I truly hope that our achievement will assist."

We thank the 'Walk 4 Whit' team for their tremendous effort and would also like to express our sincere gratitude to 'Team Endo' for the \$1940 raised by the team, and to individual runner, Dan Kundi, who raised \$1400, bringing the total for this year's City2Surf fundraiser to a massive \$17,827!

## Extreme fundraising: Ross Conwell tackles Mt Kilimanjaro in search of a cure

With countless ways to raise funds for medical research, climbing the tallest freestanding mountain in the world, Mount Kilimanjaro (the "Mountain of Greatness"), may not be the first idea that comes to mind. For Ross Conwell, the extreme nature of the challenge is a fitting tribute to the courage and strength patients show throughout their battle with leukaemia and, in particular, the determination that his cousin's son, Matthew Rennie, displayed during his battle with illness.

In the lead up to his fundraising climb on the 30th September, Ross is running between 50-60km per week, and swimming between 2-3km per session twice a week; he also climbs 188 stairs at the Woronora Bridge on Saturdays and does regular weights sessions at the gym.

Ross' commitment is driven by his aim to raise thousands of dollars towards Arrow's 'Light the Night Resources Grant' which examines how genes called microRNAs may promote cell growth and inhibit maturation of bone marrow stem cells, leading to the development of acute leukaemia.



Please show your support for Ross' climb by visiting his fundraising webpage: [http://www.everydayhero.com.au/ross\\_conwell](http://www.everydayhero.com.au/ross_conwell)  
Regular updates on Ross' climb will be posted on the Arrow Facebook page: <http://www.facebook.com/ArrowBoneMarrowTransplantFoundation>  
We send Ross our best wishes and thanks as he embarks on his own test of courage.

## donations in memoriam

We gratefully acknowledge donations received in memory of:

- Katherine Robertson
- Whitney Lane
- Jan Sparks
- Matthew Rennie
- David Cresswell

## 2012 events

**Light the Night charity benefit concert**  
Monday 22nd October, 2012

**Hawkesbury Canoe Classic**  
Saturday 27th October, 2012

**Arrow AGM**  
Friday, 7th December, 2012

**Arrow's 25th Anniversary Cocktail Party**  
November 2012 (Date and venue to be announced)

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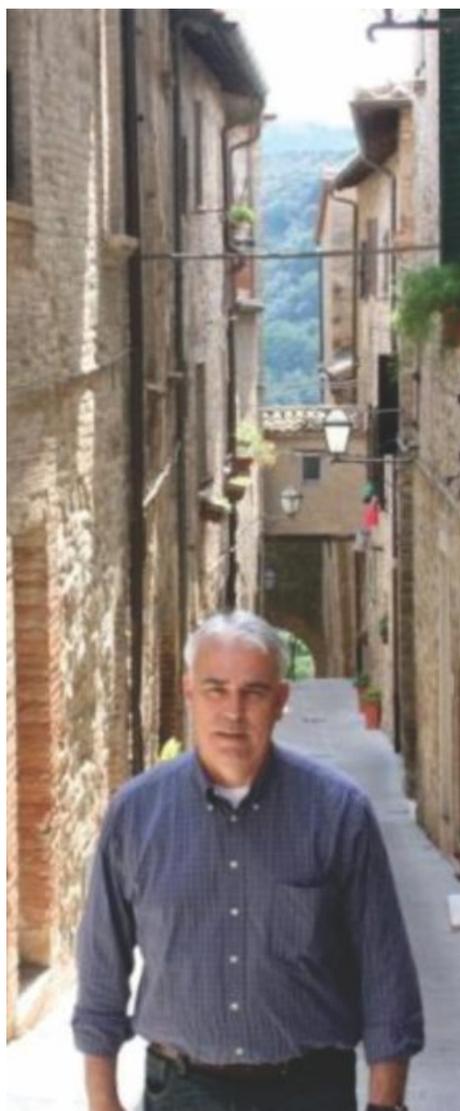
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- Supporting our nurses
- Seeking honorary ambassadors
- Become a monthly donor
- Include a charity week  
Charity greeting cards are now available

Story ideas & photos are welcome.  
Please contact Gloria Vincent:  
[gvincent@arrow.org.au](mailto:gvincent@arrow.org.au)  
or phone (02) 8382 2696.



John Fitzsimon

# A letter from Rome

By John Fitzsimon.

Just over 37 years ago I learned about leukaemia. The hard way. I was a 17 year old schoolboy with no experience of illness or accidents, nor any pointy medical instruments beyond the occasional dentist needle and drill! At that time my main thoughts were on what I might do once I finished high school at the end of the year.

All that changed one afternoon in June 1975 after a trip to the local GP in my home town of Leeton, NSW, following an extended bout of tiredness. A roller coaster ride started the same evening and continued over the next few months, as the staff of St Vincent's in Sydney and my parents, brothers and sisters joined battle with me to defeat what I later learned was a particularly tough, acute version of the disease. Our extended family; school mates and teachers present and past; and our home town friends and neighbours all provided support in many ways. I encountered in those weeks more pointy medical instruments than I could keep count of....

This was at a time when the odds of survival for my type of leukaemia were... well, pretty low in the short term and not much more than zero after that. I knew I was in a tight spot, but it never came into my head that I wouldn't beat it. I suppose I had the advantage of a teenager's sense of invincibility, and an unbounded optimism that has served me all my life. I had the utmost faith that Professor James Biggs and his team of doctors and the wonderful nurses and nurses aides who watched over me in St Vincent's could do anything. But I also knew that much of the treatment I was experiencing was experimental, and that it would contribute to the medical research of the day into the disease.

The treatment was drastic - with plenty of bizarre side effects that came and went as the treatment was modified or new treatments were added to combat them - but the drugs and the blood transfusions from my sisters, together with the fantastic care offered by St Vincent's Hospital to

me and to my family, got me through. Like all parents in their situation mine suffered terribly at the time and I believe that the comfort the doctors and nursing staff gave them was just as important as the treatment they gave me. I went into remission in October that year, completed my schooling soon after, and by early the next year had matriculated to all the Universities I had applied for.

As far as I was concerned, James Biggs and his team could in fact do anything! The team at St Vincent's Hospital, and then in Canberra under Dr. Pembrey while I studied at ANU, continued my treatment through the rest of the '70s ensuring that my remission became permanent. Since then I have worked as an Australian and international public servant in many countries, appreciating every day - no matter the challenge or set back - grateful for the investments in medical science and patient care that helped me weather the challenge thrown at me that winter of '75. Today I work for the United Nations in their specialized agency for food and agriculture in Rome, Italy.

I have spent much of my working life outside Australia, giving to leukaemia charities in other parts of the world when I occasionally come across them. I knew from my own and others' experience, and hearing about some of the scientific advances made in tackling this family of diseases, the value of continually pursuing medical research. I also knew the vital importance of promoting patient and family care and mental strength, and of helping them economically to fight the disease together. How wonderful it was for me when I recently came across the Arrow Bone Marrow Transplant Foundation, learned through its website about its record of supporting these efforts back home in Australia, and became a supporter to its cause. The same cause that - all those years ago - others had made their own, and by doing so had helped save me.



## So much more research is necessary to overcome this disease' writes Professor James Biggs

I was delighted to read John's letter and to learn about the significant contributions he has made and continues to make to society since those very difficult days at St Vincents' Hospital when he underwent chemotherapy for Acute Myeloblastic Leukaemia. In those days remissions could be achieved, but virtually all patients relapsed and subsequently died.

John was one of the lucky few cured of the disease!!

Because of these poor outcomes, we commenced the Bone Marrow Transplant programme. Early patients were treated when

they had advanced disease and none had long term cures. In 1981, we commenced transplanting patients in first remission and 50 per cent achieved long term cures, indeed, the first such patient is still alive 31 years later.

Although there have been further improvements in drug therapy and transplantation, we are still quite a long way from 100 per cent long term survival or cure in severe forms of acute leukaemia. A better understanding of the molecular changes responsible for the disease may make long term remissions possible without transplantation. So much more research is necessary to overcome this disease.



Professor James Biggs



## Support the 36th annual Hawkesbury Canoe Classic (HCC)

The Hawkesbury Canoe Classic Association and Arrow have been a formidable team in raising funds for the fight against blood related cancers for many years, but this year that bond will have greater significance when Kent Heazlett, HCC President, and Mark O'Hara, Arrow Vice Chairman, join forces to take on the Classic together, paddling a Mirage 730 double sea kayak.

This year will be Kent's 20th Classic and Mark is aiming for his 10th finish in the year that marks the tenth anniversary of his friend, Greg Neate's, passing after his courageous battle with leukaemia; so there is no shortage of experience in taking on this challenge.

Kent and Mark will be hoping to complete the 111km overnight race in around 11 hours. Their preparation for the race is well underway and involves many hours on the water and in the gym. They are also aiming at maximising their fundraising this year so if you would like to help Kent and Mark in their endeavours please visit: [www.canoeclassic.asn.au](http://www.canoeclassic.asn.au) then click 'sponsor a paddler' and enter the name of the paddler you wish to sponsor.

The HCC, which has raised close to \$3m for Arrow since 1994, will be held on the 27th October this year. Find out more at: [www.canoeclassic.asn.au](http://www.canoeclassic.asn.au)



Kent Heazlett and Mark O'Hara

# LTN'12

LIGHT THE NIGHT

## CHARITY BENEFIT CONCERT 2012

Join us for an enchanting evening of live performances at this year's Light the Night charity benefit concert to be held at 7pm on Monday 22nd October, 2012; at the City Recital Hall Angel Place, Sydney.

Funds raised towards the Light the Night Research Grant will directly support a promising 'Gene Control in Acute Leukaemia' project being undertaken by St Vincent's Hospital Sydney's Haematology Research team. An exciting line up of performers is soon to be announced so follow Light the Night on Facebook or join their mailing list to stay up to date. Tickets are now on sale and can be purchased at: [www.lightthenight.com.au](http://www.lightthenight.com.au)

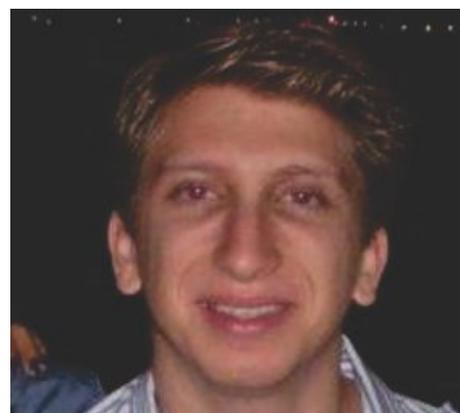
# LTN

## New Arrow / HCC PhD scholarship recipient, Dario Gerace, uses bone marrow stem cell therapy for Type 1 diabetes

Dario Gerace, a PhD student at the University of Technology, Sydney, has been awarded the 2012 Arrow/HCC PhD student scholarship for his project as outlined below:

Pancreatic  $\beta$ -cells are destroyed by an autoimmune process in Type 1 diabetes (T1D), so a replacement cell therapy which is either resistant to recurrent autoimmune reactions, or able to modulate the immune system to induce tolerance, is required.

We have already shown that we can successfully engineer artificial beta cells from hepatocytes and liver cell lines; so this study aims to determine the possibility of engineering glucose-responsive insulin-secreting cells from adult bone marrow derived mesenchymal stem cells (BMSC). This would provide proof-of-principle to formulate a Phase I safety trial using BMSC therapy for T1D.



Dario Gerace

## Professor David Ma presents at the 9th International Donor Registry Conference (IDRC)

The 9th International Donor Registry Conference (IDRC) themed 'HPC transplantation in the next decade: bringing experience to embrace the future,' was held in Sydney in May, 2012, and hosted by the Australian Bone Marrow Donor Registry (ABMDR) and the World Marrow Donor Association (WMDA). Among the prominent speakers was Arrow Director, Professor David Ma, who made a significant contribution to the conference through his presentation on Induced Pluripotent stem cells (iPSCs).

Outlined below is a summary of the presentation that Professor Ma's made at the conference which provided an opportunity for discussion and an exchange of ideas between

professionals working in clinical programs at hospitals, clinical and research laboratories, donor registries and cord blood banks.

### iPS cells: Potentials and pitfalls in regenerative medicine

By Professor David Ma.

Induced Pluripotent stem cells (iPSCs) are embryonic-like stem cells derived from genetically reprogrammed adult cells and are capable of differentiating into the three germ line lineages. iPSCs can be generated from any individual allowing for the possibility of manufacturing customized stem cells and their cell products.

This approach avoids the ethical and technical issues associated with the generation of human embryonic stem cells. A unique feature of this approach is that iPSCs can be created from patients with specific diseases, such as Fanconi Syndrome, potentially providing a renewable resource for pinpointing the pathways involved in disease development, drug screening and testing as well as genetic correction of genetic disorders. However, concerns regarding genetic and epigenetic instability of iPSCs, the challenges of producing functional tissue specific cells and safety are some of the issues that will determine its role in regenerative medicine.

