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PRESIDENT'S MESSAGE

The need to be Compassionate Singaporeans

John (not his real name) consulted me the other day for a pre-employment medical check up. John was 35 years old and diagnosed to have moderate hypertension a year ago. He had been put on medication to control his blood pressure. He was concerned if his illness would affect the outcome of his application for the new job. Since his blood pressure was now well-controlled and there were no other complications, he was then considered fit for his job as long as the condition remained stable; and he was advised accordingly.

Like John, many patients, for example, those with diabetes mellitus, epilepsy, coronary heart disease, cancer, HIV, etc., encounter a similar situation. There is often reluctance on their part to disclose their condition or illness for fear of being rejected, prejudiced or marginalized on account of their problems. Many of the members of the Haemophilia Society (people with haemophilia) also face a similar situation. The dilemma of whether or not to disclose their medical condition often deters them from applying for a job or participation of any kind in society and sometimes even further academic studies. Thus, they miss the opportunities that could have helped them to get on in life.

Luckily for John, his medical condition is a relatively common condition that is easily treated and put under control. Hopefully, it remains stable and he can carry on with his life normally. However, if John has a condition that is not so straightforward or simple, or if he has a hereditary condition like haemophilia, that will have recurrent or spontaneous haemarthrosis (bleeding in the joints), he may be absent from work frequently, have a hefty medical bill and perhaps end up with poorer work performance due to his illness even though he applies himself unreservedly to his work. The situation can become more complicated.

In reality, there are many concerns that patients with hemophilia will have. They would be concerned about:

- whether or not to inform their employers about their condition and the possible consequences if they do so,
- the attitude of their bosses and colleagues toward them if they do so,
- their medical bills and their ability to claim from their workplaces for their medical treatment,
- possible consequences if the amount claimed is large and more frequent; and
- the likelihood of getting any medical insurance from the company's insurance cover.

On the other hand, the hiring company may also have their own reservations, e.g., fear of being accused of discrimination, possible excessive medical bills, absenteeism, or impaired work performance.

However, having pointed out the above, the Singapore society of today is seen to gravitate towards being a caring community. There have been improvements in facilities for the less able such as more car park lots assigned to the handicapped, buildings and toilets that are handicap-friendly and public transport that is wheelchair-friendly. The government's recent efforts in this direction should be applauded. They have also started training centers for the disabled to facilitate their employability. For example, there have been special training and skills given to increase the employability of the less able to work as cleaners, call center operators, or even kitchen helpers.

In addition, the public today is more involved in promoting charitable acts, for example, a willingness to donate generously to worthy causes. In addition, many companies have shown their sense of social commitment by hiring disabled employees and promising to pay them fairly.

Thus, a caring society does not need to follow the principle of survival of the fittest. Instead, Singaporeans must be able to assist and help each other. The strong must help the weak. The rich must help the poor. Only then can Singapore call herself a developed society in the full sense of the word.

Dr Gan Kim Loon

A Fun-Filled Trip in Singapore

Kenji Goh, Age 11

14 March 2010, Sunday. I woke up early in the morning and was very excited to go on a one-day tour in Singapore organised by the Haemophilia Society. My Daddy, my mummy and I set off in high spirits to our meeting point at Newton Circus Hawker Centre carpark. My daddy drove and parked the car there.

We reached Newton at 8.15 am and as we were ahead of schedule, we went for a quick breakfast at the Newton Circus Hawker Centre. At about 8.30am, all our tour members came and a total of 14 people boarded our tour bus, xx 8698x with a friendly bus driver and tour guide and we set off to our first destination at the Hay Dairies Goat Farm located at No. 3, Lim Chu Kang Agrotech Park Lane 4, Singapore 718859.

The weather was so humid when we finally reached our destination. I was shocked to see big crowd at the farm even at such an early morning. Everyone was listening attentively to the talk by the person-in-charge. He spoke on how the goat's milk was being processed. After the talk, we wanted to buy some goat's milk as we had not tasted before. There were two types of milk; one was chocolate and one original. I decided to buy the chocolate flavour as chocolate has always been my all-time favourite.

For those who are interested to find out more about the goat's milk, you may check it out at <http://www.haydairies.com.sg/>. You will be able to learn more about the nutrients of goat milk and many other information.

After spending some time at the farm, all of us got onto our mini coach and headed for our next destination, the dragon fruit farm which was just next to the goat farm. In just two minutes, we reached the dragon fruit farm. Everyone took a look at the plants, but most of us were disappointed as there were no dragon fruit at all. There was no doubt we did not manage to see the dragon fruits as it was not in season, Auntie SC managed to buy the dragon fruit stems, hopefully she will be able to bring us some dragon fruits on our next meet up. To read more about dragon fruits, go to <http://en.wikipedia.org/wiki/Pitaya>

Luckily, we got to see other plants like Sweet Leaf Stevia. We tasted it and it was sweet. You may want to read more about it, log in to <http://www.stevia.net/>

Besides getting to see the plants, there was another thing which I was most fascinated about, the Koi Ponds. Auntie May's two sons and myself really enjoyed ourselves feeding the fishes. It was fun and enjoyable. But happy moments did not last for long, as we had to leave for Orchidville to visit the Orchid plantation and to have our lunch there.

Before we proceeded for our lunch at forrest@orchidville, we went to the Orchid garden and we had a good introduction on how to grow orchids by the expert. It was a nice experience. But my stomach was growling, and suddenly I felt so hungry.

Very quickly, we went to the forrest restaurant to have our lunch. My mum had some exchange of experience with Auntie Siew Chin who has a son of 16 years old. While she was happily chatting, the food came. We had sharks' fin soup, roast chicken, vegetable with mushroom abalone, sweet and sour fish, Ee fu noodle, fried oat

prawns and some fruits, together with a bottle of chocolate goat's milk given to us by the Hays Dairies Goat Farm at the end of the meal. Oh what a sumptuous lunch we had! I felt sleepy after that. I was so hungry that I had forgotten to take pictures of the dishes... I only realised it after my lunch and that was too late, sigh....

After having a sumptuous lunch, we were brought to a Taiwan Snack Shop in Woodlands with free sampling on the Taiwan products. And of course we grabbed some stuff like mango pudding, sweet plums etc. After which, we proceeded to our final destination at 42 Lorong 1 Realty Park, that is Lee Wee Brothers' otar and My Genie Gourmet, Hand-made delicacies (Chicken curry puff, Mini Soon Kueh etc). We bought our favourite nasi lemak chilli and some kuey kuey home. This was really a shopping and makan trip.

Our trip ended with a shower of blessing (it rained so heavily) when we were brought back to our meet-up point Newton. Good times are always never enough. This trip no doubt was tiring because of the hot weather but enjoyable. I must thank the organising members for their effort in planning trips for us. Looking forward to more future trips.



2010年3月14日, 星期天的早晨。今天的我起得特别早因为我们将参加Haemophilic Society 主办的一日游活动。

我们兴致勃勃的开车到集合地会合。由于时间还早, 我的父母和我先到小贩中心吃早餐。终于, 每个出席者在8.30分准时到达。我们一行17人, 14人乘搭巴士, 另外三人自己驾车。我们的第一站是Hay Dairies Goat Farm, 看羊去。

抵达目的地时, 只见人山人海, 我很惊讶在这个早晨竟然会有这么多人。羊场的负责人为我们讲解了羊奶的制造过程以及羊奶对人体的益处。在听完讲解后, 我们也买了一些羊奶回家试喝因为我们都没喝过羊奶, 而我选了我喜爱的巧克力口味的羊奶。有兴趣知道多一点羊奶的人可以点击<http://www.haydairies.com.sg/>

羊场之后, 我们继续我们行程的下一个目的地---龙珠果园。抵达果园时, 我们都感到有点失望因为我们都看不到龙珠果。原来龙珠果是有季节性的水果, 而我们来得不是龙珠果生产的时候。虽然, 果园里没有龙珠果, 但我们却参观了别的花草树木, 其中让我印象最深的是甜叶菊 (Sweet Leaf Stevia)。我们都耐不住好奇心, 每个人都把甜叶菊的叶子放进嘴里尝了一尝, 果然是甜的。想认识甜叶菊多一点的人可点击<http://www.stevia.net/>

在龙珠果果园里, 有着一个很大的池塘, 养着很多尾鲤鱼。我和朋友们都买了一些鱼饲料, 喂那些鲤鱼。饲料一丢下池塘, 只见一大票鲤鱼争先恐后地张开嘴巴抢吃, 煞是好看。

告别龙珠果果园, 我们一行人便往Orchidville参观胡姬花以及在那儿吃午餐。

我们在Orchidville 参观了很多种不同种类的胡姬花, 园主幽默有趣的讲解和色彩艳丽的胡姬花让我们都上了一个宝贵的课程。

之后, 我们就在那儿吃了一顿非常可口, 非常丰富的午餐。

用完午餐后, 我们继续我们的行程。我们的下一站是到兀兰的一间专卖台湾零食的店。我们在那儿品尝了很多不同的台湾零食, 我们一边品尝一边选我们喜欢的零食。每个人都买了许多, 人人满载而归。

离开台湾零食店后, 我们再前往今天的最后一站--- 乌打店和糕点店。同样的, 很多人都再次掏腰包买了乌打, 著名的马来椰浆饭辣椒酱, 咖哩卜还有许多不同的糕点。

回家的旅途中, 忽然下起大雨来, 把炎热的天气都赶跑了。这次的一日游虽然有些疲累, 加上天气实在太热, 但是我们都非常享受。

我要感谢Society为我们举办这样成功的聚会, 期盼未来多一些这样有意义的活动。



This seminar was held on Sunday 20th June 2010. This was part of the continuing education programme for our members and their families. Approximately 40 people attended, despite being Father's Day.

There were 2 speakers:



1. **Dr Bala S Rajaratnam**, an old friend of the society, who used to attend to our members in the late 80's, when he was working in the physiotherapy department at Singapore General Hospital. He is presently the manager (projects) of the School of Health Sciences at Nanyang Polytechnic. His topic was "How to get physical safety".



2. **Mr Sam Randall**, a practicing podiatrist with "The Foot Practice" at the Novena Medical Centre, and also at Rochester Park. His topic was "Foot and Joint Care for haemophiliacs".

The seminar commenced at 2.00pm with Dr Bala's lecture. To make it more interactive with the audience, he conducted a short quiz e.g. which is the joint most often affected by bleeding (ankle), the second most common (elbow).

His principle message was people with haemophilia must have regular physical activity as part of their daily life. The reason is that regular exercise reduces joint damage when bleeding occurs. Micro bleeds occur as a natural event in muscles during daily activity, but in the strengthened

muscle, bleeds are minimized. There is a delayed onset of muscle soreness (DOMS).

Signs of joint bleeding begin with a tingling sensation, then warmth and swelling and finally limited joint movement.

Management of a bleed involves:

1. **RICE: Rest** (the joint), **Ice**, **Compression**, and **Elevation**. To use ice effectively, it must be applied for 20 mins and every 3-4 hourly, till swelling subsides. Intermittent application of ice is more effective than a single long episode. The ice can be put in a wet towel, to reduce the cooling rate, and reduce local discomfort due to the cold. Also to keep 3-4 "Ziploc" bags of ice always in the freezer as a standby.
2. Early physiotherapy and mobilization as this improves muscle recovery with early formation of more myotubules, the basic unit of muscle fibres. It also helps nerve regeneration, and progressive reduction of swelling. Professional advice should be sought as stretches and exercises are muscle group specific.
3. Long term management clotting factor prophylaxis and professional supervision regarding regular physical activity. This involves stretching and joint protection with braces. Stretching prevents injuries by improving muscle flexibility.



Dr Bala also showed a short video clip taken from YouTube “You can be a star, living with Haemophilia”: Windows Internet Explorer.

At the end of the talk, 4 of his students demonstrated, with audience participation using resistance exercise band (donated by ANTZ Latex Pte Ltd), a set of stretching exercises. It was thoroughly enjoyed by all.

The second talk on foot care by the Podiatrist, Mr Randall focused on the importance of good supportive footwear for prevention of injury to ligament and joints.

The average person walks 10,000 steps daily, with 4 times the body weight transmitted through the foot on walking. Therefore, to protect the feet, it is important to keep the muscles strong and flexible.

Also, a good shoe can help immensely, especially on hard surfaces, and must have the following characteristics.

1. Sturdy sole.
2. Slight roller (front of the shoe).
3. Laces (for fastening).
4. Sturdy heel counter.

For these reasons, open toe “flip flops” offer no protection for the feet. The shoe with a thicker sole is better.

Sport shoes are ideal. Velcro straps, as long as they are supportive, will also be acceptable.

Insoles can control harmful feet movement, more than shoes, and reduces foot trauma. Also they offer good control of pain level, and reduce ankle degeneration. They can be custom made specific to the foot structure, to redistribute the force and pressure through the joints. This results in better mobility.

After a short question and answer session, high tea was the finale to an informative and interactive session.

It just goes to show that no matter how many times haemophilia care is talked about, each time a new perspective surfaces. The take home message as stated by Dr Bala is “Learn and understand about yourself”.



The World Federation of Haemophilia (WFH) recently published a patient information booklet called “What are Inhibitors?”. The following is an abridged version of the booklet. For more information about inhibitors, visit the WFH website at www.wfh.org.

Definition of inhibitors

Inhibitors are a serious medical problem that can occur when a person with haemophilia develops antibodies (inhibitors) to proteins in factor concentrates. This stops the factor concentrates from being able to fix the bleeding problem.

Bleeding is therefore hard to control, resulting in more bleeding and pain, with the possibility of developing permanent joint damage.

Who is at risk of developing inhibitors?

It occurs more often in individuals with severe haemophilia (less than 1% of normal clotting factor activity) than in those with mild (5-30% of normal clotting activity) or moderate haemophilia (1-5%). Most people who develop inhibitors do so within the first 75 exposures to further concentrates, with the greatest risk occurring between the first 10-20 treatments. This means that inhibitors occur mostly in children with severe haemophilia. But it can occur later in life for mild or moderate haemophilia following treatment.

Also children with haemophilia A (factor 8 deficiency) are more likely to develop inhibitors than those with haemophilia B (25-30% v 1-6%). However, some people with haemophilia B and inhibitors can experience a severe allergic reaction called anaphylaxis, if they continue to receive factor concentrates.

It is recommended that newly diagnosed children and adults should be tested regularly for inhibitors as follows:

1. Between the 1st and 50th days of treatment.
2. Twice a year until they have received 150-200 doses.
3. Once a year after that.
4. Before any major surgery.

Other factors increasing a person’s risk of developing inhibitors are:

1. History of inhibitors in the family.
2. Severe defects in the factor gene.
3. African ancestry.
4. Early intensive treatment with high doses of factor concentrates (especially in the first 50 doses).

People who receive regular treatments with factor concentrates in prophylaxis have a lower chance of developing inhibitors.

Studies are ongoing to see whether recombinant or plasma derived concentrates play a role in developing inhibitors.

Signs & Symptoms of inhibitors include:

1. A bleed is not promptly controlled with the usual doses of factor concentrates.
2. Normal treatment seems less and less effective.
3. Bleeding is more and more difficult to control.

Diagnosis

By doing a routine blood test called the activated partial thromboplastin time (APPT) assay. This test measures the how long it takes for blood to clot. When inhibitors are present, the blood takes longer to clot and does not coagulate fully, even when mixed with normal plasma. A more specific test (a Bethesda assay) will confirm the diagnosis. This test can measure the level of inhibitors i.e. high titre (more than 5 BU) or lower titre (less than 5 BU) Also it distinguishes between a “high responder” and a “low responder”. This will influence the choice of treatment options.

Treatment options

The treatment should be carried out at a haemophilia treatment centre. It can be one the following:

1. High dose factor concentrates.

Infusion of factor concentrates at higher doses and/or more frequent intervals is the preferred treatment for acute bleeding in low responders.

2. Bypassing agents

Such as activated Prothrombin complex concentrates (e.g. FEIBA) and recombinant factor 7a (Novoseven).

3. Tranexamic acid: stops blood clots from breaking down especially in the mouth and nose.

4. Epsilon Aminocaproic acid: holds clot in place in certain parts of the body e.g. mouth, bladder and uterus.

5. Plasmapheresis: to bring down inhibitors quickly e.g before major surgery or in cases where bleeding is not well controlled by bypassing agents.

6. Immune tolerance induction therapy: involves giving to person with inhibitors frequent doses of factor concentrates over several months, or sometimes years, to train the body to recognize the treatment product without reacting to it. Before undergoing this tolerance induction, it is better not to give factor products for acute bleeding, as they are likely to provide a rise in inhibitors level. Both plasma derived and recombinant factor products have similar success rates.

DR TAN HOOI HWA

Extract from WSH information book on inhibitors

VOLUNTEERS

The society is calling for members and their families to serve in the Committee.

No experience is required, just a genuine interest in helping people with haemophilia, their families and each other.

Those interested, please contact the Committee members.



Mrs. Dulcie Cynthia Wilson

Died 23 May, 1999

Mrs. Wilson was a very charming and kind Jewish lady. After learning about people with Haemophilia in Singapore and the haemophilia Society of Singapore, she decided to bequeath a share of her estate to the Haemophilia Society of Singapore in order to help the Society further its cause. She passed away peacefully on 23 May, 1999. The Society has decided to start a scholarship fund in her memory, known as the :

Dulcie Wilson Scholarship Fund.

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2009/2010**

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*The views expressed in
Haemophilia News do not
necessarily reflect those of the
Haemophilia Society of Singapore
or the Editorial Board.*

Announcements

1. Forthcoming AGM

Date : 12 September 2010 (Sunday)

Time : 1.30 - 3.30pm

Venue : Medical Alumni Association Building

2. Renewal of Membership Subscriptions

Members are kindly reminded to renew their subscriptions at the AGM or to mail their cheques to the Society's Farrer Road P O Box 0273 address. The renewal amount is \$40.00 per year or \$100.00 for 3 years. You will be issued a new membership card upon renewal.

3. Society's Constitution

The revisions to the Society's Constitution have been approved by the relevant authorities. The revised Constitution would be given to you at the AGM.

4. Merit Awards

The Society will be handing out its annual Merit Awards to members who have performed satisfactorily in the last academic year. Those who wish to be considered for an award should submit their 2009 academic results to the Society by 15 August 2010 at the latest. Results can be faxed to 64669305 or mailed to the Farrer Road P O Box 0273 address.

5. Factor 8/9 Claims

Members seeking reimbursements are requested to bring their receipts from SGH/NUH/KKCH to the AGM and see Ng Teck Hiang. Kindly be there by 1.00pm.

If you would like to give your support towards the welfare of people with haemophilia in whatever way, please drop us a line or send your donations to:

The Haemophilia Society of Singapore
Farrer Road P.O. Box 0273 Singapore 912810

If you require a tax exempt receipt, please supply your NRIC No. / Business Reg. No.