



NEWSLETTER

THE CENTRAL REGION

April & May 2011

World Haemophilia Day

Various activities took place all over South Africa in support of World Haemophilia Day.

SAHF members from Cape Town and Johannesburg were interviewed on radio and on SABC 2's Morning Live.

The PWH Dance competition was a great success and a good amount of money was raised for PWH. A group from Kimberley traveled to Sutherland for a parade through the streets on Saturday morning, 16 April and a group of young PWH was taken on a visit to Ushaka Marine World in Durban.

WFH Multidisciplinary Symposium: 25-26 November 2011

The symposium will take place in Johannesburg. Guest speakers will include WFH Vice-President, Drs Alison Street from Australia, Flora Peyvandi from Milan, Rezan Abdulkadir from the Royal Free Hospital in London and a previous president of WFH, Mr Brian O'Mahony.

A WFH Psychosocial Workshop will be held in Johannesburg on Wednesday, 23 November at the OR Tambo Protea Hotel. Social workers from other regions will be invited to attend. Sr. Anne Gillham can be contacted at 083 225 9850, for more details.

Factor Status

NBI are currently upgrading their facilities. Careful planning has ensured that there will be adequate stocks of factor throughout this period. PWH are requested to postpone any elective surgery until the second half of 2011 and to use their factor carefully without compromising care.

Transport Project

On 20 May 2011, a transport project was launched to assist PWH to get to hospital timeously for treatment. This project is funded by Novo Nordisk. If the project is successful the system will be extended to the other major centers. If you would like to be included in this project, please ensure that your clinic is aware of this and have your correct contact details.

Fear of the unknown - A life story of a mother having a son with hemophilia

Fear of the unknown is pretty common. Having a child with hemophilia can make it a daily part of life. With our first child, Samantha, there were no bumps in the road. When Lucas was born two years later, it seemed that everything was fine as well. But only two days later, after a routine procedure caused an unusual amount of bleeding. Lucas was diagnosed with hemophilia.

Because Lucas's hemophilia was caused by a spontaneous mutation, we were caught completely of guard. I did not even know how hemophilia was spelled at the time, let alone anything about the condition! I was terrified as I watched the doctors try to find a vein on our fat little, ten pound, roly-poly baby.

After the initial shock, there was denial and fear. Reading about hemophilia on the internet only brought the fear of worst-case scenarios- that Lucas would have to virtually live in a bubble and never be able to do normal things. It was all I could do to try and not think of Lucas as always being fragile and vulnerable. Fear of the unknown took a foothold in my life.

Instead of embracing milestones, I feared them. Crawling, standing up, his first steps - these were all things that I would anticipate with fear that he might get hurt, and would be unable to stop bleeding and have to spend time in the hospital. The thought of Lucas being hurt by something simple and typical - like bumping his head on a coffee table - scared me into spending the first year of his life in a constant panic. I was always chasing Lucas to make sure he wouldn't somehow get hurt by doing normal kid stuff like running around or playing rough. I would always have us drive instead of fly because I couldn't stand the idea of a hospital or treatment centre not being at arm's reach. My anxiety was putting stress on my family, and on my marriage. I wanted to have control over everything.

It took me a couple of years to get that fear - and the controlling tendencies - under control. I came to realize that the worst thing that hemophilia could do to Lucas was to make him fearful of life. I now understand that, as the mom, I set the tone for everything. I'm the gauge of reaction for other people when it comes to Lucas' hemophilia. If I'm filled with fear and anxiety, it affects how other people treat him - teachers, friends, coaches.... even other family members!

Things have evolved over the past few years, and I've learned to control my fears and let Lucas be a normal kid. As with most 10-year-olds, if you tell Lucas no, you often get the opposite response. It feels good to know that he doesn't think of himself as being delicate or different. We now understand that everybody's got something to deal with, and that we just have to embrace it and be positive.

We're lucky to have a strong support network of family and friends that can help us roll with the punches, and help Lucas if he needs it. I've learned to be okay with him playing sports and running around. I don't want people

treating him like a fragile piece of china, and I don't want him to look at himself and the world influenced by fear. Hemophilia is now just a regular part of our lives. I'm working at one of our local middle schools, and Lucas is just a regular kid. I'm happy to know that my fears won't have to be a reason for him to live his life any differently than he would without hemophilia.

Central Region Membership Fees

Cost of membership for individuals and families is R50.00 annually.

Please refer to the attached subs form.

Very Important! Head bleeds are the main cause of death in PWH. If a headache persists for more than a day the person with Hemophilia should seek medical advice as soon as possible.

