South African Bone Marrow Registry (SABMR)

Why Should You Go On The Registry?

Who are we?
How does it work?
What do we do?

Dr Charlotte Ingram
CEO & Medical Director
Background

- Every year patients
- Blood Diseases
- Survival Bone Marrow Transplant
• Established in 1991
• Non-profit Organisation
• Board 11 Members 9 Non Exec 2 Exec
• Diverse representation of expertise: economist, financial, medical, legal, patient, donor
• Liaison between 97 registries worldwide
• Provides MUDs for stem cell transplantation
• Facilitated 1st matched unrelated donor (MUD) bone marrow transplant in South Africa 1997
• Donor recruitment
World Marrow Donor Day - WMDD
21 March

....and the WMDD prize winners of 2018 are...

Grand Prize South African Bone Marrow Registry (SABMR)
Originality Prize Registrul National al Donatorilor Voluntari de Celule Stem Hematopietice
Incentive prize Canadian Blood Services

Congratulations and thank you for your wonderful presentations!
#WMDD2018 #WMDA2019 #ThankYouDonor

• International recognised registry - approved member of the World Marrow Donor Association (WMDA)
• Guidelines for the collection and transfer of stem cells
• Submit donor data to the Search and Match Service database
  - > 33 million donors and cord blood units
  - Local database ~ 73,000
• Awarded full WMDA Accreditation Status June 2018
  - Achieved in Record Time of 2 years
• WMDD Grand Prize 2018
Background

• Patient Services
  – Local
  – International
  – Family (International)

• Cost Recovery for Services
  - Donor Services
  - Patient Services
  - Technical Assistance
  - Donor Welfare Services
  - Donor Recruitment

• Self Sustainable, No State Funding
  - Alternatives in addition to Fee for Service: fund raising & other donations, benefactors, sponsorships, etc.
Background

- 492 patients in South Africa - MUD
- 156 SABMR donors
  - 129 donors for local patients
  - 27 donors for international patients
SABMR Donors Donated For
Online Recruitment:
SABMR’s propriety software program changing the face of donation for our haemopoietic stem cell (HSC) donors in South Africa
SABMR Donor Recruitment

Donor recruitment vs. donor attrition

SABMR Donor Statistics 2012-2018

<table>
<thead>
<tr>
<th>Year</th>
<th>New Donors</th>
<th>Deleted Donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>1900</td>
<td>1650</td>
</tr>
<tr>
<td>2013</td>
<td>2791</td>
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<tr>
<td>2014</td>
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<td>2017</td>
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<td>1461</td>
</tr>
<tr>
<td>2018</td>
<td>1282</td>
<td>1917</td>
</tr>
</tbody>
</table>
Donor Drives Work

• April 2018 1st SABMR donor drive since 1996
• Two Hundred and Thirty Four Donors
Donor Drives Work

• Aaron Lipschitz
• Over 300 applications
• Donor identified as match
• Local Patient
Buccal Swabs

Recruitment Reference no. / SABMR Donor ID no.

Donor Signature ___________________________ Date: ___________________________

Your Buccal Swab Kit Directions
This kit contains four buccal swabs – two per package.

Now you are ready to collect your four samples.
1. Open the swabs at the stick end; use one at a time.
2. Use one swab per quadrant of your mouth.
3. Swallow before swabbing.
4. Swab 8-10 times between cheek and gum with the force of brushing your teeth.
5. Wrap one of the completed printed labels around the stick like a flag.
6. Place the completed swab in the slit in the foam of the card/swab holder.
7. Swabs should face the same direction.
8. Do not handle the cotton tips; this will cause contamination.
9. Repeat steps 1-7 with the remaining 3 swabs.

Place cardboard kit and relevant documentation in return box.
If a swab stick is dropped, please throw it away. Kit can be submitted with fewer than four sticks.
Online Recruitment Portal

- June 2018 – new website launched
Online Recruitment Portal

The SABMR is constantly looking to increase its database both in number as well as ethnic diversity. However, potential donors need to fulfil certain criteria relating to age and health.

To find out whether you are eligible to be considered as an unrelated stem cell donor, please complete the questionnaire below:

CONGRATULATIONS!

You qualify to proceed with the registration of becoming a potential stem cell donor.

You will shortly receive an email from the SABMR with more information.

Please follow us on Facebook and Instagram to stay connected.
Proprietary Software Program

- Over 11,000 applicants have visited the online portal
Kits Sent for Testing

• Over 1500 kits sent for testing 2019
The STATS

I ♥ STATS
The STATS

Ethnicity 31 December 2018

- White: 67%
- Other / Unknown: 10%
- Coloured: 9.3%
- Black: 5.9%
- Asian / Indian: 7.8%
The STATS

- Match 1:100 000
- More likely within own ethnic group
- 2016 – 181 Preliminary Search Requests
- 50% searches for Asian, Black and Coloured patients
- Only four out of the 22 transplants that year
The STATS

New Donors Recruited 2018

- 71.9%
- 11.3%
- 8.9%
- 3.5%
- 4.4%

- Asian / Indian
- Black
- Coloured
- White
- Other / Unknown
The Future

- Increase donors - Ethnic Diversity
- Overcome cultural issues
- National footprint
Why Should You Join?

• HLA Identical Family – 30%
• Matched Unrelated donor – 70%
• More than a blood group match
Why Should You Join?

No of Variants

Chromosome 6

Father

Mother

A

B

C

DR

DQ

2,482

2,035

3,086

1,375

459

No of Variants

2,035

3,086

1,375

459

2,482

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1,375

459
You Could Be Someone’s Tomorrow