

# NEWSLETTER

THE CENTRAL REGION

January & February 2011



## WHERE TO NEXT?

This has been the biggest question asked in the 2010 year as the small Haemophilia community of the central region experienced lots of challenges. These included shortage of Home Therapy treatment for the patients due to budget constraints, lack of activities for the Central Region, lack of education among the Haemophilia community and many more.

Through the hard work and meetings amongst Health Care Providers and the Haemophilia Community, we have finally found the answer that 2011 is going to be a very good year.

### HOME THERAPY - *Sr Alice Banze*

As early as 05 January 2011, Home Therapy Training was held at Chris Hani Bara Paediatric Clinic. Five boys aged 9-11yrs were taught about the overview of Haemophilia, recognizing the bleed and how to treat the bleed. It was followed by a practical example. Thabang has been infusing himself for the past three years. He initially came to support his peers and to act as the "guinea pig" for the day. He was the first to mix Factor VIII and to self infuse it. This move made all the other boys follow in his footsteps - and they all did well. The boys will continue to practice at home and their next class will be on 8 April 2011. The last class will be in June 2011.

Thanks to the following Chris Hani Bara team: Sr. Angie Makale, Sr. Helen Koko and Dr. Linda Wainwright.

### ROCK GROUPS - *Sr Alice Banze*

On 14-16 January 2011, the ROCK group went to Magaliesburg to attend a fully sponsored Leadership Training Workshop. It all started when Sr. Anne Louise Cruickshank won the Novo Nordisk Foundation Award, in Buenos Aires in July 2010. The prize money will go towards leadership

programmes. The Central Region invited 20 candidates from the Charlotte Maxeke Johannesburg Hospital, Chris Hani Bara Hospital, Steve Biko Academic Hospital and also Dr. George Mukhari.

The boys aged 14- 30yrs managed to unleash their leadership skills including Communication and Teamwork, participated in exercises and mingled with each other. All this was lots of fun for them. Our guest speaker Mr. Tony Roberts who is a Clinical Psychologist based in Cape Town, encouraged the boys to share their stories. He then emphasized on support structures and being able to stand up for their rights. Mr. Vaughan Chamberlain SAHF informed the boys about the history of the SAHF and showed the boys where they fit in as the Central Region ROCK group.

Sr. Alice Banze, Sr. Tuwane Manalo, Sr. Thabi Mnguni and Mr. Kabelo Modisenyane worked very hard in making this camp a success. Many thanks to Sr. Anne- Louise Cruickshank for her contribution.

### COMMITTEE - *Sr Alice Banze*

On 22 January 2011, the opening meeting of the Central Region Haemophilia Foundation took place at CMJH. Many members of the Haemophilia community - even as far as the North West Province- attended the meeting. Thank you all for your presence and the input you made concerning Haemophilia matters.

The South African Haemophilia Foundation Central Region Committee was elected on 05 February 2011. Please refer to the attached list for member contact details.

A warm welcome to all the committee members and we wish you all the best in leading our community.

Behind these new leaders there is a supporting team of the previous committees to guide and support them. We would like to thank them for their ongoing support.

### **CONTACT DETAILS/ADDRESS LIST**

Please all ensure you update your contact details, especially e mail addresses with the foundation.

### **Treatment of Haemophilia - Sr Anne Gillham**

#### **When do we start treatment?**

Early and appropriate treatment of each bleeding episode is critical to minimizing the complications of bleeding in patients with haemophilia.

#### **How much clotting factor replacement is necessary?**

To understand this we must know:

- The severity of the person with Haemophilia.
- Understand the Biologic half life of factor VIII and IX.
- How severe the bleed is.
- Is it being treated early or late.

#### **The goal:**

To raise the factor level from baseline to a desired % correction.

As a rule bleeds treated early need to raise level to 40%.

Late treated bleeds and severe bleeds need raise levels to 80 - 100 %.

The traditional goal of therapy in Haemophilia is to:

#### **1. Replace the deficient factor at the first sign of bleeding to stop the bleeding and prevent resulting complications.**

In some cases to use prophylaxis to prevent any bleeding episode.

#### **Factor replacement:**

Give factor replacement daily until the heat of area has subsided, the swelling is down, the pain gone and some range of motion has returned.

(Use a tape measure and chart sizes for more accurate assessment)

- If the bleed is caught early, only one dose may be necessary.
- If moderately early usually need 3 daily doses.
- If caught very late may take a week or more depending on extent of bleed infiltration.
- If severe life or limb threatening bleed, use 12 hourly treatment or continuous infusion.

#### **2. Immobilize the area that is bleeding**

- By using a splint and Crutches.
- Complete immobilisation the first day.
- Start to remobilise as pain allows.

Try to keep muscle bulk and strength by starting static exercises as soon as possible (usually day 2). These can be done whilst icing affected area .

Weight bearing only commences when there is no pain, swelling down and no heat and full range of motion.

#### **3. Ice the affected area**

### **HOW TO APPLY ICE**

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- 5 mins on 10 min off circumferential.
- If at home 2 - 3 times per day for at least 1 hour, depending on school /work schedule.
- Morning and evening if possible lunch time.

**4. Rehabilitation of the affected area once the bleed has resolved**

**How do we know when the bleed is better and we can commence rehabilitation?**

- No Pain, Reduced Swelling, no heat and return of range of movement. will indicate that it is time for rehabilitation.
- Physiotherapy - guiding principle is that it should not induce pain.
- Exercises to ensure full range of motion (flexion and extension).
- Strengthening exercises.

To avoid a re- bleed when it is necessary to come in daily for factor and physio and ice, immobilise well with a splint and use crutches whilst travelling and catching taxi's.

**To avoid this scenario implement home therapy**

**Signs of a bleed - How do we know when there is a bleed?**

There will be:

- Pain or discomfort
- Swelling
- Heat
- Stiffness or a "tingling "sensation
- Reduced range of movement

**WORLD HAEMOPHILIA DAY**

*Be ready to come and support the dance competition - "Dance for PWH" - on 16 April 2011 at Berario Recreation Centre, Dolores Ave (corner King Str)Berario from 10h00 - entrance is R50. Make the circle bigger - bring family, friends and all.*

*Our sincere condolences to Dr. Rosemarie Schwyzer on the recent passing of her husband.*

**CENTRAL REGION COMMITTEE**

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