



## NEWSLETTER

### THE CENTRAL REGION

August & September 2011

#### Central Haemophilia Annual General Meeting

The Central Haemophilia AGM will be held on 12 November 2011 at 10am, Charlotte Maxeke Academic Hospital (Block1 - Red Block, Level 5, Room 4D). Guest Speakers will be Dr Rosie Schwyzer & Vaughan Chamberlain. We urge all PWH and their relatives to attend. Please refer to the inserted invitation.

#### The National Bi-Annual General Meeting of the South African Haemophilia Foundation

The meeting will be held on Saturday 26 November 2011 at the Protea Hotel OR Tambo Conference Centre (cnr York / Gladiator Streets, Rhodesfield, Kempton Park). The Guest Speaker will be Mr Brian O' Mahony (Past President WFH).

To RSVP please contact either Judy on 021 785 7140 or alternatively email [butlersr@iafrica.com](mailto:butlersr@iafrica.com) or Paul on 011 425 2116 or email [paul.scott@mweb.co.za](mailto:paul.scott@mweb.co.za).

Please refer to the inserted invitation.

**PWH must please ensure that they wear their Medic Alert bracelet or chain at all times. It informs Medical staff that you have the disorder when you are unable to speak and could save your life.**

#### Reflections On An Imperfect Gene - John Bradley Chairman CHF

Five years ago my son was diagnosed with severe Haemophilia B, at the age of six months. At that time my only reference to this disorder came from my matric history on the Russian revolution i.e. the Tsar's son was a haemophiliac. Rasputin could control the boy's bleeds and thus exerted major influence over the Royal Family. All very theoretical and remote. Suddenly it had become a lot more personal. After the initial shock, we settled down to the voyage of discovery that seems to occur in every haemophiliac family.

Having a child with a lifelong, potentially life-threatening disorder is a humbling experience. Before this I genuinely

believed that most things could be controlled or resolved, with enough resources or effort. After this diagnosis I wondered if anything could be that certain again. Initially every fall and bump was analysed, and more tears resulted from the application of ice packs, than from the bumps themselves. As we understood more about the disorder, we panicked less, and got on with the grind of organising early treatment for every bleed.

The journey into home treatment was a traumatic one, with the frustration of not being able to find the vein on my son's hand influencing the complete family in a soul destroying way. Our tears of rage and frustration, and the pleading screams of my son are forever etched in my being. My son now has a port, which has revolutionised his treatment and our family's ability to manage the disorder in a sustainable long term manner.

I am struck by the fact that treatment regimens for blood disorders are improving over time, and the progress made in treating haemophiliacs over the last 50 years. To quote the WHF president, Mark Skinner: "When I was born with haemophilia, treatment did not exist. My parents were told that it was doubtful that I would live into adulthood. Today, someone born with haemophilia can lead a relatively normal life if they have access to proper treatment. "Every day I give thanks for the selfless people who develop these treatments, and for those heroes who administer them.

Our family's journey has been disrupted by my son's haemophilia. However, with the support of his medical team, he leads a normal and fulfilling life. Vigilance, attention to detail and prompt treatment will ensure this.

**PWH who have private medical aid should inform the scheme that they are a haemophiliac. Haemophilia is a PMB (Prescribed Minimum Benefit) on medical aid schemes and therefore your factor must be covered by the scheme. If you are a haemophiliac on a private medical aid, but receiving factor from a state hospital, you are depriving another haemophiliac from treatment.**

## CHF Bursary

If you are intending to study next year (i.e. 2012), and you are struggling to find a bursar to fund your studies then the CHF invites you to apply for limited financial assistance for your education. The application criteria are set out below, and all applications must be received by 15 November 2011.

### Application Requirements:

- Applicant must be a Haemophiliac.
- Applicant must be physically capable of completing the course of study, and doing the chosen job at the end of the day, taking into account your Haemophilia condition ie: No physically intense jobs that would be severely affected by bleeding episodes.
- The institution of study must be residential university or registered, recognised institute of study.
- Applicant must provide a full CV.
- Applicant must provide a letter from the tertiary institute stating you have qualified for the course and obtain a provisional acceptance to do the course.
- Applicant must provide us with copies of letters sent out to three other companies/institutions requesting financial assistance - The Foundation does not have large amounts of money for educational assistance and so is therefore a last resort. You will only be considered for assistance if you can show us that you have done your very best to obtain a bursary elsewhere.
- Applicant must provide the Foundation with a letter from the chosen institution of study illustrating all the costs of the course you intend doing.

### Educational Assistance Rules:

- Should all requirements be met then the Foundation - Central Region Committee will vote on whether to grant assistance. The decision of the committee is final.
- Money will be paid directly to the education institution by cheque. Any refunds **MUST** be returned directly to the Foundation.
- Money for books will only be provided upon receipt of a written quotation and a full receipt for the purchase of the books is required.

- No stationary will be provided.
- Cost to redo failed subjects are for the costs of the individual. Should more than two subjects be failed, then all financial assistance will be stopped until the subjects are passed.
- A copy of all results is required after each exam.
- Should the Foundation hold any event where volunteers are required, the individual will make himself available. Failure to do so will result in a review of the bursary status.

Hope Promotions are having two fundraisers on behalf of the CHF.

- Riverdance on 08 October 2011 at the Teatro Theatre.
- Dancing in the Street on 05 November 2011 at the Cresta Barnyard Theatre.

Please support them in this cause.

## What to tell my child's teachers about Haemophilia - Julie Malan

Every parent with a child with haemophilia fears that day when their son has to go to school. What do I tell the school and teachers? It is important that parents talk to the school and teachers before their son with haemophilia starts school. Knowledge is power and when a teacher knows what to expect, everyone feels reassured and confident. I've found that the teachers are also worried about my son, and need to have all the information necessary for them to feel comfortable about my son's haemophilia.

How do I deal with this situation?

Make an appointment to speak with the teachers before school starts. During this parent/teacher conference, the following information should be discussed:

- The diagnosis and basic details about haemophilia including definition, types and severity of your child's haemophilia.
- Types of bleeds, complications of bleeding and early recognition of bleeding (the knowledge that

your child could inform them that he has a bleed, before there is anything to see, will reassure them).

- First aid recommendations.
- Who to contact and how.
- What treatment is given.
- Will special provision be needed in school (sometimes limitations on physical activity might be necessary when a child has a bleed).
- Any effects to other children.
- A make-up plan for missed schoolwork.

#### Five things all teachers working with your child need to know.

1. My child's blood doesn't clot like most people, and he may be prone to internal bleeding which would not be obvious to onlookers. Please take him seriously if he says he is not feeling well.
2. Protective gear may sometimes be necessary for my child to enjoy physical activities, but he should be allowed to participate. Please work with me on helping him to be as safe and active as possible.
3. My child has a serious health condition, but he is still a child with ordinary interests and hopes and dreams. Haemophilia does not affect my child's ability to learn or perform academically. Please help us keep his life as normal as possible.
4. "He is a boy first. Haemophilia comes second." Boys with haemophilia are interested in getting on with their lives. While haemophilia must be respected, it does not need to dominate his life. Students with haemophilia get up to the same mischief and participate in the same interests as their peers. They have their own dreams and aspirations. This is perfectly normal and the student will significantly benefit by participating with his peers.
5. Please keep the lines of communication open between our home and the school. My child needs to have all of the adults in his life working together.

#### The following information can help reduce the fears that the teachers might have:

- Many people think that a person with haemophilia will bleed to death from a minor cut. This is NOT

true. Bleeding will stop, though it takes a little longer. Bruising is common in PWH. These bruises can often look confronting and usually last longer than the bruising of someone without haemophilia.

- Sometimes parents have been wrongly accused of child abuse because of these bruises, which is devastating for the parents.
- The biggest problem for PWH is internal bleeding into joints and muscle. These bleeding episodes are extremely painful. Bleed sites become swollen and even slight movement can be extremely painful. A person with severe haemophilia may have a bleed after being hit, falling etc. Enough bleeds into the one spot can cause long-term damage, leading to arthritis and immobility.
- PWH have a personalized treatment plan. Treatment is usually given at home by a parent or the student himself. The teacher will not be expected to give the PWH an intravenous "injection". PWH are encouraged to have treatment on the morning of the days they are most physically active.

Because children's veins are small and can be difficult to access, many children with haemophilia have a port-a-caths, often just called 'ports'. A port is a small intravenous device surgically implanted under the skin on the chest. Assure the teacher that he/she will never need to use the port at school.



Should you wish to contribute or have suggestions regarding the monthly newsletter, please forward them to [leonie@lampets.co.za](mailto:leonie@lampets.co.za)

Hope to hear from you soon.

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