Aplastic Anaemia from Past to the Present in Middle-Income and Low-Income Countries

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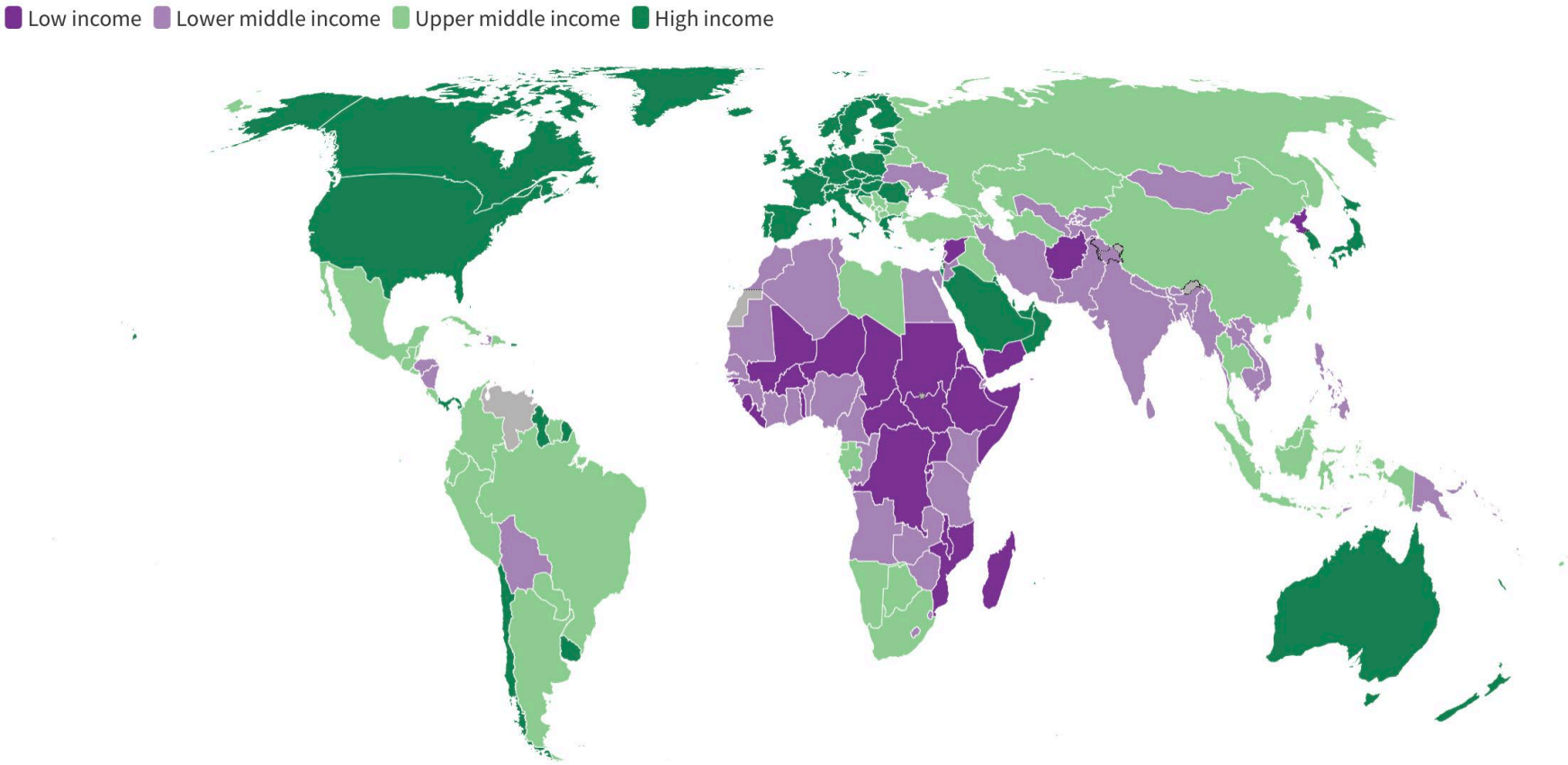
The challenge at home…World Bank Development Indicators

Allogeneic Transplantation Activity in Sub-Saharan Africa

- Low-income
  - Malawi
  - Mozambique
  - Sudan
  - Uganda
- Lower-Middle Income
  - Lesotho
  - Eswatini
  - Zambia
  - Zimbabwe
  - Angola
  - Tanzania
  - Kenya
  - *Nigeria*
  - *Ghana*
- Upper-Middle Income
  - **South Africa**
  - Botswana
  - Namibia
  - Mauritius



The challenge at home…World Bank Development Indicators

Allogeneic Transplantation Activity in Sub-Saharan Africa

- Low-income
  - Malawi
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  - **Lesotho**
    -> DKMS Patient Access Program
  - Eswatini
  - Zambia
  - Zimbabwe
  - Angola
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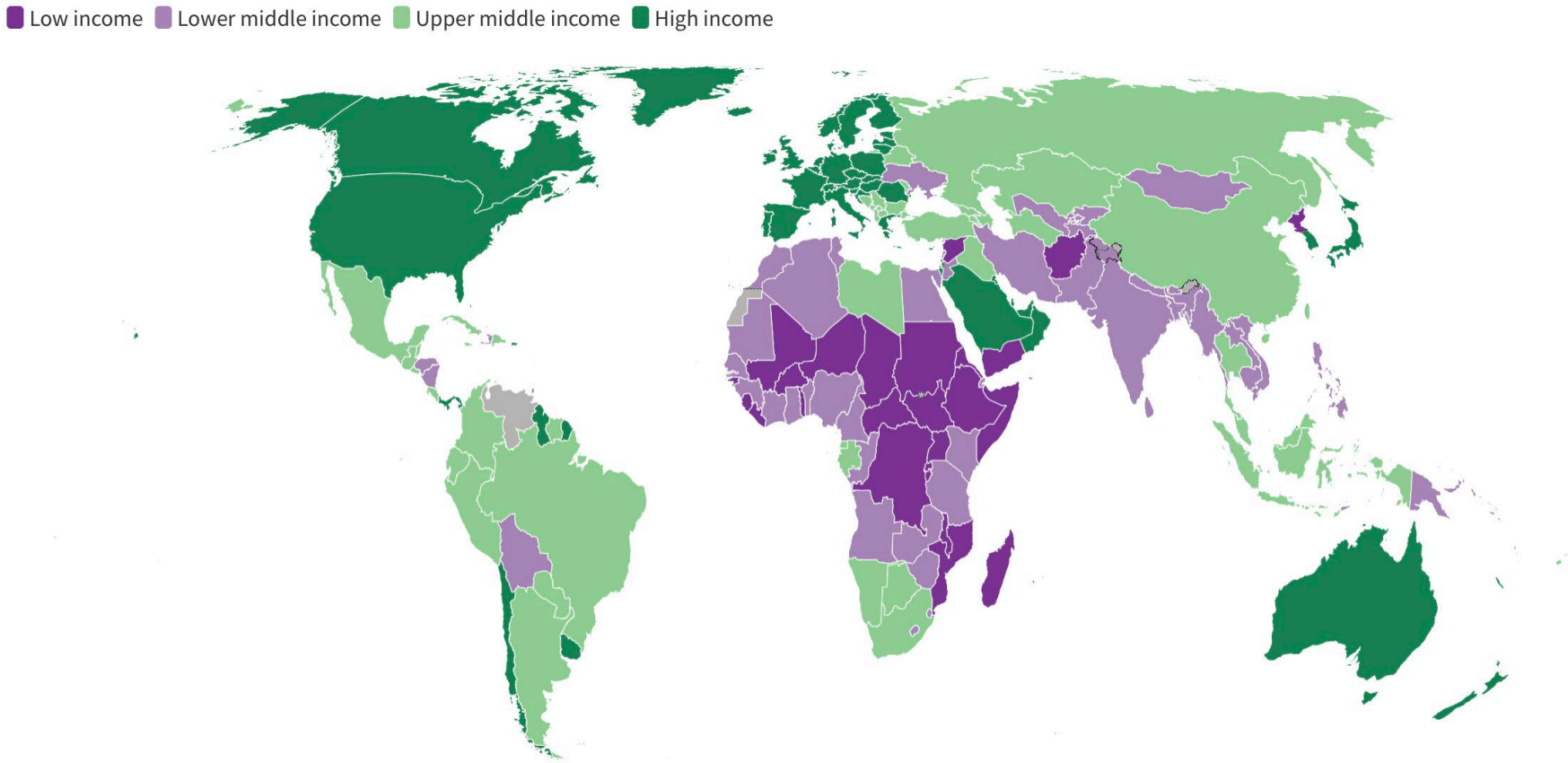

The challenge at home…World Bank Development Indicators

Addressing the Gap with transplant training and activity

- Low-income
  - Malawi
  - Mozambique
  - **Sudan**
  - Uganda
- Lower-Middle Income
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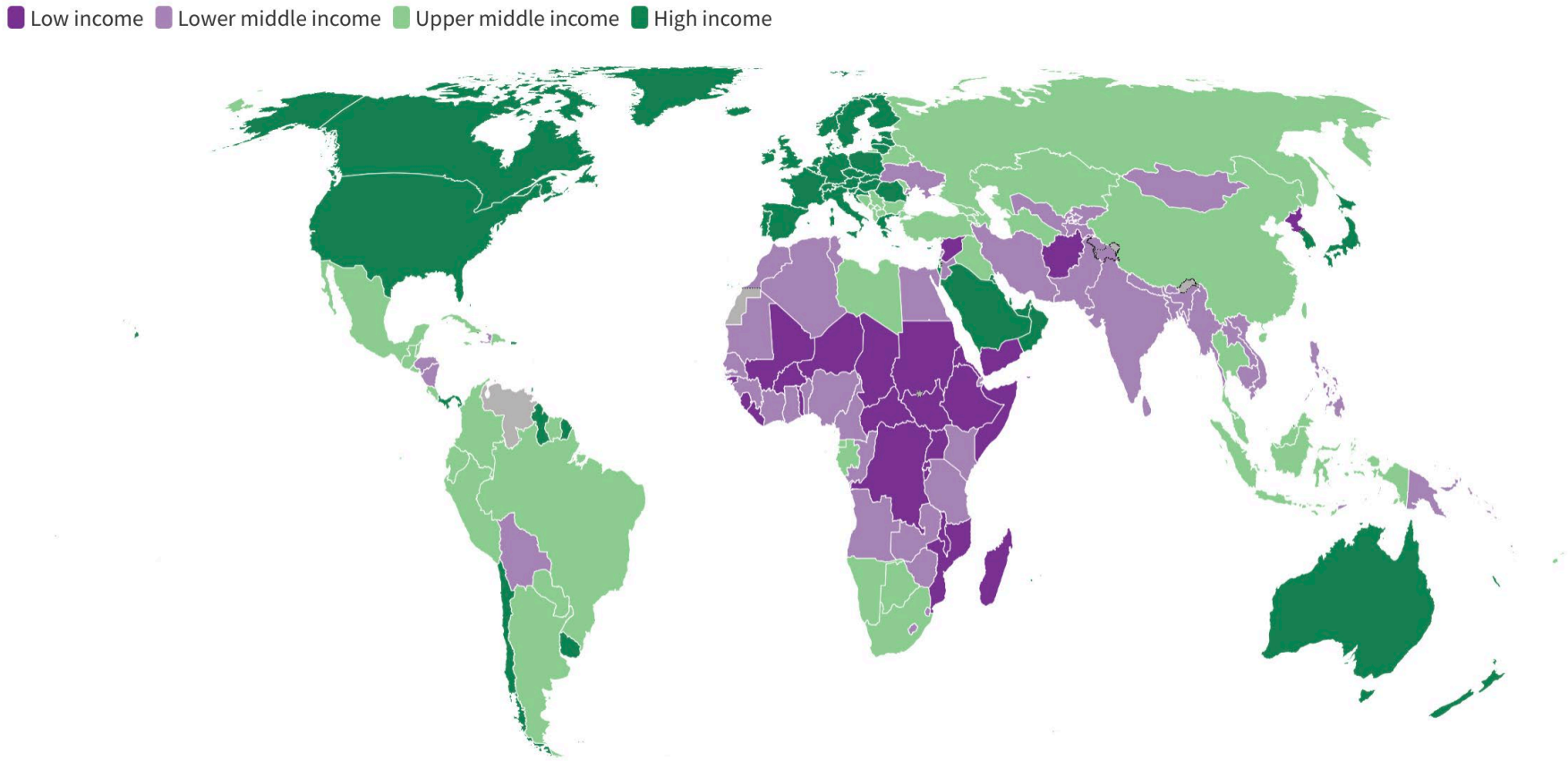
  - Eswatini
  - Zambia
  - **Zimbabwe**
  - Angola
  - Tanzania
  - **Kenya**
  - Nigeria
  - Ghana
- Upper-Middle Income
  - **South Africa**
  - **Botswana – SANBS AUTO Program Support/Training**
  - **Namibia**
  - **Mauritius**

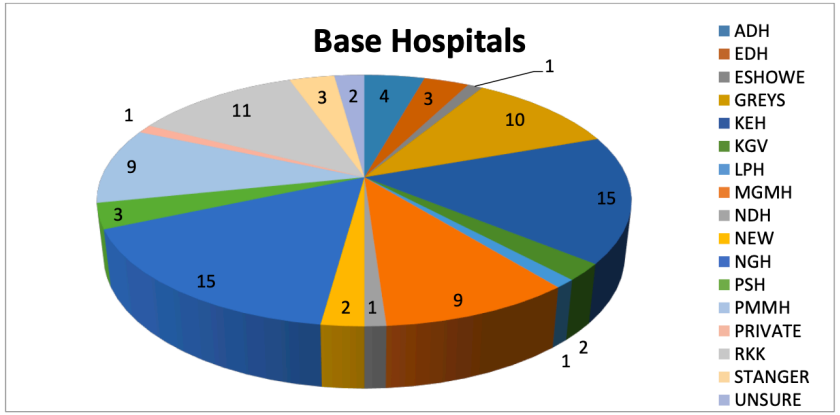


Data from KwaZulu Natal (KZN) for incidence and treatment of Aplastic Anaemia

- Study in Public Service Patients (83% of South African population)
  - In KZN province there are 8 million patients in public care

- Over an 11 year period (2005-2015) 92 SAA diagnostic BMATs at Albert Luthuli Central Hospital were reviewed
  - Median age: 24, M:F ratio 0,8:1, 16% patients HIV positive
  - VSAA 29
  - SAA 36
  - NSAA 27
- 13 patients not referred to Albert Luthuli Hospital
- 6 patients seen once and not treated
- 28% of patients LTFU

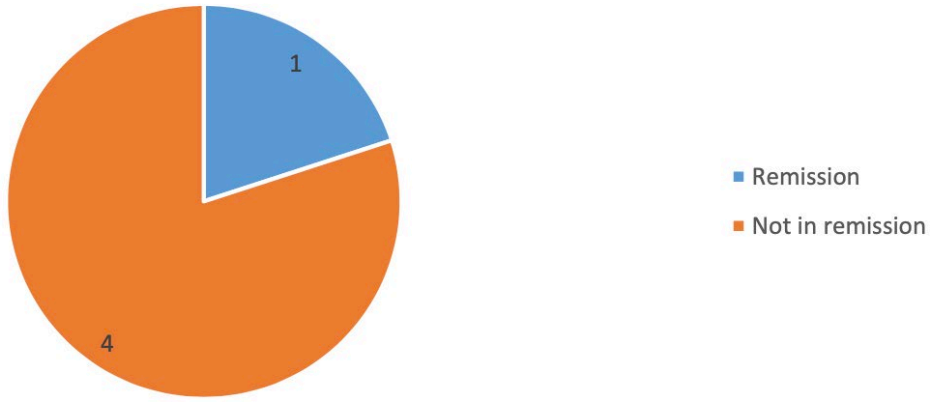
- 4 patients referred for a BMT (2011-13)
  - 2 patients alive and well
  - 1 patient died due to primary graft failure
  - 1 patient had TRM – due to aGVHD



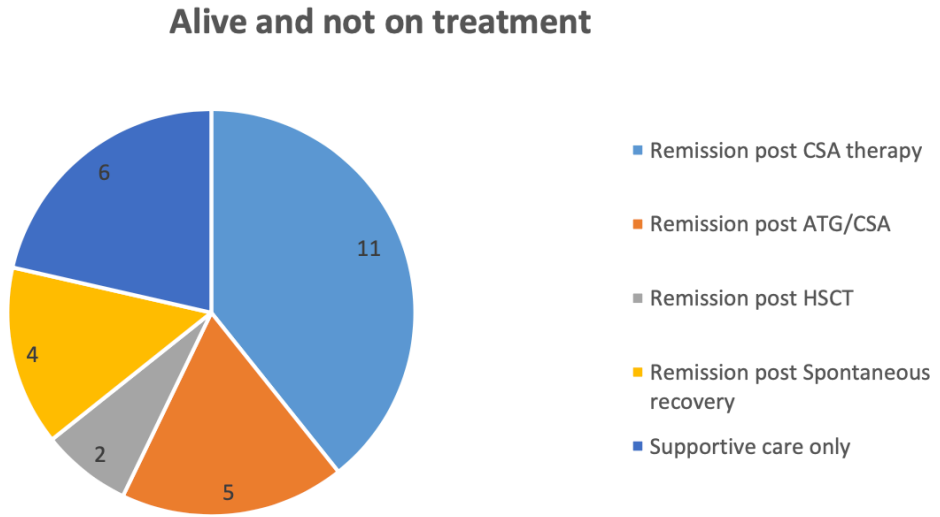
ADH- Addington Hospital. EDH- Edendale Hospital. KEH- King Edward Hospital. KGV- King George V Hospital. LPH- Ladysmith Provincial Hospital. MGMH- Mahatma Ghandi Memorial Hospital. NDH- Northdale Hospital. NEW- Newcastle Hospital. NGH- Ngwelezane Hospital. PSH- Port Shepstone Hospital. PMMH- Prince Mshiyeni Memorial Hospital. RKK- R K Khan Hospital

Zeenat Moorad, MMed Thesis, UKZN

Data from KwaZulu Natal (KZN) for incidence and treatment of Aplastic Anaemia



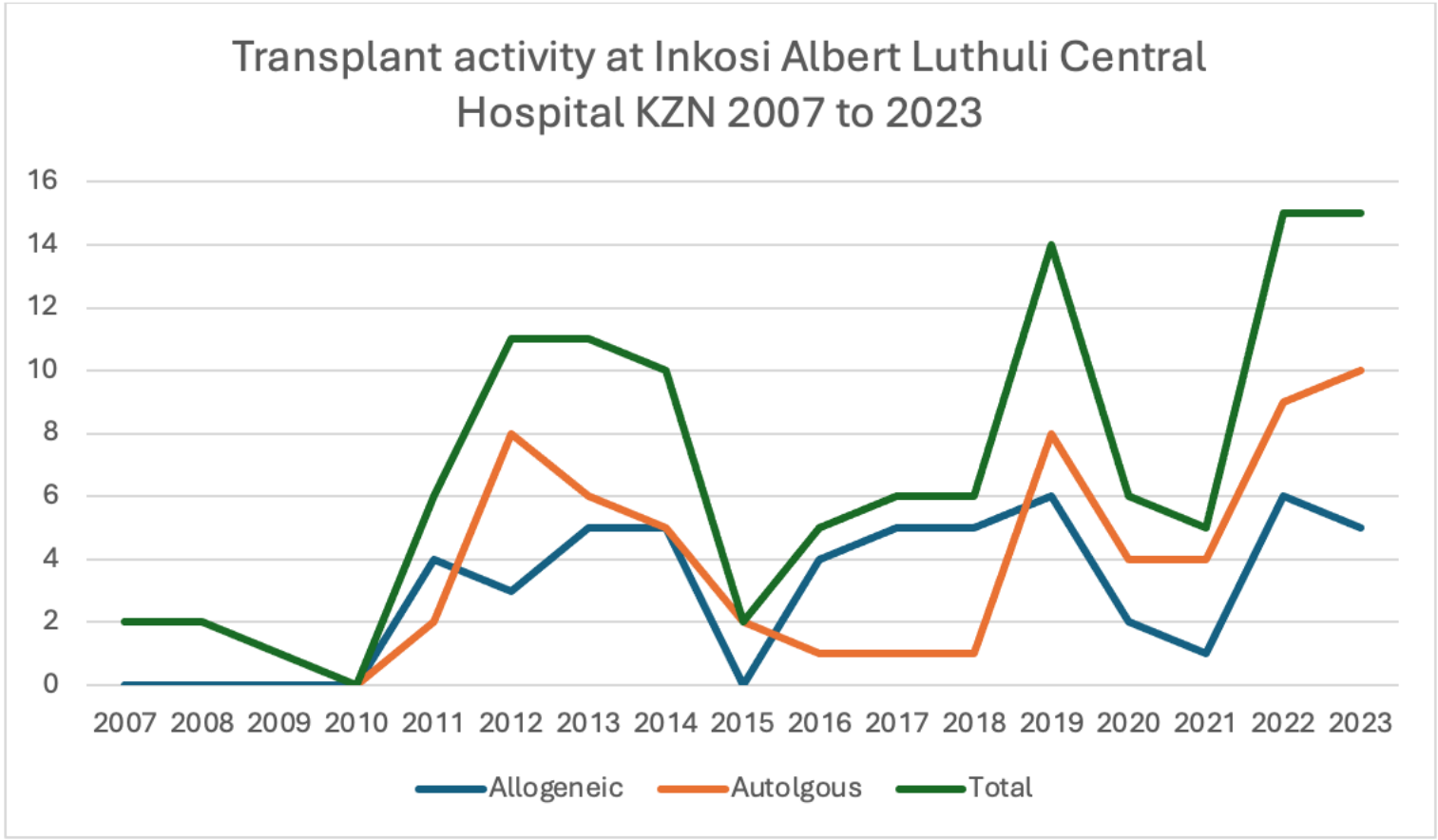
N=5 patients



N=28 patients

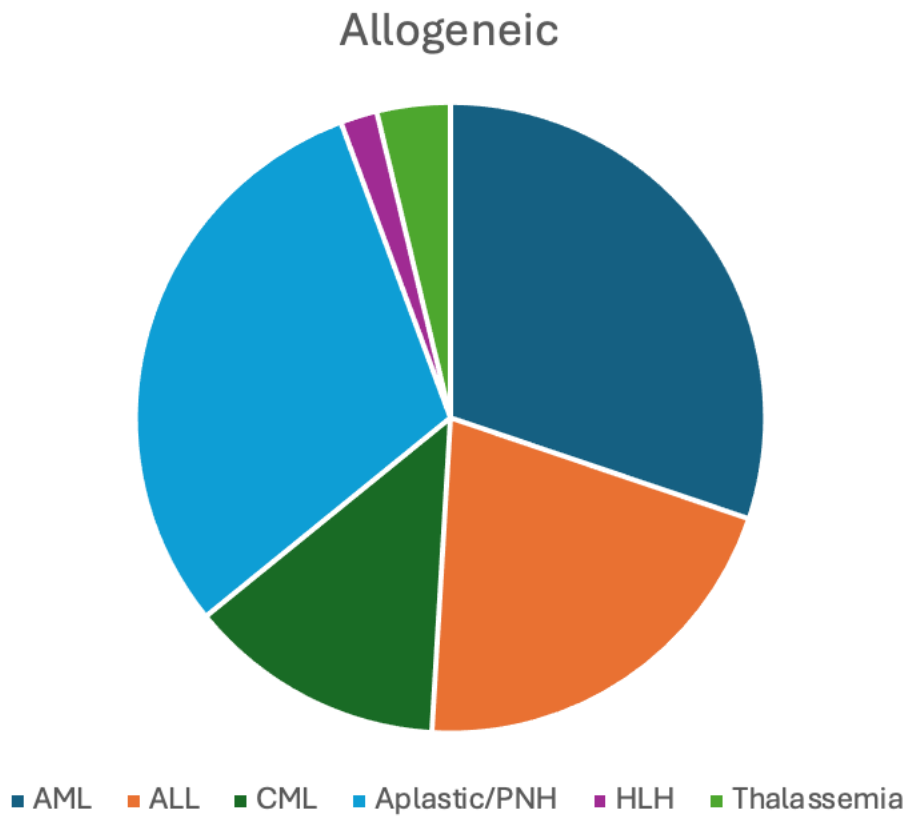
Zeenat Moorad, MMed Thesis, UKZN

2007 Establishment of an Allogeneic Transplant Centre in Durban for Public Patients



Communication Sharlene Parasnath IALCH in Durban

2007 Establishment of an Allogeneic Transplant Centre in Durban for Public Patients



Of 118 transplants, 52 patients received an allogeneic transplantation, 16 for SAA:

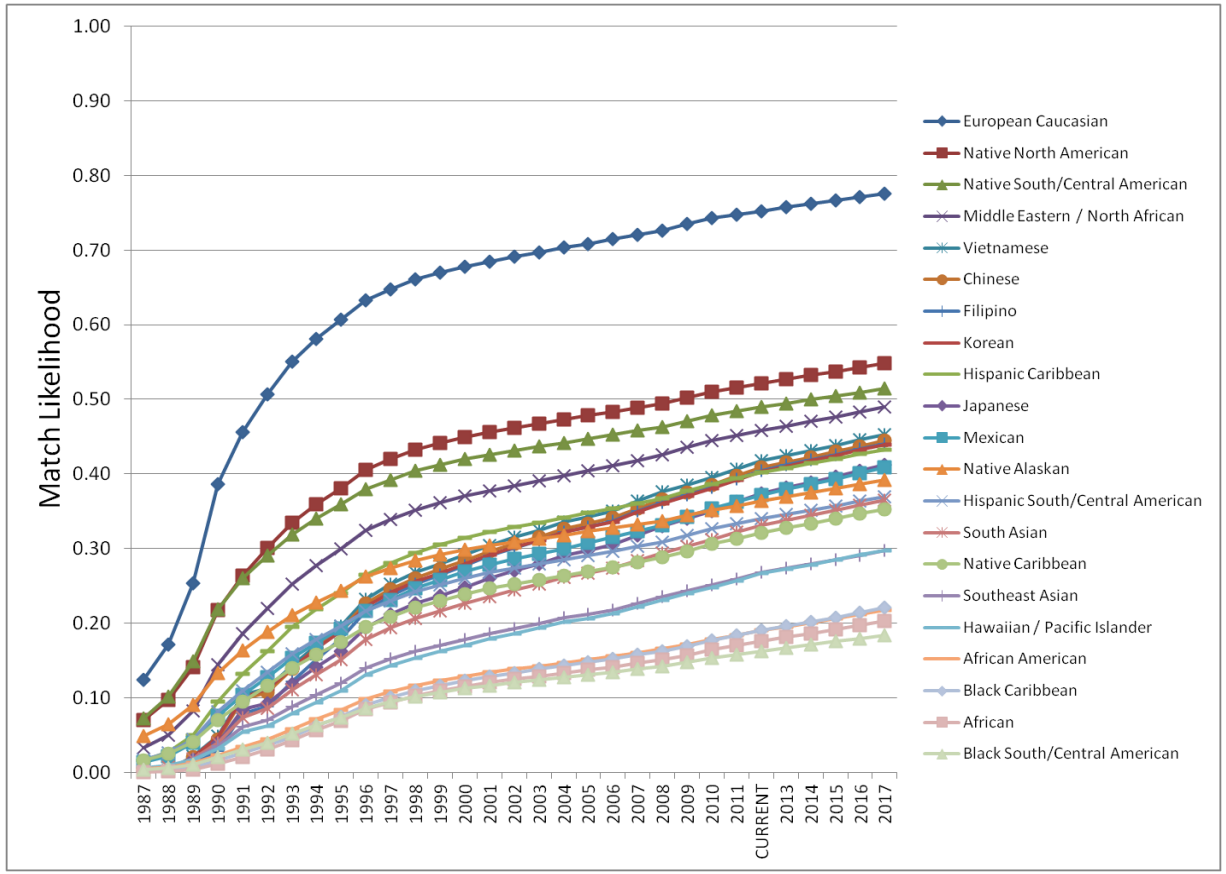
Year	Age at HSCT	Sex	Diagnosis
2011		F	Aplastic
2011		F	Aplastic
2012		F	Aplastic
2013		F	Aplastic
2013		M	Aplastic
2013		F	Aplastic
2013		M	Aplastic
2013	6	M	Aplastic
2014	15	F	Aplastic
2014		F	Aplastic
2017		M	Aplastic
2017		M	Aplastic
2018	13	M	Aplastic
2019	12	M	Aplastic
2022	13	M	PNH/Aplastic
2023		F	Aplastic

South Africa *incomplete* WBMT/EBMT Activity Surveys 2007 to 2022

Year	Number of reporting teams	**Allo 1st HCT**	**Allo non 1st HCT**	Total ALLO HCT	Total AUTO HSCT	Total all HCT
2007	4	**21**	**1**	22	42	64
2008	7	**82**	**2**	84	111	195
2009	2	**10**	**0**	10	10	20
2010	7	**78**	**7**	85	98	183
2011	6	**120**	**5**	125	98	223
2012	5	**96**	**8**	104	126	230
2013	6	**93**	**9**	102	134	236
2014	7	**107**	**4**	111	148	259
2015	5	**98**	**2**	100	129	229
2016	6	**110**	**9**	119	125	244
2017	5	**126**	**0**	126	118	244
2018	9	**129**	**14**	143	160	303
2019	11	**151**	**6**	157	200	357
2020	9	**121**	**4**	125	185	310
2021	8	**106**	**4**	110	187	297
2022	10	**122**	**3**	125	261	386

In South Africa in 2019 there were 9 transplants reported for Aplastic Anaemia:
6 matched sibling
2 haplo
1 MUD

Disparity in access to optimally-matched transplants – Change to come!



In South Africa in 2019 there were 9 transplants reported for Aplastic Anaemia:

6 matched sibling

2 haplo

1 MUD

Gragert, N Engl J Med 2014; 371:339-348

WBMT/EBMT Activity Surveys *as well as* SANBS Patient Services 2023

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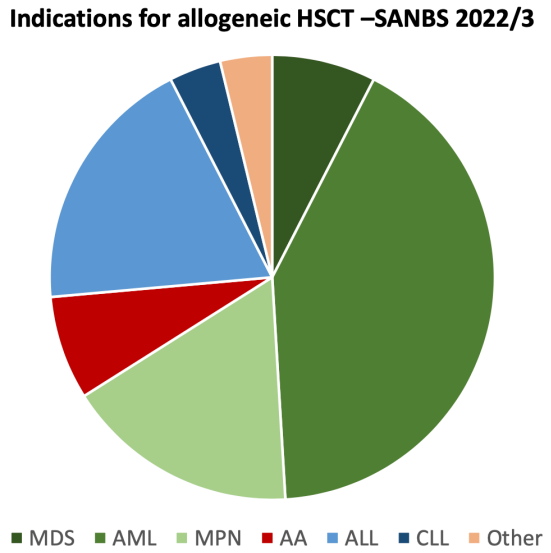
- 313 patients services in 2023
- Auto: allo 2.3:1
- 60% public, 40% private – patients
- 55% private, 45% public – clinical units



SANBS data – Tanya Glatt

Outcome of 30 allogeneic transplants for SAA at Groote Schuur/Red Cross Paediatric Hospital - past 5 years

18 adults

13 (73%) patients are alive

Cause of death in 5 patients:

3 early deaths:

- 1 Patient died of Covid during transplant
- 2 Patients died due to multi-resistant CRE

2 late deaths

- 1 Patient died at referral centre
- 1 HIV positive patient with Graft failure

12 paediatric patients

11 (92%) of patients alive

Cause of death in 1 patient:

- 1 early death (MUD transplant) due to ATG followed by severe CRS/MOF

Gateways to Stem Cell Transplantation in Africa

Gateways to Stem Cell Transplantation in Africa

MULTIPLE MYELOMA AUTO TRANSPLANT

- Gateway to HSCT knowledge and establishing practice in context of environment

APLASTIC ANAEMIA ALLOGENEIC TRANSPLANT

- Gateway to ALLO TRANSPLANT in all other conditions

→ Gateway to PAEDIATRIC Transplantation in Africa

→ Gateway to Effective Referral Pathways and Collaboration Across Africa

Gateways to Stem Cell Transplantation in Africa

Building Back to Basics to Deliver Effective Treatment

What happens before diagnosis
&
What happens after diagnosis

What can we do to improve early diagnosis
&
What can we do to build pathways for referral and treatment

Haematology Collaboration in Africa

BLOODSA FOUNDATION

Concerns

"Casting Lifelines to **Patients**" | "Throwing Deadlines at **Projects**" | "Providing Platforms for **Processes**"

- No / *Incomplete Process* Documentation
- *Lack of Standardization*
- Projects earmarked by *Long Lead Time* and *Failure*
- *Critical Resource Shortages*
- *Knowledge Sharing* limited by a *Lack of Collaboration*

Haematology Collaboration in Africa

BLOODSA FOUNDATION

Alternative

"Casting Lifelines to **Patients**" | "Throwing Deadlines at **Projects**" | "Providing Platforms for **Processes**"

- Stem Cell Transplantation is an environment of accelerated opportunities that warrants rapid effective decisions related to quality management and best practice pathways.
- This calls for agility and the promotion of rapid transformation:
  - **Centre of Excellence** - ensures that change initiatives are delivered consistently and well, through standard processes and competent staff
  - **Shared Services Hub** – to develop, maintain and promote best practices in Stem Cell Transplantation

    -> Cape Town Quality Management Collaboration supported by DKMS-Africa
  - **Programme Management** - revitalize stalled initiatives and enable effective programme management

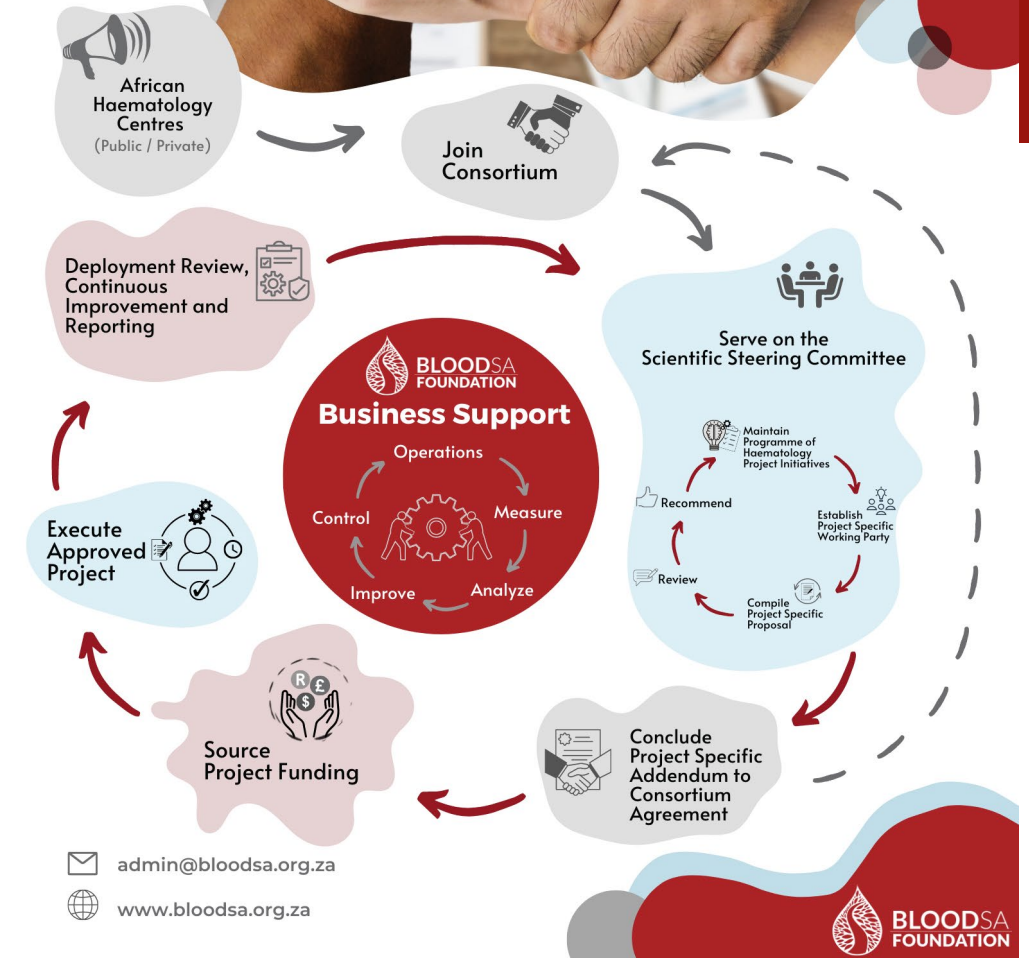
    -> HSCT Working Groups, Myeloma Working Groups

Stem Cell Transplantation Collaboration in Africa

Getting Involved

"Casting Lifelines to **Patients**" | "Throwing Deadlines at **Projects**" | "Providing Platforms for **Processes**"

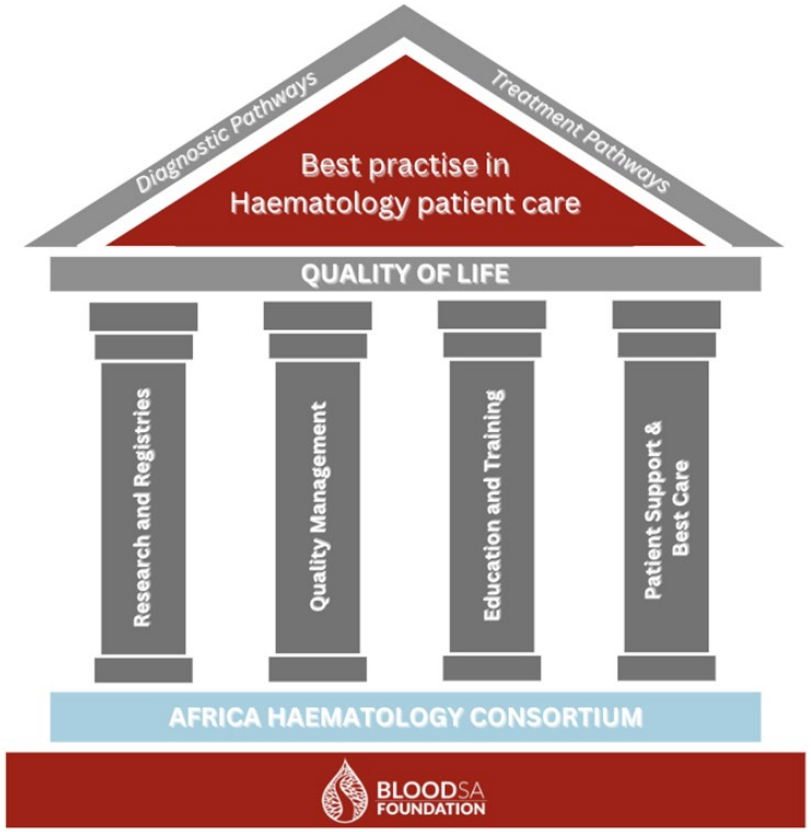
- Advance the training of Clinical Haematologists
- Advance the training of Stem Cell Transplanters
- Participation in the ***Scientific Steering Committee & Working Groups***
- Collaborate in establishing Best Practice, Quality Processes, Grantwriting, Fundraising, Awareness, Advocacy, Outreach
- Make available and share ***'Best Practice Pathways'*** and ***Standard Operating Procedures*** (SOPs)



Access to Stem Cell Transplantation Collaboration in Africa

Strategic Focus Areas

"Casting Lifelines to **Patients**" | "Throwing Deadlines at **Projects**" | "Providing Platforms for **Processes**"



BLOODSA ***House-of-Values***

- **Strategic Focus ONE:** *'Pioneer a Haematological Treatment Consortium in Africa: **build capacity for functional registries** to improve patient care'*
- **Strategic Focus TWO:** *'**Implement Quality Management Systems** in Haematology: Improving sustainable Health Care in Africa'*
- **Strategic Focus THREE:** *'**Transform Healthcare Education in Africa**: Cultivating Haematology Excellence from Grassroots to Specialist level'*
- **Strategic Focus FOUR:** *'**Patient Quality of Life**'*

Collaboration for education and implementation

BMT CLASSROOM

06/09/2023

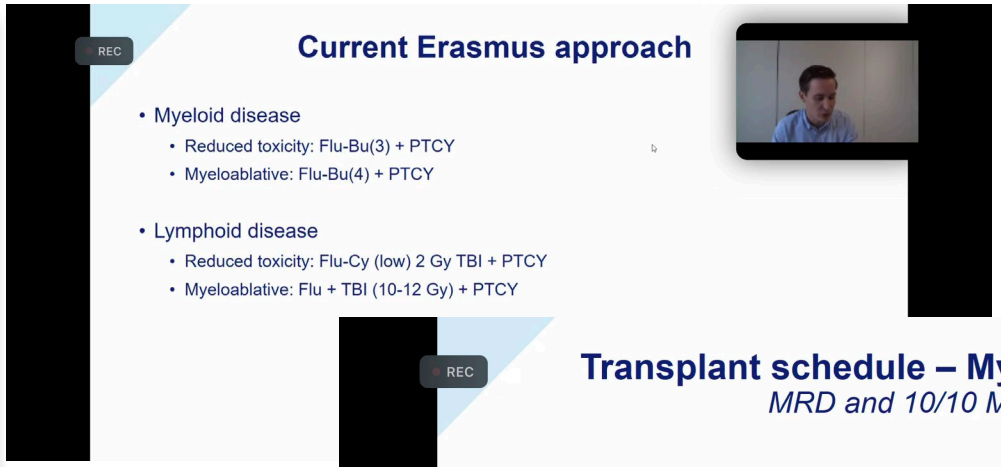
Case Discussions

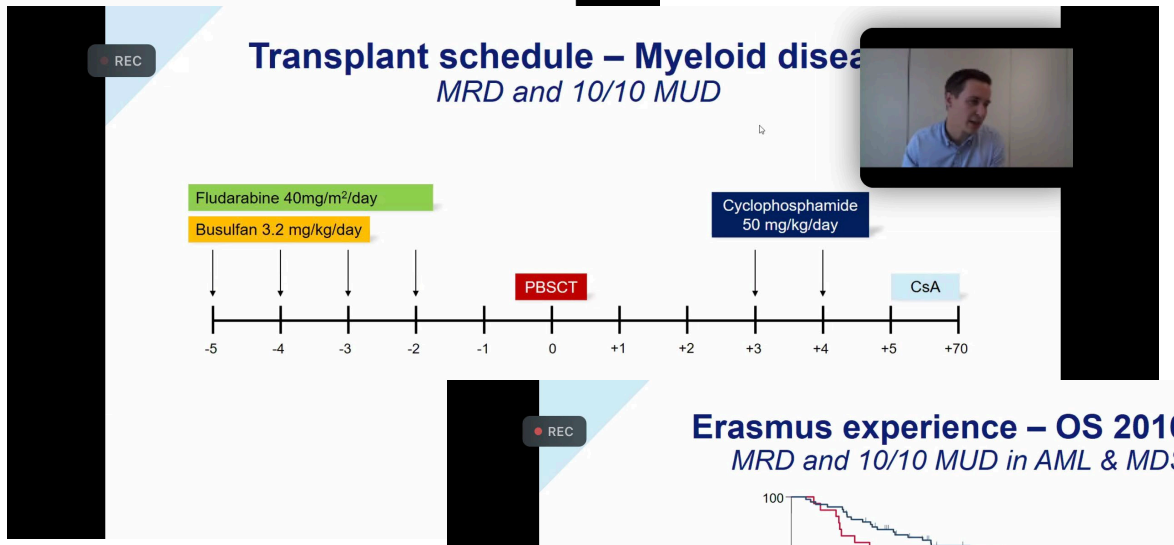
2023-09-06 BMT Classroom: Case Discussions

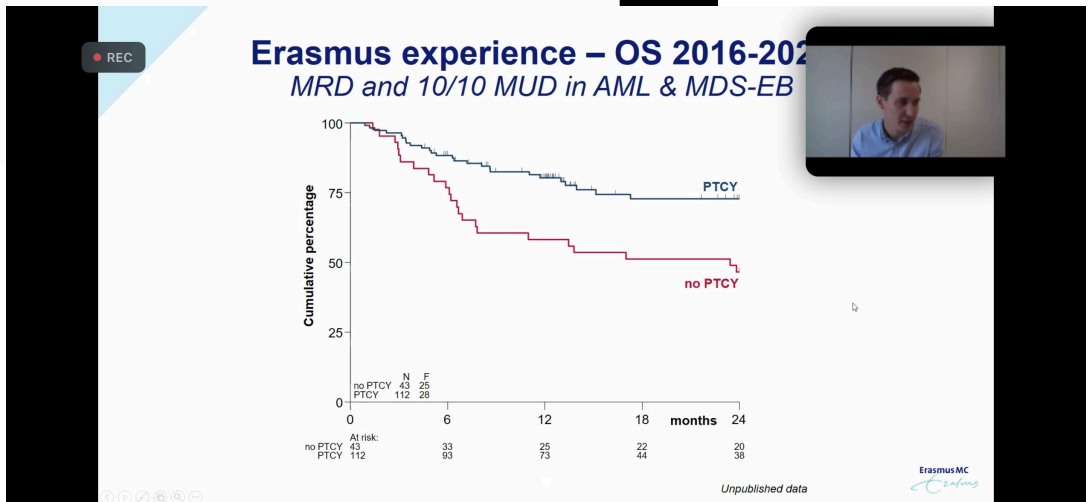
Resource Type: Training

READ MORE

11 October 2023







Collaboration for Patient Registries & Best Care Pathways in Africa

- Namibia
- Botswana
- Zimbabwe **Parirenyatwa Hospital, Harare, Zimbabwe**

- Continue Outreach

Continuing UCT's leading role in bone marrow transplantation

Collaboration – Quality Management - Care

PUBLIC-PRIVATE PARTNERSHIPS

- ❑Myeloma Collaborative Network in Africa Established in September 2023
- ❑Cape Town Collaboration for Quality Management established July 2018
- ❑HSCT Working Group established in 2023 with first aim to implement
    - a Diagnostic and Treatment Guideline for Aplastic Anaemia in Africa

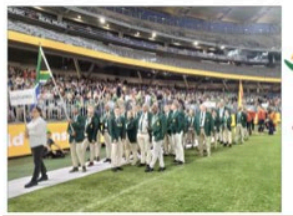
Continue to build African Pathways to bone marrow transplantation

Our patients are the goal and the prize

Find A Treatment Centre

Myeloma

- Information Leaflet
- Patient Stories
- Support Group
- https://cansa.org.za/



South African Bone Marrow Transplant Champions competing at the World Transplant Games in Perth!

Bone Marrow Transplant Journey of Melda Ruiters

In gratitude to all our colleagues and patients, and for the support of government and non-governmental organisations

Estelle Verburgh

Groote Schuur Stem Cell Transplantation Unit

University of Cape Town

DKMS
WE DELETE BLOOD CANCER

Blood **R**esearch and **E**nh**A**nced **T**raining against **H**IV – **S**outh **A**frica (**BREATH-SA**)

NIH Fogarty

BLOODSA FOUNDATION

SASCETS

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