**DoRN Presentation Notes**

* Introduce self (no medical or research background – my background is in Marketing and HR – lived experience) - story and background of UR the Cure (make emphasis on how hard it was to hear they couldn’t find a match due to ethnicity)
* Powerpoint click – Media
* The extreme lengths we went to campaigning etc to try and reach middle eastern networks. Meeting President
* Powerpoint click – President
* Remission since end of 2012
* Powerpoint click – healthy again
* Recovery –lots of patient stories extreme campaigning/reactive mode
* Powerpoint click – abmdr graph
* ABMDR graph and low representation of different cultural groups
* Ur the cure idea
* Now grown - It became a registered charity in 2015 – all volunteers – official partner of ABMDR/Strength to Give – very exciting as it has just become easier to join through cheek swabs
* 2 parts to what we do - Advocacy Work and Education + Recruitment!
* Powerpoint click: advocacy
* Advocacy: like what I’m doing today, meeting with politicians and other key stakeholders and organisations, wrote a submission to the Australian Bone Marrow Transplant sector review which was supported by a survey of over 500 people
* Powerpoint click – education
* Education - social media, workplace education, we have done work with community groups, schools and universities, running stalls and drives. We also support and empower others to run events, education at their organisations and drives.
* So going to the question “how do you attract donors from a culturally diverse background?”

**Discussion point 1: Back to basics – setting up your organisation with this message/structure etc**

* Powerpoint Click: UR the Cure examples of diversity message
* Setting up organisation to be open and welcoming to those groups
* UR the Cure – written into our mission and all of our communications and simply doing this attracts people from diverse groups – they often contact us and then we use their networks to support them to do drives, education events etc and that’s how we reach those groups (not saying they have to plant it absolutely everywhere but it needs to be somewhere)!
* So for example Is attracting ethnically diverse people written into your strategy and plans?
* Look at your organisation’s people - are your committees and boards representative of people from diverse communities? Diversity needs to be implemented throughout the core of your organisation (simply having a photo of ethnically diverse people in your promo materials is not enough)!
* Powerpoint click: CCV example
* Example of Cancer Council Victoria and their cultural diversity plan –– strong commitment (no need to read screenshot, visit site)
* PowerPoint click: Defining the issue
* Clearly identifying the issue and taking the next step and implementing a plan. Important to identify how many people it affects, but also being transparent about it – reporting it and making it publicly available (this helps to continually educate the public and pushing that same message)
* CCV identifies 22% of cancer diagnosis’ in Victoria are people born in non-english speaking countries
* Lifeblood’s article that was published and authored by some people in this room, “Australia’s ethnic face is changing and so are our blood types”
* At The Registry we know that 850 patients initiate a stem cell search in 2018/2019 year and 321 of those make it to transplant, as reported in the Annual Report. And just recently I have finally got my hands on data about the ethnic break-down so I don’t have a slide for that - but 45% of those patients are North Caucasian (384 people), 28% have a culturally diverse background (234 people), and 27% unknown (so potentially more than 28% are diverse if we consider there’d be some in that unknown category.
* PowerPoint click: Strength to Give translated pages example
* Eg of Strength to Give drop down box online to translate pages
* Ensure you have mechanisms to simply identify people you are interacting with who have a culturally diverse background (we ask this question on the form when people order their kit) – for example at the blood service, simply adding a question onto the blood donor form asking them what their cultural background is a good start and an opportunity to educate every person coming through the blood donor centres – word of mouth
* We need to look at the people we are servicing and who we are trying to attract – we are trying to educate the general public and specifically members of the public with a diverse background – we need to involve these people in our committees and boards to help shape our activities. There’s no point trying to reach them if we don’t learn from them and involve them at a higher level!
* A lot of the services are very medical and research based, and of course they have to be to deliver the service! But this also generally means you are only getting a narrow view point when you only have medical or research background people on your committees and in key areas of your organisation. Utilising consumer representatives is very powerful
* UR the Cure is set up this way – we are representative of patients and the public, everyone who contacts us basically has had an experience so we have learnt a lot by simply listening to them and their experiences of joining the registry (ie – the survey we did of over 500 people)
* To make a point here on the power of social media and its ability to connect with people
  + UR the Cure always has the same consistent messages, it’s built into everything we do, the culturally diverse message is strong – we don’t have a radical amount of followers (almost 5000) but built contacts and networks in the right groups so when cheek swabs was announced we were able to very quickly and easily have over 600 people order their kits to join The Registry with about a 60/40 split of diversity – preliminary data and it’s all still very new so still plenty of room for improvement. And in all honesty we feel like we haven’t tried that hard yet and have plenty more ideas up our sleeves! No targeted campaigns as yet, no paid advertising dollars and done on a very tiny budget– a good example of how by doing the basics and building it into the core of your organisation can deliver results
* Powerpoint click: dot points of where the audience is

**Discussion point 2: Where is the audience and how to find them**

They are everywhere! Working with organisations and just being consistent with the message of who we are trying to attract and why

* Workplaces, schools, community groups (ie sporting clubs), religious institutions – they are everywhere in society and remember not just looking at being born overseas, many people here are 2nd or 3rd generations and have that heritage, some you may not even realise! But its about educating everyone about it and letting them know why we need diverse people to join so they can self-identify
* How do you spread the message with the organisation? how does the group/organisation function and how they communicate, eg cotton on – well-being newsletter and gym (posters in the gym)
* Finding their motivations/goals and how it lines up with what we do (cotton on have strong social responsibility and for example Deakin uni med and bio med students – great response, already have an interest in the area)
* Targeting certain suburbs, certain events where there are high numbers of them gathering together
* Powerpoint click: Champions and hospitals to find them

**Discussion Point 3: finding and connecting with champions in the community**

* Further to this about where to find and target these groups, I wanted to make a specific point finding your champions in the community and people with a lived experience are your biggest advocates – harness that ,they have the passion but don’t know the how – and that’s where we come in
* (ie- connecting with transplant hospitals)
* Nearly all patients who struggle to find their match have a diverse background (as mentioned earlier they run their own campaigns – we need to go in to not only support them but also it helps connect us to their culturally diverse networks)
* Powerpoint clicks: different cultures (flag image)

**Discussion point 4: Understanding the audience**

* Every culture has different values and beliefs and behave differently – so understanding this is also key so we can better target them.
* For example Western society/white are more individualistic vs many other cultures such as Asian, Middle Eastern and so on – in many other cultures the decision to become a stem cell donor is not an individual one, they consult with family and they are a big influence on the decision
* Identifying leaders and influential people and who they are for every group – ie Arabs – Muslim and catholic religion is very strong (priests and religious leaders), Elders in Aboriginal community, who is it for Indians and so on? In a workplace it may be a manager who helps drive the message
* Powepoint click: Challenges dot points

**Discussion Point 5: Challenges**

* Looking at the challenges, some I have already briefly mentioned
* So many **different cultural groups all with different beliefs and values**. Working with them to learn and summarise what these values are and their behaviours which I’m sure many people in this room are already looking at (a lot of info already out there…CCV, Greek, Indigenous).
* Working with ethnic community councils (I have begun discussions with a local one) – to learn and understand but then also utilising these people as your key champions – remember we don’t necessarily have to do all the leg work ourselves – it is in their communities interest to take part in this because it affects them (most of the time it’s simply awareness a lot of the time, they don’t realise that this is an issue until it happens ) – we can simply guide, support and provide the right resources and work together.
* And again using key influential people in those communities to help
* A few other **challenges UR the Cure has faced specifically**
  + One major challenge we are finding **– more females joining vs men** (higher social media users, and simply human nature – overseas organisations using bigger marketing dollars and specific campaigns to try and counteract this)
  + When working at universities which really are great places to promote this type of thing - young, motivated, educated) – **international students and Permanent Residency to Citizenship/Medicare** – capturing them
  + **Language** we have found is a big one …we are slowly changing from using “ethnically diverse” to “culturally diverse” – it resonated better with people and for whatever reasons the word “ethnic” we find can sometimes have negative connotations with people…also using the words background and heritage and educating people what this actually means (lots of people still identify themselves as “Australian”)! So we always make sure we have explanatory text.
  + The need to add “indigenous” in communications and not just “culturally diverse”
  + **Complexity of the topic and little awareness** – explaining from absolute scratch and then building on that with other key messages
  + Another challenge has been trying to **engage and contact the right people in the different organisations** to have this conversation and get some changes happening – large organisations with complex structures, relationships between services, funding structures and so on - for example still haven’t had an outcome from the government review.
  + Blood Service is a big organisation with various complexities and hard to know where and how you can even influence, up until a few months ago it was the only place you could join the stem cell registry and it has been a challenge to properly engage with simple ideas like adding a question to the blood donor form to identify diverse candidates and offer them info about joining the stem cell registry and better promoting it– and although cheek swab recruitment is available now, I believe the blood service can also play an important role to encourage more people from diverse backgrounds onto the registry but also using this for blood donation goals too – I’ve mentioned earlier how people with a lived experience are your biggest advocates and nearly all of the time they are people with a diverse background who struggle to find a match – so utilise this as an avenue to also attract more culturally diverse blood donors too
  + Even the ABMDR itself for a long time was difficult to engage again due to different complexities and I think there’s more opportunities for a better synergy between the 2 services (blood service or now known as “life blood” and The Registry), and the government and its funding plays a big part in that – the people in the organisation themselves want to do more but their hands seemed to be tied. And because of this it made what I was trying to achieve with UR the Cure difficult. The introduction of cheek swabs is a huge step forward and for eg now we actually have reporting to see how many people have joined through UR the Cure – beforehand I could talk to thousands of people to join but never really knew if they actually joined. I needed to be sensible and didn’t even focus on fundraising because I couldn’t ask for funds if I couldn’t even measure the outcomes of the work!
  + Commend the blood service/life blood and ABMDR for the important work they do
  + Everyone’s challenge – money! I work on this voluntarily around my part time job and all people involved volunteer their time including my colleague Kate – we have been able to achieve a lot but could do so much more if I had more time to focus on this, but now with recent changes it’s becoming more viable to start looking at funding to take it further.
* Powerpoint click: Future

**Discussion Point 5: Working together and looking at future possibilities**

* I’m excited for the future and I think there are many opportunities and possibilities, I’m excited that we are here today and grateful for the Donor Research Network for putting this together because we have now really started this conversation together and not just each individual organisation working on its own….working together is going to be key and this meeting is great first step
* As just mentioned streamlining and creating a better synergy between the different organisations will be important – we have a common goal and each service has its own individual goals, but lets find ways to help one another out for the benefit of all (remember it also streamlines the message to our target audiences)!
* Lots of different ideas - for example when people apply for a drivers license, there’s info there about organ donation, but why not include info about stem cell donation and blood donation – including communications that it’s targeted for people of diverse backgrounds
* Australian citizenship and Permanent Residency
* Programs with targeting schools and the education systems – specifically targeting those in suburbs with a higher density of diverse populations – a systematic way with year 12 students
* Getting government on board and understanding the issue to help implement some of these ideas
* Think outside the box – ancestry.com (or pathology groups)…next level creating an “opt out” system

**Conclusion and thank you**

* Thanks again for listening - more than happy to chat afterwards and exchange details
* Here are some slides just to hit home on some of the people affected by this and also a short video
* Powerpoint slide: patients
* Powerpoint slide: Ness (time is now)
* Powerpoint slide: video