



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 2020

Milestones for the formation of UR the Cure

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 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

Recruitment drives and 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 there were no official means of reporting. The below data relates to official reporting numbers, however actual numbers since UR the Cure was incorporated is expected to be much higher.

- Middle Eastern recruitment drive, no official reporting but 30 confirmed people joined the donor registry by giving a blood sample at the event (2014)
- Under 18 contact program developed (2016)
- Ready to Cure resource kit program developed (2017)
- Workplace education program developed (2019)
- Online recruitment: Over **1000 people provided their details through the UR the Cure "Order Swab Kit" web page, with 710 people registering to order their kit** with Strength to Give. UR the Cure was the second highest contributing partner for online registrations, just behind the Leukaemia Foundation (Sept 2019 to April 2020)
- Supported, facilitated and ran a number of donor drives and recruitment related activities around Australia (Geelong Cricket Association, Perth Baseball Club, Light the Night event, Deakin University U Belong Event, Sacred Heart College education day, information and recruitment stalls at a number of different events, workplace drives including a "Swab to Save" day at Telstra Store Waurin Ponds and a "Superhero Stem Cell Day" at the Alfred Hospital – subsequently establishing a continued presence at the hospital with UR the Cure resources made available). These activities resulted in **65 confirmed people joining the donor registry** by completing a swab at the donor drive event plus **another 71 unconfirmed people joining** by completing a swab. Note "unconfirmed" relates to people who were at least provided a kit to join, prior to the introduction of the "live drive" kits which were needed to officially track and report registrations (September 2018 to April 2020)
- Cheek swab program paused as the government reviews the Strength to Give project (April to June 2020)
- A large pipeline of opportunities for future drives established with a number of community groups and workplaces including Perth Sikh Games and the Perth Indian community, Brisbane Indian community, Technology One, Victoria Police, Australian Rotary and Rotary Health and many others (April to June 2020)
- "Sporty Stem Cells" program developed with the Geelong Cricket Association, to be extended to local football and other sporting groups (April to June 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 now)
- 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 now)
- Educational presentations at community groups including Saint Bernard’s church, Our Lady of Lebanon church and youth group, and Saint George church and youth group in Melbourne, which resulted in 30 known Australian Bone Marrow Donor Registry (ABMDR) registrations (2015 to 2016)
- Presentation at the Transport Accident Commission resulting in over 60 known ABMDR registrations (2017)
- 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)

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 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 receive 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 them to contact their local MPs 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. We received an official letter response from the Health Minister. Many of our supporters also contacted their local MPS using the letter template we provided (2020)

Networking and relationship building

- Discussions held with the President of Lebanon, Michel Sleiman; face to face discussion regarding the potential establishment of a Lebanese bone marrow donor registry (2012)
- Established communications 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 (2015)
- 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 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)
- Australian Bone Marrow Donor Registry Annual Report, “Partner Stories” (2019)
- 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)
- 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)

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)

Website and social media

- 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 (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, currently with 550 followers (2014)
- Engaged with 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)
- 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

- Engaged in a public relations campaign on all major Australian TV network channels (including news and other television programs like The Project, Sunrise and the Today Show), radio, newspaper, online news centres and magazines. 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)

- Three 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)
- UR the Cure has featured in over 30 direct newspaper and magazine articles in Australia and many more indirect newspaper and online articles (2015 to current)
- Appeared on Network 10's "The Project" television program as the only representative organisation. UR the Cure provided the program with information about the ABMDR 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)
- "Voice of Charity Australia" Arabic radio interview, recorded and translated as a valuable resource for the Arabic community and SBS Arabic radio interview (2017)
- Channel 10 news report for the introduction of cheek swabs (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, 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)
- The Pulse radio interview, promoting UR the Cure and Sporty Stem Cell program with local cricket (2020)

Fundraising and Sponsors

- UR the Cure has secured donations from Highgate Primary school through various bake sales (2015 to now)
- Grill'd restaurant chain through the "local matters" program (2017)
- 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 approved (2020)
- 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)