The South African Bone **Marrow Registry** (SABMR) Who are we? How does it work? What do we do? "Overcoming the Challenges to Stem Cell Transplantation"

Dr Charlotte Ingram
CEO / Medical Director



### SABMR - Background

- Established in 1991
- Non-profit Organisation
- Board 11 Members 9 Non Exec 2 Exec
- Hub Centre for SA
  - Liaison between 137 registries world-wide
  - Provides MUDs for stem cell transplantation
- Facilitated 1st matched unrelated donor (MUD) bone marrow transplant in South Africa 1997
- Donor recruitment
  - Past = Sunflower Fund
  - Present = SABMR



#### **SABMR Services**

- Donor Services
- Patient Services
- Technical Assistance
- Donor Welfare Services
- Donor Recruitment
- Well established >28years
- Self Sustainable, No State Funding ,
- Alternatives in addition to Fee for Service, Fund raising & other donations, Benefactors







#### World Marrow Donor Day - WMDD

21 March · 😡

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

In Grand Prize South African Bone Marrow Registry (SABMR) Originality Prize Registrul National al Donatorilor Voluntari de Celule Stem m Hematopoietice (V

Incentive prize Canadian Blood Services

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

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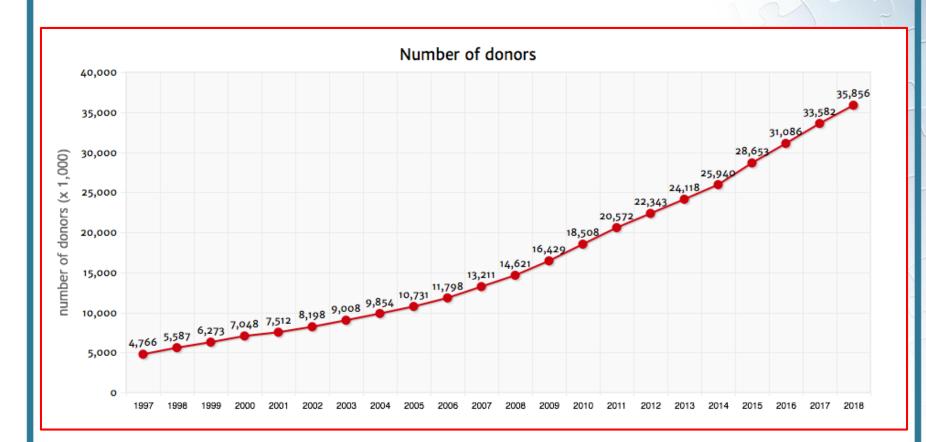


**MDA** 

Match

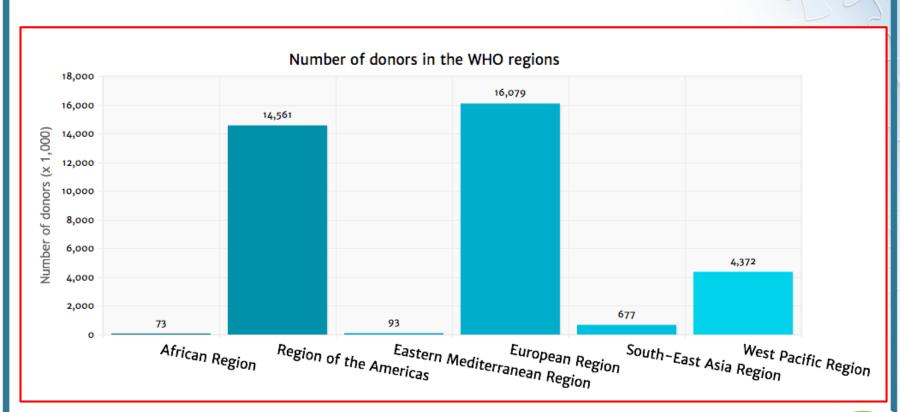


#### **Number of Donors**





#### Distribution of Donors - 2018





#### **Current Status**

- To date, 500 patients in South Africa MUD-Matched Unrelated Donor
- Currently, 75% of the donors for South African patients have come from other countries
- 163 SABMR donors
  - 130 donors for local patients
  - 33 donors for international patients
- SABMR key Global role player and a must for SA patient BMT needs

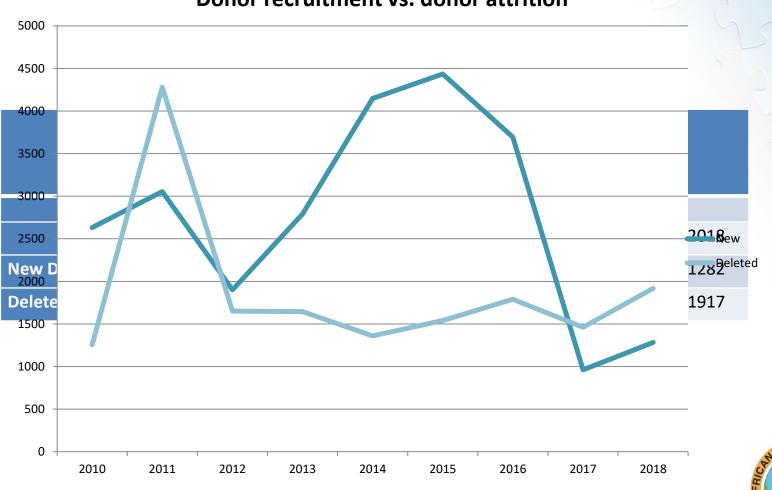






#### SABMR Donor Recruitment





#### SABMR Donor Recruitment

April 2018 1<sup>st</sup> SABMR donor drive since 1996





#### SABMR Donor Recruitment

June 2018 – new website launched





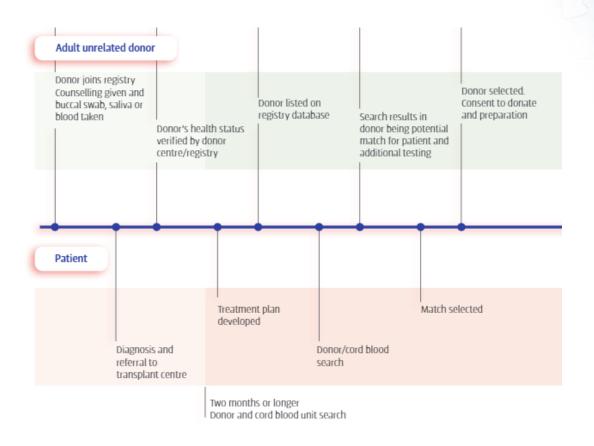
### Challenges

Change in donor medical status

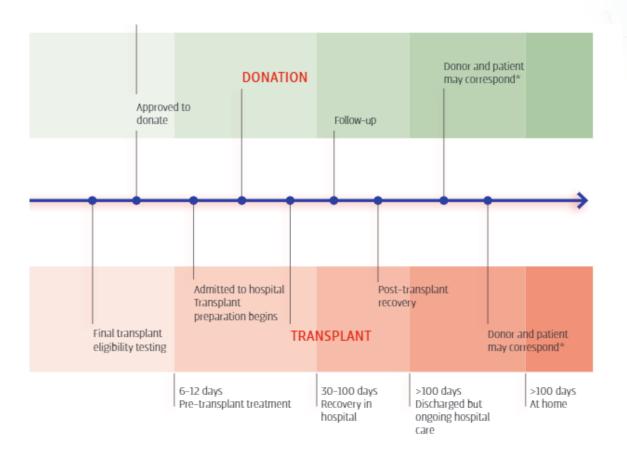
Time

Donor diversity











- Primary donor and secondary donor selected
- Confirmed matches in Leiden
- Both from Indian Registries
- Retrospective typing on HLA ABDR SABMR donors
  - one potential match
- Only at Intermediate and low resolution
- Primary donor declared medically fit
- Everything on schedule



- Patient admitted Monday
- Tuesday mid-morning
- Donor with sore throat
- Tough decision by all
- Swine Flu
- The race against time





- Back-up donor requested
- Parallel with local donor VT
- Back-up donor writing exams only available in over a months time
- Setbacks local donor
- Urgent medical and PBSC collection within a month



- How many back-up donors should be requested?
- Who pays the price?
- The "Costs"

**Patient** 

**Medical Aid** 

**Transplant Centre** 





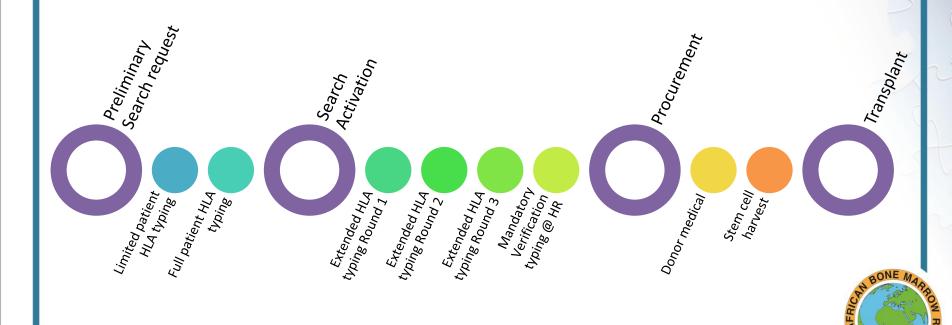
# Challenges - Time

In the interest of time, it is critically important to have the patient's

HLA typing at high resolution when performing a matched unrelated donor search.

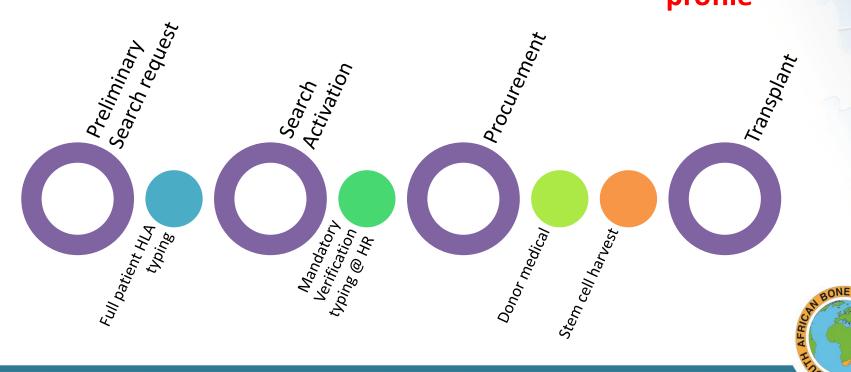
#### Challenges - Time

Time 6 to 8 months
\*pending donor
profile



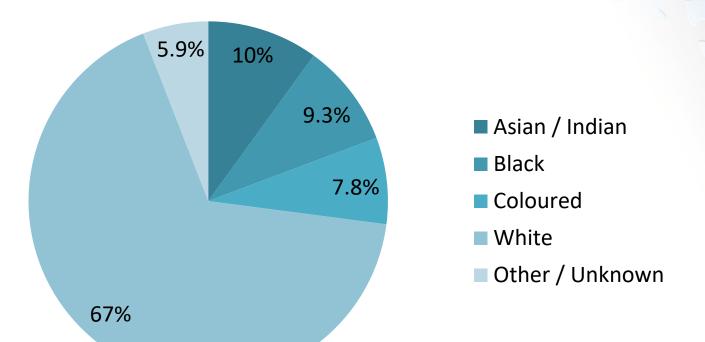
## Challenges - Time

Time 3 to 4 months
\*pending donor
profile



# Challenges – Donor Diversity

**Ethnicity: 31 December 2018** 





## Challenges – Donor Diversity

- Match 1:100 000
- More likely within own ethnic group
- 2018
  - 229 Preliminary Search Requests
  - 52% searches for Asian, Black and Coloured patients
  - Only three out of the 40 transplants that year



# Challenges – Donor Diversity

- Increase donors Ethnic Diversity
- Overcome cultural issues
- National footprint





## **Thank You**





