



## UR THE CURE

Education – Awareness – More lifesaving matches

*Improving ethnic diversity on the Australian and worldwide stem cell registries*

### UR the Cure - Key Achievements

2015 to 2023

#### Milestones for UR the Cure charity

**2012:** Pamela's Facebook search campaign goes public and she meets with the President of Lebanon (2012)

**End of 2012:** Pamela is declared "cancer-free"

**2015:** UR the Cure is founded by Pamela and officially registered as a charity with the Australian Charities and Not-For-Profits Commission

**2016:** UR the Cure is listed on the Australian Bone Marrow Donor Registry (ABMDR) website as a valuable resource

**2019:** UR the Cure becomes an official partner of the ABMDR and their Strength to Give cheek swab program

**2023:** UR the Cure changes its legal structure from an Incorporated Association to a Company Limited by Guarantee; forming a Board of Directors and acquiring DGR status (deductible gift receipt).

**2024:** UR the Cure gains accreditation and continues the official partnership with the ABMDR

#### Recruitment drives and recruitment related activities

Official numbers of how many people have joined through UR the Cure drives and activities only began to be reported on in September 2019 with the introduction of cheek swab testing and our partnership with Strength to Give. Prior to this, recruitment was done only through Red Cross Lifeblood and there was no official means of reporting possible. The below data relates to official reporting numbers, however actual numbers since UR the Cure was incorporated is expected to be much higher.

- Supported, facilitated and ran a number of donor drives and recruitment related activities around Australia. Some key events and activities listed below:
  - Middle Eastern recruitment drive via blood samples, resulting in 30 registrations (2014)
  - Educational presentations at community groups including Saint Bernard's church, Our Lady of Lebanon church Youth Group, and Saint George church and youth group in Melbourne, which resulted in 30 known registrations (2015 to 2016)
  - Education and presentation at the TAC - Transport Accident Commission resulting in over 60 registrations (2017)
  - Deakin University U Belong Event (2019)
  - "Superhero Stem Cell Day" at the Alfred Hospital (2019)
  - Sacred Heart College education day (2019)
  - Geelong Cricket Association donor drive (2020)
  - Perth Baseball Club donor drive (2020)
  - Information and recruitment stalls at a number of different events including Light the Night Leukaemia Foundation, Perth Diwali festival and more
  - "Swab to Save" donor drive event at Telstra Store Waurin Ponds (2020)
  - Donor drive events with the Egyptian Orthodox community in Sydney (2020)
  - Donor drive event with the Manly Surf Lifesaving Club in Sydney (2020)
- Social media campaigns and online donor recruitment with a focus on key educational messages and how to join the Australian Bone Marrow Donor Registry (2015 to current)
- As a donor recruitment partner of Strength to Give during the cheek swab pilot program, a total of 1,370 cheek swab kits were ordered online and 604 cheek swabs kits were completed at community donor drive events. UR the

Cure was the 2<sup>nd</sup> highest performing partner in relation to the number of people joining the registry, just behind the Leukaemia Foundation. UR the Cure was the only partner during the pilot program to deliver a matched donor (September 2019 to May 2021, with a program pause for several months due to government funding issues and the covid-19 pandemic)

- Various other information sharing and education conducted with a number of other workplaces and community groups (2015 to current)

## Resources and program development

- Under 18 contact program developed (2016)
- Ready to Cure resource kit developed (2017)
- Workplace education program developed (2019)
- “Sporty Stem Cells” program developed with the Geelong Cricket Association, to be extended to local football and other sporting groups (April to June 2020)
- Online fundraising store launched (2020)
- Resource kit developed further with a number of different resources created; including educational PowerPoint presentations, newsletter article templates, social media resources, information sheets, posters, training presentation for volunteers and more (2020)

## Educational presentations

- Poster presentation at the Australian Cancer Survivorship Conference, Adelaide (2015)
- Educational presentations at three Barwon South Western Integrated Cancer Service (BSWRICS) consumer forums (2015 to current)
- Educational presentations at a range of fundraisers including the Cancer Council Victoria “Relay for Life”, “Scott No Cancer”, Maronite Youth Group cancer awareness day and a number of Leukaemia Foundation “Light the Night” events (2015 to current)
- Educational presentation at “La Dolce Vita” fundraiser (2018)
- Presentation at Red Cross Lifeblood donor centre in Geelong (2019)
- Presentation at Haematology Society of Australia and New Zealand (2019)
- Presentation at the Donor Research Network meeting in Brisbane, “How to attract culturally diverse donors” (2019)
- Presentation with the Indian Sikh community in Perth, in partnership with Healing International (2021)

## Advocacy Work

- Meetings with MP, Sarah Henderson (Federal Member of Corangamite) and MP Richard Marles (Federal Member for Corio) and other politicians; donor recruitment improvements in Australia discussed and a letter response was subsequently received from the Health Minister of Australia (2015)
- A written submission to the government-funded independent review of the Australian Bone Marrow Transplant Sector, highlighting 6 key recommendations to improve donor recruitment strategies (2017)
  - A survey commissioned by UR the Cure received over 500 responses, providing data, direct experiences, insights and opinions to inform the submission recommendations
  - A written letter received by the Minister of Health, the Hon. Greg Hunt MP in response to the submission
  - The submission has been shared throughout various networks and key stakeholders including at the annual ABMDR national donor coordinators meeting
- Correspondence with the New Zealand government, seeking support in our advocacy work in Australia in response to a New Zealand citizen struggling to find her stem cell match due to her Chinese heritage. We received an official letter response from David Clark the New Zealand Minister of Health (2018)
- Letters sent to 5 key politicians requesting one on one meetings (2018)
- Mass email marketing campaign sent to the 500 survey respondents from the 2017 survey, asking for support to write a letter to their local MPs regarding funding for cheek swab testing in the lead up to the election (2019)
- Conducted a “Save Our Swabs” campaign and ran a petition and survey, with almost 300 people submitting a response with detailed commentary. The survey summary report was provided to the ABMDR to assist their business case, to the Federal Health Minister Greg Hunt, other politicians and key stakeholders. Many of our supporters also contacted their local MPS using the letter template we provided (2020)
- Involved in the feedback panel for the Leukaemia Foundation’s National Strategic Action plan and encouraged the Leukaemia Foundation to advocate for cheek swab testing to help achieve their strategic goals (2020)

- Feedback provided to the INCA Consulting group and ABMDR evaluation report regarding the Strength to Give pilot program for cheek swab donor recruitment (2020)
- Video developed for World Marrow Donor Day urging the world community to support our campaign to introduce cheek swab testing into Australia, shared through the World Marrow Donor Association networks and media (2021)
- Involved in various media stories to shed a spotlight on the issues around Australia's donor pool (see below "media and public relations")
- Social media campaign and education regarding the importance and need for cheek swab testing in Australia (2022)
- UR the Cure's statement of support published on the Australian Bone Marrow Donor Registry website as a peak patient organisation, for the introduction of cheek swab testing (2022)
- In conjunction with @Biffrunner, "The 20-50" campaign launched to raise awareness on the need for cheek swab testing, encouraging the public to sign the petition and write letters to the Federal and State Health Ministers with letter templates provided by UR the Cure made available to download on our website. We also engaged with a number of different organisations calling for their support (2022)
- "The 21<sup>st</sup>-50" campaign launched, with over 6,000 signatures reached on the petition, UR the Cure coordinated volunteers around Australia to hand-deliver the petition to the State and Federal Health Ministers which sparked a series of meetings with various Health Ministers and politicians including with the Assistant Federal Health Minister Ged Kearney, NSW State Health Minister Brad Hazzard, QLD State Assistant Health Minister Julianne Gilbert and staff from Health Minister D'Aths office and more (2022)
- Worked closely with MP Robbie Katter's office who helped advocate for the introduction of cheek swab testing into Australia; assisting with feedback for media releases and government correspondence and providing information (2022)
- Meeting with the Deputy Prime Minister Richard Marles about the need for governments to approve the use of funds for cheek swab testing (2022)
- Presented to the government's Clinical Advisory Group on the need to introduce cheek swab testing and other specific matters regarding how the cheek swab program should be rolled out (2022)
- Various correspondence and letters written and received by the Federal Health Minister and State Health Ministers
- UR the Cure submission -Victorian Parliament Inquiry into increasing the number of registered organ and tissue donors (2023)
- Meeting with South Australian Health Minister Chris Picton to gain South Australia's support in releasing held funds for cheek swab donor recruitment (2023)

## Networking and relationship building

- Meeting held with the President of Lebanon, Michel Sleiman to discuss the potential establishment of a Lebanese bone marrow donor registry (2012)
- Established communications in 2015 with the Australian Bone Marrow Donor Registry (ABMDR) with a key initial meeting setup with the National Executive Officer and the Project Manager. Common goals and future strategies were discussed and UR the Cure has subsequently maintained a strong relationship with the ABMDR, establishing an official partnership (2015 to current)
- Various networking over the years, engaging with other key players and stakeholders has included the CEO and Head of Research and Advocacy at the Leukaemia Foundation, founder of UK based foundation "Team Margot", Project Manager of US based bone marrow donor registry "Gift of Life", CEO and Nurse Manager at the Cancer Council Victoria, CEO of Lymphoma Australia, founder of the Green Button Foundation, various hospitals and bone marrow transplant coordinators, New Zealand Bone Marrow Donor Registry, Federation of Ethnic Communities Councils of Australia and more (2015 to current)
- Development of strong relationships with patients and their family and friends from at least 12 different ethnic communities, the database of these contacts continues to grow (2015 to current)
- Engagement with prominent community leaders such as religious leaders, the President of the Geelong cricket association, Presidents of other key organisations and more. Community leaders are integral in accessing and educating the different community groups (2015 to current)
- Sponsored by Cancer Action Victoria to attend the Victorian Integrated Cancer Service Conference in Melbourne for networking purposes (2019)

## Publications

- Royal College of Pathologists of Australasia ePathway newsletter, "Ethnic diversity is vital to finding the perfect stem cell match" (2015)

- Team Margot foundation website blog post, “UR the Cure; awareness, education and more lifesaving matches” (2015)
- Australian Bone Marrow Donor Registry Annual Report, “UR the Cure; improving ethnic diversity on the Australian and worldwide stem cell registries” (2015)
- Know Pathology Know Healthcare newsletter, “Get on the list to be a lifesaver” (2015)
- Haematology Society of Australia and New Zealand newsletter, “UR the Cure; improving ethnic diversity on the Australian and worldwide stem cell registries”, Volume 9: Issue 1 (2015)
- Royal College of Pathologists of Australasia ePathway newsletter, “Cancer survivor now pitching for a more ethnically diverse bone marrow donor registry to help others find their perfect match” (2017)
- Stratel Group (Telstra Stores in Geelong region) newsletter article, “Swab to save a life” (2019)
- Cotton On Group’s Health and Wellbeing Newsletter article, “Bone Marrow Registry” (2019)
- Information about UR The Cure and stem cell donation published in the FECCA - Federation of Ethnic Communities Councils of Australia E-News publication (2019)
- Barwon Health (Geelong University Hospital) Auricle publication, “A simple cheek swab can save a life” (2020)
- Queensland Health article in The Drift publication, “A simple cheek swab can save a life” (2020)
- Australian Bone Marrow Donor Registry Annual Report, “Partner Stories” (2020)
- Blog post published through the Donor Research Network , “Blood cancer patients are dying waiting for their stem cell match” (2022)

## Awards and recognition

- UR the Cure founder, Pamela Bousejean was nominated for the “Pride of Australia” medal for work done in increasing awareness and number of donors on the Australian Bone Marrow Donor Registry and blood donors at the Australian Red Cross Blood Service (2013)
- Pamela nominated as a baton bearer for the Gold Coast 2018 Commonwealth Games Queen’s Baton Relay (2017)
- Pamela nominated for the Telstra Business Women’s Award (2020)

## Website and social media

- Website developed (2015)
- UR the Cure mobile phone app developed (2015)
- YouTube channel created, showcasing videos developed by UR the Cure including explainer videos, educational and inspirational videos with over 24,000 views (2015)
- Website developed and verified by a health professional and subsequently listed on the ABMDR website as a valuable resource with over 15,000 unique website visitors (2016)
- UR the Cure Facebook page continues to grow and has one of the highest followings in the industry with close to 5000 followers, it has appeared in more than 1.2 million newsfeeds and counting (2012 to now)
- Over 200 Facebook posts and social media advertising campaigns published containing educational messages, stories of patients searching for their match and other content (2012 to now)
- Instagram account created and continuing to grow its base, with 885 followers and counting (2014)
- Engaged with a patient and his family who involved well-known Australian professional footballer Archie Thompson who shared an educational message about UR the Cure to over 37,000 followers (2019)

## Media and Public Relations

- UR the Cure has featured in and directly involved in over 50 media stories in Australia (newspaper, radio, magazines and television) and many more indirectly (2012 to current)
- Engaged in a public relations campaign on all major Australian TV network channels (including interviews in the news and other television programs like The Project, Sunrise and the Today Show), radio, newspaper, online news centres and magazines, as well as international media outlets. This resulted in the Australian Red Cross Blood Service receiving “four times the number of usual phone calls” relating to ABMDR enquiries and appointment bookings (2012)
- Featured on a live television program in Lebanon promoting the need to establish a bone marrow donor registry in Lebanon (2012)
- Several press releases facilitated by UR the Cure on behalf of patients searching for their match resulting in newspaper articles and a major news channel 7 report (2015 to current)
- Geelong Advertiser newspaper article, “Saved – Pamela takes a lead to help others” (2015)



- Geelong Advertiser newspaper article, “Matching story an inspiration” and “Pamela leads campaign, sign up to save lives” (2015)
- Geelong Advertiser newspaper article, “Drive for more ethnic donors – Pamela’s push to save lives” (2015)
- Appeared on Network 10’s “The Project” television program as the only representative organisation for official comment and provided information about stem cell donation, with Pamela appearing in the report and addressing common misconceptions, answering questions and providing information to the 228 comments that appeared on The Project’s Facebook page afterwards which received over 72,000 views and 929 shares (2016)
- Geelong Advertiser newspaper article “Rethink gay donor bans” (2017)
- Geelong Advertiser newspaper article, “Bone Marrow Pleas – Cancer survivor seeks help for national review” (2017)
- “Voice of Charity Australia” Arabic radio interview, recorded and translated as a valuable resource for the Arabic community (2017)
- SBS Arabic radio interview (2017)
- ABC Online article, “Bone marrow transplants: When your heritage leads to a needle-in-haystack search” (2017)
- Channel 10 news report for the introduction of the cheek swab pilot program (2019)
- ABC Online article, “Bone marrow donor registry pleas for more diversity to help save people with cancer” (2019)
- Krock radio interview, promoting the Chuckles for Charity fundraiser and the ABMDR (2019)
- Surf Coast Times press article, promoting the Chuckles for Charity fundraiser and the ABMDR (2019)
- Geelong Advertiser newspaper article, “Laughs stem from Pamela’s cancer battles” - promoting the Chuckles for Charity fundraiser and the ABMDR (2019)
- JOY FM radio interview, promoting cheek swab recruitment to the LGBTQI community (2019)
- ABC 7:30pm report, Melissa Baker’s stem cell transplant (2019)
- Channel 9 Win News report, Roxanne Hodda - World Kindness day promoting UR the Cure (2019)
- 990 4ROAM radio interview, Roxanne Hodda - World Kindness day promoting UR the Cure (2019)
- Engaged with Channel 10 TV show Gogglebox and their social media account to share an educational post about Strength to Give and UR the Cure to over 114,000 followers (2019)
- The Pulse radio interview, promoting UR the Cure and Sporty Stem Cell program with local cricket (2020)
- Central Queensland Today newspaper letter to the editor published (2020)
- Fat & Ginger radio podcast interview (2021)
- The Age newspaper article, “Blood cancer patients at risk as donor body pleads for funds” (2021)
- Surf Coast Times newspaper article, “Bone marrow donor registry in need of signatures for cheek swab program (2021)
- Geelong Advertiser article, “Survivor joins call for registry funds” (2021)
- ABC Radio National broadcast on the call for governments to fund cheek swab testing (2022)
- Channel 10 news report for World Marrow Donor Day calling governments to release the funds to introduce cheek swab testing into Australia (2022)
- Geelong Advertiser article, “Cancer survivor’s call for aussies to get cheeky for donor registry” (2022)
- Geelong Advertiser article, “Cheek swab test victory – Boost for Torquay cancer survivor’s campaign” (2023)
- Channel 7 news report on the launch of online cheek swab availability (2023)

## **Fundraising and Sponsors**

- UR the Cure has secured donations from Highgate Primary school through various bake sales (2015 to now)
- Grill’d Burgers restaurant fundraising through the “local matters” program (2017, 2021 and 2022)
- Victorian Chamber of Commerce and Industry donation through a Casual Friday Charity Donation initiative (2019)
- Chuckles for Charity Comedy Night fundraiser hosted by Locally Grown Funnies (2019)
- Sacred Heart College High School, education day and Year 12’s parting gift donation (2019)
- Ruby and Lea boutique gift store donation for in-store gift wrapping service (2020)
- \$1500 volunteer government grant secured (2020)
- Fundraising activities with Loobylou Candles for World Marrow Donor Day (2020)
- Over \$30,000 raised by Sonny Leaudais and Ben Newton for UR the Cure in memory of Harrison Roufogalis (2022)
- \$4,500 raised by Hannah and Sophie Clarke’s Sydney Marathon fundraiser (2023)
- Sponsors and major supporters include Harwood Andrews, Barwon South Western Regional Cancer Service, Barwon Health, Walters Visual Media, Freckleberry Chocolate Factory, Get Logo’d and Stratel (Geelong Telstra Stores), Loobylou Candles