# UR THE CURE

**Education - Awareness - More Lifesaving Matches** 

## **Workplace Education**

Host a "Superhero Stem Cell" day



"Improving ethnic diversity on the Australian & world-wide stem cell registries".





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### **Education - Awareness - More Lifesaving Matches**

### ABOUT US

UR the Cure was established by Pamela Bousejean, an Australian woman who was diagnosed with a blood cancer when she was 24

years old. Pamela needed to find a stem cell match to have a lifesaving stem cell transplant (also known as a bone marrow transplant) as her last chance for a cure. A blood cancer patient is more likely to find their stem cell match with someone who has the same ethnic background/heritage. Unfortunately, there are not enough people from diverse backgrounds registered as potential stem cell donors on the world-wide bone marrow donor registries for doctors to search. Pamela struggled to find her match because of her Lebanese background, her family became so desperate they launched a Facebook campaign which saw the story shared through the media worldwide and she even met the President of Lebanon during this time. Still without a match, Pamela was lucky enough to try "plan b" and eventually had a successful cord-blood transplant which has made her cancer-free!





Unfortunately, this story of a desperate search is not uncommon and Pamela continued to hear stories of patients struggling to find their match due to their ethnicity, she was surprised to find there was not one organisation in Australia actively promoting the cause so she established UR the Cure. Through education and awareness, our mission is to increase the numbers and diversity of donors registered on the Australian Bone Marrow Donor Registry (ABMDR) to find more lifesaving matches for patients in need. Everyone should have the same chance for a cure, no matter what their heritage!

The cure to some blood cancers is in your body! You just need to join the bone marrow donor registry to be searched and matched with a patient in need. You are the "UR" in the "Cure"!

### WHY GET INVOLVED

Australia is a multicultural country and this issue affects many Australians. Workplaces can help spread this important message to save lives and also improve their "employer" and

company brand by showing it embraces diversity, promotes inclusiveness and celebrates our multicultural society!

Your workplace may have been specifically selected because of its diverse workforce, we believe the workplace is a great place for people to learn about the cause as people are already in a setting where they can be engaged and ready to hear the educational messages. The topic can initially seem complex, so we find running education campaigns throughout the community is an effective way to educate people about the cause.

**Promote a happy and more engaged workplace** – according to a Business News article, "70% of Australian workers are willing to accept less pay to work for a company whose values are aligned with their own...and often this translates as work practices that support corporate and community responsibility". You can promote a happy and more engaged workforce and save lives at the same time!

## Your workplace can help save lives!

A simple morning tea or a 15 minute meeting is all it takes - A little effort for a big outcome!

### WHO ARE WE

UR the Cure educates people about the Australian Bone Marrow Donor Registry (ABMDR) and encourages people to join as potential stem cell donors to help find lifesaving stem cell matches for blood cancer patients.

### HOW YOU CAN HELP

Educate your workplace through a "Superhero" themed awareness day, morning tea or a short 15 minute meeting with your team. We particularly encourage those with an ethnic or indigenous heritage to join the donor registry.

# WHY IS ETHNICITY IMPORTANT?

A patient is more likely to find their lifesaving stem cell match with someone who shares a similar heritage to them. Unfortunately the different ethnic groups are grossly under-represented on the ABMDR which means patients with any sort of ethnic heritage (Italian, Asian, Middle Eastern & more) will struggle to find their lifesaving match.



### WE MAKE IT EASY FOR YOU

Hosting a "Superhero Stem Cell Day" at your workplace is easy and fun! We will provide all the resources needed to educate your workplace including a short and inspirational video. To register visit:

www.urthecure.com.au/superhero-stem-cell-day



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# Australian patients are struggling to find their lifesaving stem cell match

There is very little awareness about the Australian Bone Marrow Donor Registry (ABMDR) which means patients searching for their stem cell match go to desperate measures to educate their networks about the importance of joining the ABMDR



Tania is from Adelaide and was diagnosed with Acute Myeloid Leukaemia in July 2016. Tania can no longer undertake chemotherapy as a form of treatment and needs a stem cell transplant as her chance for a cure. Due to her Southern European heritage, Tania has been struggling to find her stem cell match. Tania has launched a Facebook campaign, "Find Tan A Donor" and her story has appeared in newspaper articles and on Channel 10's Television program, "The Project"

Kate was diagnosed with Acute Myeloid Leukaemia in July 2016 and unfortunately passed away in August 2017, leaving behind her young family. She was unable to find a matched stem-cell donor due to her Hungarian heritage. Kate was passionate about raising awareness of the ABMDR, running a Facebook campaign while going through treatment and sharing her story through the media. Rest in peace Kate.





Jake is a young boy from Perth. He has a rare form of blood cancer called Chronic Myeloid Leukaemia. He was diagnosed in July 2013 and needs a stem cell transplant as his chance for a cure. Due to his Samoan heritage, Jake has been struggling to find his stem cell match. Jake's Mum, Renee has been campaigning for years through the "Jake's Quest For A Cure" Facebook campaign. They have travelled to New Zealand to engage with different organisations over there and have also been involved in advertising campaigns.

"Improving ethnic diversity on the Australian & world-wide stem cell registries".





# It's easy to host a Superhero Stem Cell Day!

### > CHOOSE A DATE

Pick a date and how you'd like to run it - a morning/afternoon tea? During a team meeting? Or simply deliver the information throughout your organisation.

### >>> PROMOTE THROUGHOUT YOUR WORKPLACE

Make the resources and information available in the lead up to the day (tea room, emails, posters). Make sure the staff know the date and what to do - dress up in theme and bring a multicultural or superhero themed plate of food to share.

### >>> RUN THE SUPERHERO THEMED DAY

Enjoy the day whilst taking the opportunity to learn about the cause! Take 10 minutes to watch the inspirational video and you can even choose to have special guest speakers to address the team (where possible the founder of UR the Cure, representatives from the bone marrow donor registry). You can add a fundraising component to the day and raise funds for UR the Cure. For example, staff can bring a gold coin donation on the day.

# PROVIDE ACTION CARDS & ENCOURAGE PEOPLE TO BOOK AN APPOINTMENT

Hand out the "action cards" for people to fill in and encourage people to book their appointment to join the bone marrow donor registry. It can be done on the spot using their smart phone via the website listed on the action card or they can take away the information to think about it.

### >>>> AFTER THE DAY SEND OUT REMINDERS

In the following weeks, be sure to send out reminders to the team to book their appointment.

We can provide you with everything you need to host a day including a free resource kit! We understand each workplace is different and the above format may not suit certain environments, we can work with you to adapt and tailor make any resources to run an education campaign for your staff and/or customers. Your "day" can be as small or large as you like it to be, the most important thing is the message is being spread!

If you wish to host a Superhero Stem Cell Day, please fill in your details at www.urthecure.com.au/superhero-stem-cell-day

# "Yes - we want to host a Superhero Stem Cell Day!"

Simply fill in the online webform & we'll send everything you need

www.urthecure.com.au/superhero-stem-cell-day



### FREE Ready to Cure Resource kit

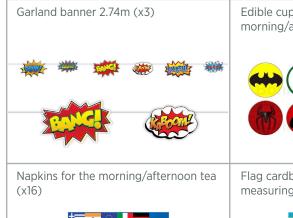
Contains a short and inspirational video which explains everything you need to know about being a stem cell donor. Plus resources, information sheets, posters and more to print and distribute throughout your organisation.

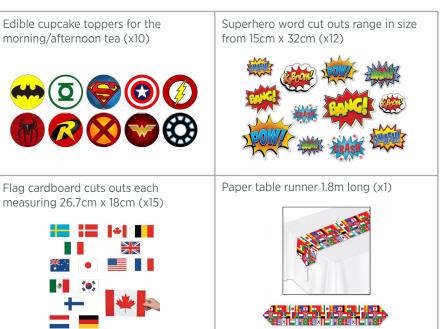




### Superhero and Multicultural themed decorations

Make your day fun and decorate your work place! For a \$65 donation we will send you a pack of decorative items to use on the day. To reduce admin costs, UR the Cure does not actively fundraise and instead treats each request for a Superhero Stem Cell day like a standard "cost for a product" transaction. The \$65 donation covers the purchase and delivery of the pack so you know exactly where your donation money is going! If you're planning to incorporate a fundraising component to your day where you anticipate \$65 or more will be raised, then the \$65 donation is not required. Visit www.urthecure.com.au/dollar-donations





# Save a life - Join the Blood Stem Cell **Donor Registry!**

#### WHAT IS THE AUSTRALIAN BONE MARROW REGISTRY & WHY IS IT IMPORTANT?

- Many people who have a blood cancer or other type of blood disorder rely on having a bone marrow transplant, also known as a stem cell transplant as their chance for a cure. This means they need to find a stem cell match.
- The Australian Bone Marrow Donor Registry (ABMDR/stem cell registry) is a register that people • It's difficult because 81% of people on the ABMDR voluntarily join, so doctors can search for lifesaving stem cell matches for cancer patients.

70% of patients searching for a match will not find one in their family.

They rely on finding a match on the bone marrow registry.

• Only 30% of patients find their match with a family member, the other 70% rely on finding their match on the Australian and worldwide bone stem cell registries.



#### WHY IS MATCHING & ETHNICITY **IMPORTANT?**

- A patient is more likely to find their match with someone who shares a similar ethnic or indigenous heritage as them.
- It is extremely difficult for a patient with an ethnic or indigenous heritage find their lifesaving match.
- are of North West European background and the rest of the ethnic groups are split across tiny percentages.

Percentage of ethnic backgrounds represented on the Australian Bone Marrow Donor Registry

0.5% ABORIGINAL

0.6% MIDDLE EASTERN

0.7% UNKNOWN

**1.3% MIXED** 

**1.8% JEWISH** 

**2.3% ASIAN** 

3.3% AFRICAN

**3.8% SOUTH EUROPEAN** 

4.9% PACIFIC ISLANDER

**80.8% NORTH CAUCASIAN** 

"Improving ethnic diversity on the Australian & world-wide stem cell registries"



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### HOW TO JOIN THE AUSTRALIAN BONE MARROW DONOR REGISTRY

Joining is easy & free - simply swab your cheek & your saliva sample will be tested & added to The Registry!

- 1. Order your cheek swab kit online: www.urthecure.com.au/swab
- **2. Once your kit arrives in the mail, swab your cheek**. Fill in the forms & mail it back to The Registry

#### We need people to join who are:

- Aged between 18 to 30 (up to 35 is OK)
- Have a culturally diverse background
- Males are ideal (any background is OK)
- Females with a culturally diverse background

## HOW OFTEN WILL YOU BE SOMEONE'S MATCH?

• Only 1 in 1500 Australians are a match in any given year. Although the chance of being matched is low, by simply joining gives hope to many patients.



- You are not obligated to donate your stem cells when you are contacted. However once the patient receives their high dose chemotherapy, this is the "point of no return" as the patient would not survive without receiving the stem cells.
- You need to be prepared to show a level of commitment when you join as it's unfair for patients to receive false hope.

## WHAT HAPPENS IF YOU ARE SOMEONE'S MATCH

- Donating your stem cells is made easy these days and is not as scary as it sounds.
- Stem cells can usually be taken straight from the blood stream, much like in a blood donation.
- A small daily injection is given 4 days prior to the stem cell collection day. It's safe and harmless and allows stem cells to flow through the blood stream.
- On the stem cell collection day, the non-surgical procedure takes 3-4 hours and you can often watch TV or read a book during it and return to normal activities afterwards.
- For more information about what's involved during the donation process please visit the website below.



A donor in the middle of donating his stem cells.

Photo courtesy of Gift of Life.

THE CURE TO SOME BLOOD CANCERS IS IN YOUR BODY!
YOU JUST NEED TO JOIN THE REGISTRY TO BE SEARCHED
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### WE ALL WANT TO HELP! WHY DON'T YOU ENCOURAGE EVERYONE TO JOIN REGARDLESS OF ETHNICITY?

We often get asked why we focus so heavily on the "ethnic diversity" message. Everyone wants to help which is amazing, in an ideal world we could just have anyone and everyone join! We see these education programs as an opportunity to increase awareness on the cause amongst the entire public regardless of their cultural heritage, but we are aiming to target people with culturally diverse backgrounds to take action and join the Australian Bone Marrow Donor Registry (ABMDR).

Other than the fact that a patient is more likely to find their stem cell match with someone who shares a similar ethnic or indigenous background to them, and we know that these groups are under-represented on the ABMDR meaning these patients are often the ones who struggle to find their match, there are a couple other reasons why we heavily focus on diversifying the ABMDR.

Did you know the science says that if we were to DOUBLE the number of people currently on the ABMDR as it is, it would only increase the chances



of overall matching by 5%....and that's because it's heavily skewed to representing people with a North Caucasian background. On top of this with limited funding and a limited number of samples that can be collected each year, people joining who have a North Caucasian background essentially



uses up funding to test a sample type that we already have plenty of and doesn't necessarily increase overall matching. So it becomes even more important to make sure the "right" type of samples are collected which are those with any story of ethnic or indigenous heritage!

"Improving ethnic diversity on the Australian & world-wide stem cell registries"



## A BIG THANKS TO OUR SPONSORS & SUPPORTERS











- Telstra Store Leopold
- Telstra Store Waurn Ponds
- Telstra Store Geelong CBD
- Telstra Business Centre Geelong







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### CONTACT US

For any questions or further information, please do not hesitate to contact us.



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