The South African Bone Marrow Registry

Successes and challenges:
Overcoming Obstacles to Stem Cell Transplantation

Dr Charlotte Ingram
CEO and Medical Director
SABMR - Background

- Established in 1991
- Non-profit Organisation
- Board 11 Members 9 Non Exec 2 Exec
- Hub Centre for SA
  - Liaison between 97 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 - Activities

- Stem Cell Transplantation offered in 3 regions
- Total number of SA patients transplanted – 492
- Total number of SA donors donating stem cells – 156
  - For SA patients – 129
  - For international patients – 27
International recognition:
- Internationally recognised registry
  - Approved member of the World Marrow Donor Association (WMDA)
  - Guidelines for the collection and transfer of stem cells
- Submits donor data to the WMDA Search & Match Service (WSMS) database
  - > 34 million donors and cord blood units
  - Internet search engine
- Awarded full WMDA Accreditation Status June 2018
  - Achieved in Record Time of 2 years
- Started own donor recruitment in Nov 2017
  - WMDD Grand Prize 2018

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 Hematopoietice
Incentive prize Canadian Blood Services

Congratulations and thank you for your wonderful presentations!
#WMDD2018 #WMDA2019 #ThankYouDonor
Donors for South African patients
3 Major Transplant Challenges

- Committed Donor
- Access to Funds
- Time
Committed Donor

▪ Since 2018 the SABMR recruits all of its own donors
▪ Current recruitment initiatives by online platform and donor drives
▪ Frequent contact with all registered donors
▪ Involve them in education and awareness campaigns
▪ No cost to donor when identified as match, we only ask their time
▪ 10 year medical follow-up post donation
▪ Possibility to meet their patient after 3 years with mutual consent
▪ SABMR strategic goal to increase size of database
▪ ~73,000 to 90,000 by 2021

3 Major Transplant Challenges
3 Major Transplant Challenges

Prior to 2018:
6 to 8 months
*depending on donor profile
3 Major Transplant Challenges

Post 2018:
3 to 4 months
*depending on donor profile
3 Major Transplant Challenges

- Donor related costs:
  - Local donor = R 200 000 – R 300 000
  - International donor = R 400 000 – R 800 000
- Medical aid often only covers the cost of a SA donor
- SABMR Patient Assistance Program
  - Financial assistance for South African citizens in need of a MUD SCT and who do not have the financial resources to formally activate their donor search.
  - Launched in November 2018 – already funded 4 successful MUD SCTs
Operational Challenges

- Financial
  - No state funding
  - Cost recovery for services not sufficient: Sustainability Plan
- Cost of HLA typing
  - HLA typing from buccal swabs performed in USA
- Poor ethnic diversity
  - Recruited volunteers to help address the issue
- Alternative therapies
  - CAR T-cell and Haploidentical transplantation
  - Still require MUD BMT support
- Decline in donor database noted 2016
  - SABMR started doing its own donor recruitment
  - Implemented a new business model to enable rapid growth
BMT in Africa

Where are we in 2019?

- By 2019 the world had hit 1 million HSCT
- Africa ...
- Only South Africa & Nigeria report in SSA

Where do we want to be?

How could we get there?
Transplant Programmes in SSA

- South African
  - Continuously expanding from 1 to 3 Paediatric
  - Adult from 5 in 2016 to 12 in 2019
  - SABMR (45 MUD transplants/Yr)
- Nigeria
  - 4 Transplants over 5-6 yrs
- Ghana
  - 5 Transplants – Sickle Cell only
- Kenya
  - Mainly Sickle Cell & Haploidentical referred to India or SA - cost related
Stem Cell Registries in SSA

- South African Bone Marrow Registry (SABMR)
  - 72,350*
- Bone Marrow Registry Nigeria (BMRN)
  - 924*
- The Sunflower Fund
  - 557*
- Other - Ghana donor panel
- Above excludes EMR Countries- Middle East, North Africa, the Horn of Africa and Central Asia
- (21 Member States in Total)

*WMDA Share: 24 May 2019
BMT Options for African Patients

- Many African patients in need of a BMT are currently being referred to transplants units in India and South Africa
- EMR/AFR High frequency Allogeneic compared to Autologous & almost exclusive use of family donors compared to Global
- EMR/AFR tend to use Haploidentical donors rather than cord blood
Comments from Prof N Novitzky as head of this group

- First meeting in Casablanca, 2018
- Very little presented from SSA
- Only 6 countries do transplantation: Egypt, Tunisia, Algeria, Morocco and South Africa
  - Nigeria did 4 transplants over 5-6 Yr period
  - Ghana set up a small program over a period of 4 months
    - 5 patients sickle cell - All HLA ID Siblings only 2 successful
- Largest number are from Egypt & then South Africa
State Funded Facilities = 6

Privately Funded Facilities = 9

Data taken from SAScETS website
Current Status of SABMR

• Donor database
  • ~73,000 Active adult donors

• Distribution of SABMR donors to
  • Local patients: 129
  • International patients: 27

• Patient statistics
  • Total MUD transplants facilitated: 492
  • African patients transplanted in SA: >12
Current Status of SABMR

- SABMR Family Donor Assistance for Africa
  - Kenya
Current Status of SABMR

- SABMR Family Donor Assistance for Africa
  - Somalia
Current Status of SABMR

- SABMR Family Donor Assistance for Africa
  - Ghana
Current Status of SABMR

- SABMR Family Donor Assistance for Africa
  - Nigeria
Where do we want to be?

As per WHO

Haematopoietic Stem Cell Transplantation is:

“A routine treatment without equivalent”

that is

ACCESSIBLE TO ALL IN NEED OF BMT!
How could we get there?

✓ Best Utilisation and possible expansion of existing services
✓ Partner management of patients
✓ Training and support programmes in the establishment of new BMT units
✓ Embrace new developments and treatments
✓ Education of Health Ministries
Paediatric MUD BMTs Facilitated by the SABMR since 1998

- 111 Patients
  - Aged between 3 months and 18yrs of age

- Gender split

- Males
- Females
Paediatric MUD BMTs Facilitated by the SABMR since 1998

- **111 Patients**
  - Aged between 3 months and 18yrs of age

- **Diagnosis split**

  - ALL
  - AML
  - FA
  - SAA
  - SCID
  - JMML
  - MDS
  - NHL
  - BTHAL
  - CML
  - HURLER
  - IPEX
Paediatric MUD BMTs Facilitated by the SABMR since 1998

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  • Aged between 3 months and 18yrs of age

• Product split

PBSC = 70%
Paediatric MUD BMTs Facilitated by the SABMR since 1998

- 111 Patients
  - Aged between 3 months and 18yrs of age

- Ethnicity split

  White = 79%

(Access to treatment and funds)
Making it all Worthwhile