Haemophilia Patient Perspective : The SA experience

The role of the SAHF in promoting optimal patient care

Intervention for Improvement to Haemophilia Care & PwBD

The International Plasma Fractionation Association (IPFA)

SAHF: Bradley Rayner (Chairman & PwH <1%)

Member of the

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACION MUNDIAL DE HEMOFILIA

Our Wish… [SAHF]



No child born with a bleeding disorder should have to live with pain, disability, or the prospect of early death in South Africa's new democracy

or

globally (WFH - Frank Schnabel's vision)

SAHF seek to address these challenges through our Strategic Plan & our TCPiD Values

Teamwork, Communication,
Personal (Partner) involvement and Dedication

Extract from PwH letter to SAHF

"The Haemophilia foundation has been a great pillar of strength during the most challenging years of my life. They made me believe that there is good out there, there is people who are willing to believe in you even if you do not at times. They made this Haemophiliac believe that he can make a difference in this world. No matter how big or small. All we have to do is step into our destiny…

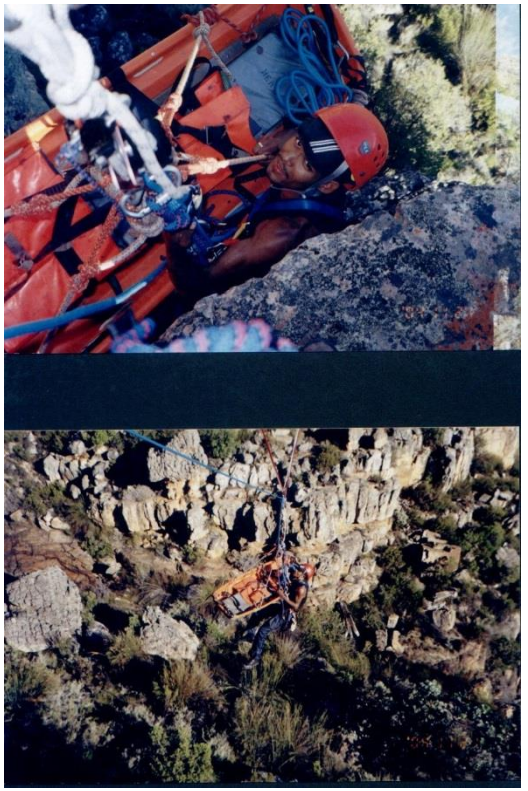
Everyone will die someday, but not everyone ever really lived…

This is my life story… and it's only just beginning

Riaan Opperman

Future Paramedic"

He qualified with SAHF assistance & Working as a Paramedic for a number of years

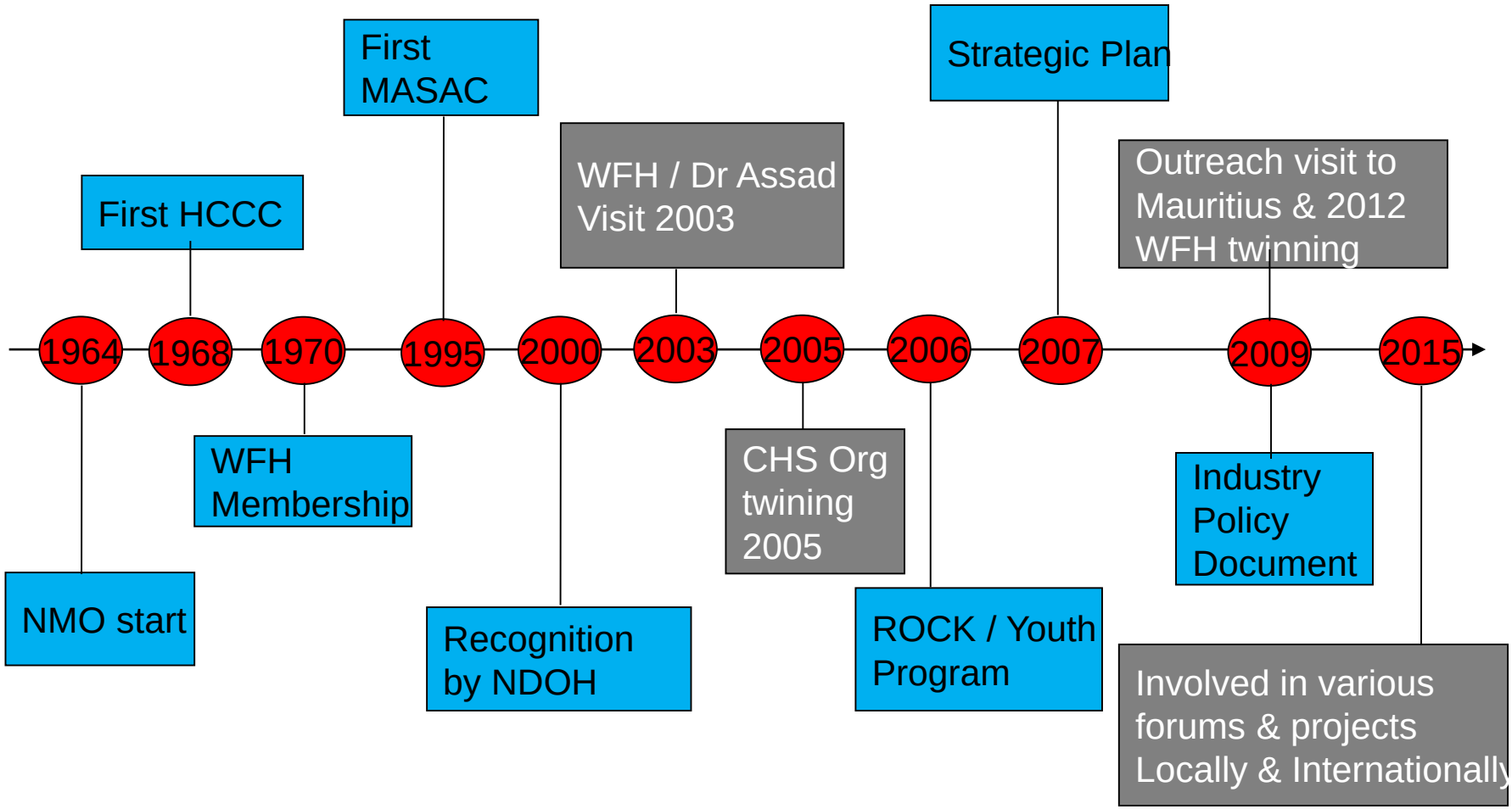


Agenda



1. Brief History – "Journey of Discovery"
2. Summary of Organisation
3. Mission
4. SAHF Strategic Objectives
5. Situation in SA
6. How do we seek to achieve our Objectives
7. Roles & Responsibilities (MASAC & NMO)
8. Examples x 3
9. It is in Our Hands
10. Acknowledgements & Thanks

Brief History – Journey of discovery



Summary of the Organisation



- The SAHF is a **volunteer organisation**
- **Member of the World Federation of Haemophilia** (WFH)
- Networked in **more than 130 countries**
- Seeking to **improve quality & access to care** for PwBD
- Seeking to **assist with various barriers** to access care
- Have programmes to **train/educate Medical Staff & patients** (nationally & internationally through our network)
- **No** government or Lotto **financial support**
- Has **won international awards** for it's work & represented on international committees and conferences

Mission



- The SAHF strives to ensure that all people with inherited bleeding disorders are **accurately identified & diagnosed**
- **Receive quality care** and treatment regardless of **where they live**; improving their health and quality of life
- SAHF aims to **maintain and improve** the level of expertise and treatment facilities in SA consistent with World Federation of Haemophilia (WFH) standards
- Support initiatives to find a cure

SAHF Strategic Objectives



1. Organisational Development (Develop Leaders/Volunteers)
   - Representation of patients & community with voices to express patient plight/problems
2. Advocacy
   - Empower patients/health officials with knowledge to advocate for quality care close to where you live
3. RURAL
   - Improve Care & Access in Rural & disadvantage areas to reduce crippling & death
4. Treatment
   - Safe & Access of Managed Care/Treatment for all, including inhibitor patients
5. Government
   - Improve relationships with Government to educate for the safest & most optimal care delivery process

Situation in South Africa



- Have not!
- Govt Hospitals
- Budget Contraints
- Access to treatment sometimes limited
- Consequences (long term) – Short-term goal





International & Industry Partners

- Have!
- Private Insurance
- Prescribe Min Benefit

Collaborating to bridge the treatment gap for PWH

- Approx 50%of Patients diagnosed
- ~ 1 IU/Capita (mainly due to Private Insurance & PMB)

How do we seek to achieve our Objectives?



- Lets review the ethical principles governing healthcare delivery
  - Health care is a human right
  - The care of individuals is at the centre of healthcare delivery
  - The responsibilities of the healthcare delivery system include the prevention of illness and the alleviation of disability
  - Cooperation between those providing services or receiving services is imperative
  - All individuals and groups involved in health care have a responsibility to help improve the quality of care

How do we seek to achieve our Objectives? Cont.







International Partners

Industry Partners

- Partnerships

6 X Ps = Patient, Practitioner, Public, Private, Partnership & the Politician

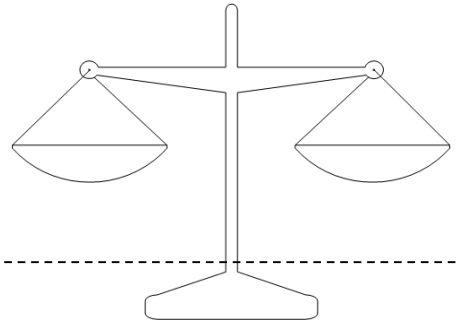
All working together with a common focus
to strengthen the health delivery system and treatment for PwBD

Partnership is a critical ingredient to the success of a Haemophilia healthcare delivery system

Smith *etal* BMJ 1999; 318:248

Roles & Responsibilities (NMO/MASAC)

Shared Responsibility



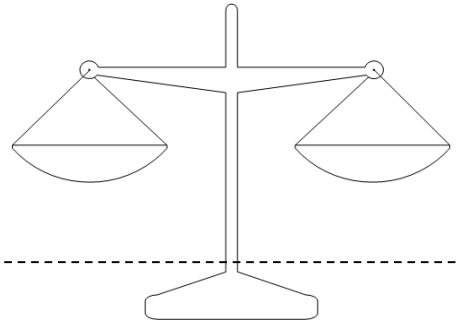
Equality in Decision Making

Strategic Planning
National Haemophilia Treatment Plan

MASAC **Lay Person**

Roles & Responsibilities (NMO/MASAC)

Shared Responsibility



Equality in Decision Making

Strategic Planning
National Haemophilia Treatment Plan

MASAC

- Treatment Standards
- Health Care Advocacy
- Clinical & Technical Expertise
- Haemophilia Treatment Centre
- Treatment of ALL PATIENTS

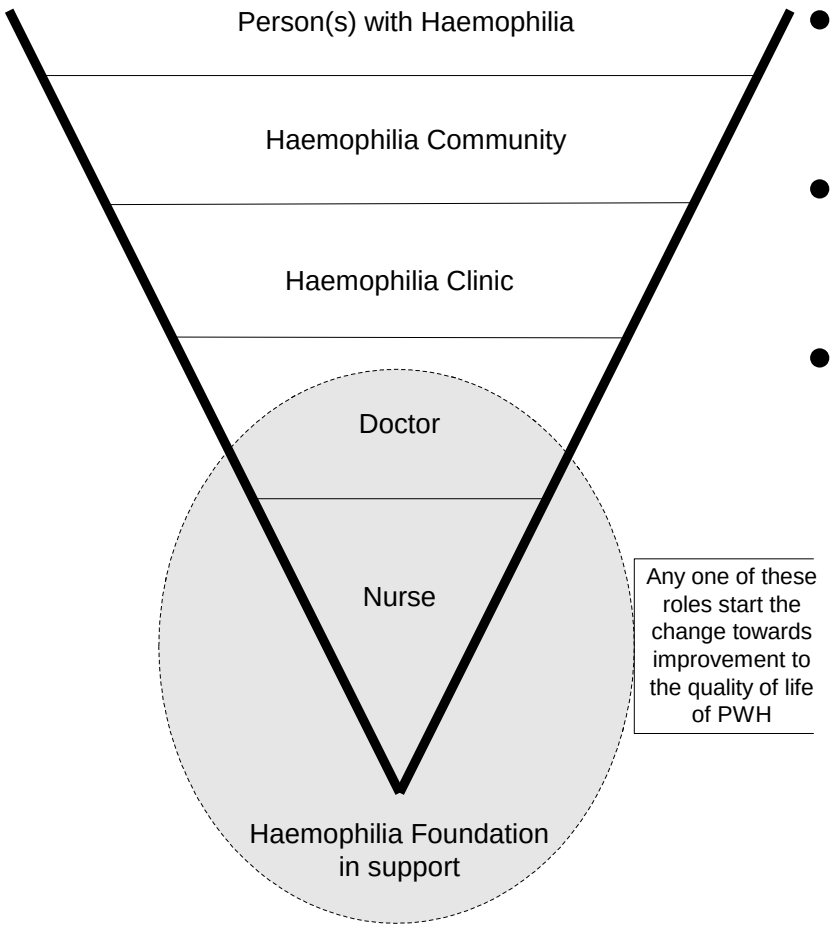
NB: Focus on Healthcare delivery system - Generally employed in Public Sector

Lay Person

- NMO & Operational Management
- Lead Advocacy & Access to Treatment
- Facilitation of Treatment process
- Treatment for ALL PWBD

NB: DO NOT BURDEN the HCW – SEEK TO ASSIST & IMPROVE the healthcare delivery system

Example: Developing the opportunity HTC : Point of Service



- Moving the Point of Service to communities
- Establish funding mechanism [Pharmacist/Hospital CEO]
- Industry support assist to train or establish the facility and thereby achieving our common aims and objectives in improving Health care Delivery System

Example : Overcoming Barriers

- Overcoming Challenges
  - Communication : Cellphone with pre-paid SIM
  - Communication Barrier bridged utilising the “call me” service – free in SA.
  - Transport : introduced a managed petty cash system



Trained Haemophilia Nurses SA- March 2014

North West
55

Population:* 3.56 million

1 nurse / 64 727 people

Limpopo
62

Population: 6.62 million

1 nurse / 106 774 people

Gauteng
86

Population:* 12.73 million

1 nurse / 148 023 people

Northern Cape
3

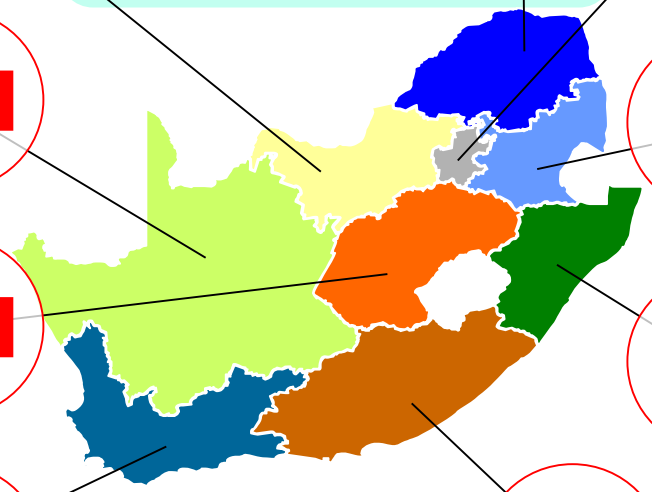
Population:* 1.16 million

1 nurse / 386 667 people

Mpumalanga
92

Population:* 4.13 million

1 nurse / 44 891 people



Free State
55

Population:* 2.75 million

1 nurse / 50 000 people

KwaZulu-Natal
101

Population:* 10.46 million

1 nurse / 103 564

Western Cape
53

Population:* 6.02 million

1 nurse / 113 585 people

Eastern Cape
175

Population:* 6.62 million

1 nurse / 37 829 people

= Trained haemophilia nurses

* Population figures:
Stats SA P032 Mid-year 2013

total South African population mid-year 2013
= 52 989 000

total number of nurses trained = 682

1 nurse / 77 696 people

It is in OUR HANDS



- **SAHF shares knowledge & experience via various projects in Africa with WFH:**
  - Nigeria, Tanzania, Zambia, Malawi, Namibia, Botswana, Zimbabwe, Lesotho, Mauritius amongst others
  - Currently part of a WFH twinning programme with Mauritius to develop the Local Organisation [HAM] & advocate for improved Haemophilia Management & Treatment
- Involved in various International Commitees & programmes

It is in OUR HANDS cont Priceless!!



At a youth camp end Oct 2015.

A 14 yr old encourages a 13yr old to self infuse

Acknowledgements & Thanks

The arm is **PAINING DOC**!!
Any monkey knows the
GOLDEN RULE….
FACTOR FIRST!!!!



- To the SAHF team
- Your attention
- The Organising Committee
- The funders of this event