

## To the South African Haemophilia Foundation

December 2015

With much appreciation for your love and support Anne -Gillham

I thought I would leave you with some archive of events as they unfolded

You all can be so proud of the enormous work load that was undertaken by the early pioneers lobbying for the right to haemophilia care from the 1960's.

In 1994 The Catalyst for the next step and renewed effort was a change in Government and health Policy "health access for all".

I was privileged to be part of the SAHF team that worked tirelessly to advocate for the recognition of the Haemophilia comprehensive care program during this time.

This represented many letters written, follow up, and meetings held with the directorate Maternal Child and Women's health, director Dr. Eddie Mhlanga and sub directorate Women's Health Genetics. Director Dr. Busi Madola.

Dr Madola's active participation particularly with South African Inherited disease association, (SAIDA) enabled her to understand the actual needs of People with Haemophilia and other inherited bleeding disorders. She was a true inspiration in her department with her continued efforts to put a haemophilia program in place

The Lobbying process resulted in the recognition of the Comprehensive haemophilia care program by Minister of Health Dr Manto Tshabala-Msimang In 2000.

In 2001 this was celebrated country wide

The speech prepared for the National function on 29<sup>th</sup> October 2001 at the Johannesburg hospital (now the Charlotte Maxeke Johannesburg Academic hospital) was given by Dr. Shaheen Khotu – Director – National Health Information System.

The speech he delivered is as follows (and I quote)

*"Today we celebrate with the haemophilia Foundation, the official recognition of the haemophilia treatment centers by the Minister of health.*

*Since last year when the minister endorsed initiatives by the South African haemophilia foundation, a partnership between the foundation and the government has developed and along with this a consensus on management agreement.*

*This management will be outlined in the model of care presented later.*

*It must however be mentioned that the support of this Comprehensive haemophilia Care Centers is pivotal in ensuring the aims of the program.*

*This is the providing of equitable care to all People with Haemophilia*

*As more patients are effectively treated, according to the standard treatment guidelines developed by the SAHF Medical Advisory committee, and as this care extends across the country we are sure to see a reduction in disability and death due to under- diagnosis and untreated haemophilia.*

*Haemophilia is the most common hereditary bleeding disorder and can occur in people of any race or creed. It occurs as a result of a deficiency of a blood clotting factor. Some of the problems this deficiency can cause are hemorrhages into joints, muscles, intra-cranial, mouth, gums, urinary tract and digestive tract. If left untreated, a hemorrhage can result in crippling, permanent muscle damage and paralysis and in some cases, death.*

#### *Why Comprehensive care centers?*

*Treatment of Haemophilia consists primarily of the intravenous replacement of the missing factor. Persons with Haemophilia (PWH) in South Africa are treated with a locally produced, virally inactivated factor product.*

*Treatment offered to PWH needs to be comprehensive and some of the very important aspects of Comprehensive haemophilia care are the prevention and management of musculoskeletal complications, physiotherapy, occupational therapy and genetic counseling.*

*This requires the patient to have access to a multidisciplinary team consisting of a doctor, nurse, physiotherapist, occupational therapist, dentist, orthopaedic surgeon, social worker, a laboratory and a pharmacy. Central to this team is the haemophilia nurse coordinator.*

*South Africa has a combination of sophisticated treatment services and sub-optimal medical facilities. In 1968, the first two haemophilia treatment centers were established at the Johannesburg Hospital and the Red Cross Children's Hospital. Today there are four comprehensive Haemophilia centers and three treatment units, which have been established by volunteer treater's and the South African haemophilia foundation in six of the nine provinces. Patients that are currently referred to this hospital come from Mpumalanga, North West and Gauteng.*

*I am informed that it has taken the Haemophilia Foundation thirty years of advocating to various Ministers of health for them to get recognition of these centers.*

*We therefore congratulate the Johannesburg hospital for having supported the work of the haemophilia foundation from the very beginning and celebrate this recognition with you. We hope that this will encourage the hospital and province to lend further support to the work of the haemophilia foundation for the benefit of people with haemophilia.*

#### *What does this recognition mean?*

*This recognition will enable the expansion of the program of outreach and referral to touch the lives of all people with haemophilia in our country. Most importantly, it will enable those PWH who live in remote parts of our country to have access to equitable care. This should therefore reduce the untimely death and premature disability often experienced by PWH.*

*The recognition of the program ensures that:*

- *All PWH will be referred to their nearest recognized comprehensive haemophilia care centers for assessments and treatment protocol.*
- *PWH will then be referred back to their Province health authorities and or local hospital*
- *All eligible PWH will be on Home Treatment programs and where necessary will be financially assisted in order to reach haemophilia centers*

*I would therefore like to commend the haemophilia foundation for the work that has been done to date. You have continued to provide a service for PWH despite all odds. You have made a difference to the lives of people from all walks of life. You have made a difference to many parents who would have otherwise prematurely buried their young sons. We therefore encourage you to continue with the work you have started as a department of health pledge our support to you. '*

Meetings continued to establish methods of implementing the program at grass roots level.

In 2002 Dr Madolo having identified the risks affecting the delivery of care to PWH, engaged the SAHF in Risk management strategies.

The identified risk categories were sent to all MCWH coordinators and heads of pharmaceutical services for comment before being tabled at the Provincial Health Restructuring Committee (PHRC) meetings.

In particular the main area of discussion was the budget lines.

At the second PHRC meeting on 20<sup>th</sup> February 2003 , the PHRC stated their 'commitment to ensuring that haemophilia treatment program be treated as a National service, whereby treatment will be accessible to all people with haemophilia and to ensure equitable treatment to all PWH, funding will be from the National Tertiary Services Grant.'

This document was signed by Dr Louisa Mpuntsha on behalf of the Director General Health on the 29 August 2003 .

The chief negotiators *at the time* were, Mr Paul Scott, Mr Vaughan Chamberlain Prof Karabus, Prof R Cohn, Dr r Schwyzer, Dr D Brittain, Sr Anne Gillham, Sr Anne –Louise Cruickshank, Sr Mirriam Mokwena .

Other role players were Dr Brian O Mahoney from the world Federation of haemophilia

And then of course many behind the scenes, who may not have been the 'front men' but worked tirelessly in supportive administrative roles.

So much work, planning and meetings went into getting this final recognition.

I so loved being part of the team. I thank every one of the then committees, and I am sure all would agree if I say a big shout out to Dr Madolo from National Department of health MCWH sub directorate Human Genetics for fighting in our corner until we achieved recognition.

The then settling in period, and continued work, brought many more players into the fore from all the regions and the WFH.

The twinning program consolidating the SAHF regions

So many wonderful folk, I am afraid to name them for fear of missing one special person.

You have all been so special

Fighting your cause in a upright ethical and persistent way

I stand in awe.

May I just give special mention to dear Judy Butler – always holding things together for us all. Tirelessly and lovingly.

And to the captain of the ship, Bradley Rayner, Brian O'Mahoney and Assad Haffar and staff of the WFH office for believing in me.

There is nothing more a person can ask for in their working life than to be “seen and acknowledged”

Thank you for all your kind words of appreciation and love.

My heart is full.

Anne Gillman.

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