HAEMOPHILIA NEWS

A Publication of the Haemophilia Society of Singapore | MICA (P) 250/06/2006 | Vol 12 Mar 2010

WHAT'S INSIDE

EDITOR'S MESSAGE

Confidentiality

One of the grumbles that the Society has is the lack of information as to when a member is admitted to hospital for a crisis or for surgery.

It makes it difficult for the Society to provide the social support to the member and his family in a time of anxiety or bereavement.

People with haemophilia are a small village, and are normally supportive of each other. For those who give, it is an instinctive caring for people in similar circumstances, and a sense of reassurance that if the situation were reversed, the same would be offered. For those who receive, it is a source of comfort to know that one is not alone, and it is beneficial for healing.

How do we remedy this situation? Several suggestions have been raised.

Firstly, to request the cooperation of the care givers at the Haemophilia Treatment centres to inform the ex-co members whenever a member is admitted. However, there is the problem of patient confidentiality, whereby the patient would not like his condition to be made known to people other than his immediate families. The Society has to respect this argument, in view of possible medico legal implications. However, if at admission, the caregiver can remind the member or his family members to contact and inform the ex-co, themselves, then this confidentiality hurdle can be circumvented.

Secondly, the member and his family can on their own inform the ex-co members, when things are more stable.

Finally, other members who are aware of the medical situation can also help by informing the ex-co.

This is a step towards a caring and sharing society. Sure, it is not possible to cover everybody, but we should do our best to make a first step.

Dr Tan Hooi Hwa

Rapid or Early Response:
Part Of A New Customised Approach To Hep C Treatment

Mary Sawyer

Treatment for hep C has come a long way over the last 20 years. Treatment can lead to a complete cure and it can reduce your chance of long-term complications such as liver failure and liver cancer, improve your quality of life and prevent you from spreading hep C.

Since 2004, standard treatment for hep C has consisted of weekly injections of pegylated interferon with twice-daily oral doses of ribavirin for six or 12 months. This treatment gives a cure rate of 50-80%, but it has its problems - it's time-consuming and can have unpleasant side effects.

The latest development is the move to respone-guided treatment which can be tailored to the individual person to maximise the chance of a cure while minimising the side effects.

How do you know if have been cured of hepatitis C?
You are cured of hep C when there is no more virus in your blood.

Your doctor will be able to tell you that you are cured if you have a sustained viral response (SVR) to treatment which means that no hep C virus can be detected in your blood six months after you finish treatment.

Research has shown that an SVR to treatment is a good indication that you have cleared the virus for good.

How can you tell how successful your treatment is going to be?
Not everyone has the same results from antiviral treatment for hep C. For example, women do better than men, younger people do better than older people, people with a normal body weight do better than those who are overweight or obese, and people with less liver damage have a better chance of successful treatment. Your iron levels and your alcohol consumption can also affect how well you will go on the treatment.

Two of the most important factors that will predict whether you will have an SVR are the strain of hep C virus (genotype) you have and the amount of virus in your blood (viral load) before you start treatment.

How can your genotype affect your treatment success?
There are six known strains of hep C virus, known as genotypes 1 - 6. Each of these can be further divided into subtypes, such as genotype 1a, 1b, 2a, etc. Some genotypes are easier to treat than others. Your doctor can do a genotype test to determine your viral genotype and help decide the dose of treatment, how long you should stay on it and how likely you are to reach an SVR.

In Australia about half the people with hep C (54%) have genotype 1, about a third (37%) have genotype 3, and genotype 2 accounts for approximately 5%.

If you have genotype 1 or 4 you are generally given 12 months of treatment and have about 50% chance of a cure. If you have genotype 2 or 3 you are generally given six months of treatment and have a 70-80% chance of a cure.

How can your viral load affect your treatment success?
Hep C viral load is the amount of hep C virus in your blood. The results of the viral load test, known as an "HCV RNA quantitative test", are given as the number of International Units of virus in each millilitre of blood (IU/mL). Most people with chronic hep C have between 50,000 and five million IU of hep C virus in each millilitre of their blood. When the test cannot detect any virus in your blood, the level is "undetectable".

- A high viral load is considered to be above 400,000 IU/mL
- A low viral load is considered to be below 400,000 IU/mL
- Changes in viral load are sometimes expressed in terms of logs:
  a 1-log change means a 10-fold increase or decrease;
  a 2-log change is a 100-fold increase or decrease.

Viral load cannot tell you how serious your infection is or how much damage the infection has caused your liver. Its main purpose is to predict how well you will do on antiviral therapy and to monitor how well you are doing once you start. The lower your viral, load when you start treatment the better your chance of an SVR.

With viral load testing and genotyping, your doctor can tailor both your treatment dose and your treatment duration to avoid the downsides of treatment and give you a better chance of an SVR.

Viral load monitoring during treatment
An early decrease in viral load while you are on treatment indicates that it is working. Research shows that people who respond early and rapidly also have a better chance of being cured.

- **Rapid viral response (RVR)**: a viral load of less than 50 IU/mL four weeks into treatment. If you have an RVR your chance of cure is better than 85% and your doctor may recommend that you shorten your treatment.

- **Complete early viral response (cEVR)**: a viral load of less than 50 IU/mL 12 weeks into treatment. If you have a complete EVR you have a good chance of being cured.

- **Partial early viral response (pEVR)**: a drop in viral load of at least 2-log (e.g. from 600,000 IU/mL down to 6,000 IU/mL at 12 weeks of treatment, but still detectable virus in your blood. In people with genotype 1 the chance of viral clearance is low and treatment is generally stopped.
  If the virus in your blood is still detectable at week 24, you have a poor chance of having an SVR: it's very unlikely (only a 1 - 2% chance) that you will clear the virus and therefore treatment is generally stopped.

- **Non-response (non-EVR)**: no significant drop in viral load in the first 12 weeks of treatment.

Summary: Respone-guided treatment recommendations
Having a treatment schedule designed around how you respond to treatment is possible because the diagnostic tests are now available for genotyping and accurately measuring viral load. The main diagnostic test to measure as accurately as possible the levels of virus in your blood is the supersensitive polymerase chain reaction (PCR) TaqMan HCV test.

Give yourself the best chance
There are effective treatments for chronic hep C. Getting the correct treatment at the correct time gives you a chance of clearing the virus from you bloodstream.

Recent research and advances in sensitive diagnostic tests have allowed doctors to make changes to the standard treatment to get you the best results: not all people with hep C should be treated the same. With viral load testing and genotyping, your doctor can tailor both your treatment dose and your treatment duration to avoid the downsides of treatment and give you a better chance of an SVR.

For more information on hepatitis C treatment, talk to the medical specialist who treats your hepatitis C or contact the national hepatitis infoline 1300 HEP ABC (1300 437 222).

Acknowledgement : Haemophilia Foundation Australia

Focus On Footwear

Matt McMillen

Whether you are running a 10K race or simply walking the links at your local golf course, it is important to wear a good pair of shoes or inserts. After all, every step you take puts a little more wear and tear on your ankles. That can quickly add up to a lot of pain and discomfort, especially if you have a bleeding disorder. Wearing proper footwear, however, can reduce the risk of ankle bleeds and arthritic pain, and that means you can stay active and on your feet.

"Being active and healthy is harder to do with bad feet", says Ruth Mulvany, RPT, of the Department of Physical Therapy at the University of Tennessee in Memphis. Mulvany was awarded a National Hemophilia Foundation Physical Therapy Excellence Fellowship for her study of rocker-bottom shoes and their effect on the comfort and gait of people with hemophilic ankle arthropathy, a painful degenerative condition caused by recurring bleeds. "Studies have shown that 6,000 to 10,000 steps a day are recommended for good health" she says. "But when your feet hurt, taking even one step is discouraging".

John McNeil, who has severe hemophilia A, takes footwear seriously. That's why he wears high top sneakers, which provide both ankle support and stability whenever he is on the basketball court.

"I have arthritic ankles" says McNeil, 28, of Charlottesville, Virginia. "If I do something active in the wrong shoes, it hurts the next day."

That kind of pain and discomfort can begin a vicious cycle, says Nicole Hroma, PT, the senior physiotherapist at the Comprehensive Hemophilia and Thrombophilia Program of Children's Memorial Hospital in Chicago.

"If you hurt your ankle and get a bleed, then you will rest it so that it doesn't bear weight." Hroma says. "But when you do that your muscles tighten. That can cause you to lose range of motion and make you more susceptible to future bleeds."

To find the right footwear, Mulvany recommends shopping at a shoe store rather than online. While the internet may be convenient, you need to try on a shoe before you buy it. Look for shoes with good cushioning arch support and plenty of wiggle room for your toes, says Mulvany.

"People with bleeding disorder who have foot and ankle problems do better with sturdy, laced-up, high top shoes that support the arch and the ankle," Mulvany says. "Those who have limited ankle motion often report that they do best if the shoe has a bit of a heel, like a cowboy boot would have. This puts the foot in a position that supports their limited motion."

When McNeil needs shoe advice he turns to his physical therapist.

This is a good idea for anyone with a bleeding disorder. Consult with your physical therapist, podiatrist or orthopedist before buying your next pair of shoes. Such experts can identify problems and provide recommendations while steering you away from styles that could do your feet more harm than good.

Custom-made inserts for people with bleeding disorders keep the foot in place and properly aligned. That, says Hroma, helps to prevent bleeds. An added advantage is that they fit inside most dress shoes, which often lack support. For a study that gathered data from 1999 to 2006, Hroma and her colleagues recruited 60 children who were patients at the Children's Memorial Hospital's HTC. Half of the children wore inserts, while the other half did not. Hroma and her colleagues presented the study at the World Federation of Hemophilia Congress in Istanbul, Turkey in June 2008.

"We had clear results - the kids wearing the inserts averaged about seven bleeds in seven years." Hroma says. "The other kids averaged 30 bleeds."

"Sometimes, inexpensive, commercially available shoe inserts can make a huge difference in comfort and function." Mulvany says. Again, check with your physical therapist or podiatrist to learn what is right for you.

Don't wait to determine what fits your needs best. If you have problems with your feet or ankles, early and aggressive intervention is essential so that you don't lose your stride.

"You need to take care of your feet and ankles early,: Hroma says.

Note from the editor
It is recommended that people with bleeding disorders discuss footwear issues with their physiotherapist. A referral to a podiatrist or other specialist may be necessary. Some state/territory Haemophilia Foundations offer subsidies for footwear.

Rice And Factor..... A Really Smart (And Age Old) Recipe!

Catherine Piggott

Minor and recurrent joint bleeds are the trademark of haemophilia A and B, and the compound effect of damage caused during each episode commonly leads to the alteration of joint function, deformity and pain.

Recognition of a bleed and prompt attention to treatment is necessary to prevent and minimise these long term complications.

You know all about your clotting factor - how much you may need, and how often - and the nurses and doctors at haemophilia centres can help or review your treatment requirements. But having your clotting factor is not all you can or should do for effective treatment. There is other basic SMART stuff that everyone should be reminded of.

Rest/Immobilise
Ice
Compress
Elevate

Rest the joint in a position of comfort - it may need a temporary splint or brace for full immobilisation. Reduce your activity.

For the elbow or wrist you could use a sling.

During a period of major swelling of either the knee or the ankle, when the muscles may be weaker and joint instability may also be a problem, the use of crutches could be recommended for walking and "relative rest" of the joints.

ICE - first check your skin sensation that you can feel and tolerate direct application of the cold temperature, and check throughout the time that there are no redder spots or pressure areas etc - incorrect application can burn the skin!

Remember that swelling often encircles a whole joint, or a large thigh area, so a small gel ice pack will not be a smart choice!

A swollen joint (no matter what the underlying reason) is always painful and has reduced movement.

Try this:

- Ankles, hands, wrists and elbows can all be immersed in a bucket of cold water
- Knees and thighs - get an old towel and fold it into four, wet it, squeeze it, put it in a plastic bag (so it doesn't stick to everything else!), freeze it, remove from the bag, and put it around your knee, thigh, or elbow
- Do cold application for 10 to 15 minutes, perhaps gently moving the joint while the pack is on, and do it 3 times a day while it is still swollen. Smarter, because if you sense a bleed and you are out somewhere, you can always grab an old towel to use!

Compression - to stops excessive swelling, and control swelling after you do the ice packs, the pressure may also slow the bleeding.

A smart choice would be an elasticised circular pull-on bandage such as "Tubigrip". These are available in many sizes - smaller for elbows, medium for ankles, bigger for knees and huge (if necessary) for swollen muscly thighs!

- A double layer worn in the day, but not at night as you have the limb at rest and elevated.

Smart people would have a length of each size in the glove box of the car for instant help at any time! Ask the physiotherapist at your clinic for some next time you are there.

Elevation - this lowers the pressure of blood in the veins, and limits its escape into tissues, thus limits bruising and allows swelling to reduce.

- Place the affected limb on a pillow as you rest, up on a chair or the bed for lower limbs, or high on the table for elbows and wrists. Gently move the limb occasionally so stiffness doesn't set in and to keep the muscle pump action going.

So Remember:
Clotting factor alone is not the only treatment. Also remember that the doctors and nurses at your haemophilia centre are there to help manage the condition, the physiotherapist will be very helpful in advising on a range of paced exercises for mobility and strengthening as you improve, and you can have a great impact on the outcome.

Quick and effective use of these age old hints should improve your own management of a bleed - recovery can be optimised, pain reduced, and restoration of function hastened.

Smarter thinking puts RICE into your factor recipe.

Acknowledgement : Haemophilia Foundation Australia

Taiwan –Visiting of Hemophilia Care and Research Center, Taipei (12/11/2009 – 15/11/2009)

Representing a hemophilia patient family, I joined with SGH hematologist Dr. Ng Heng Joo, senior nurse Lillie Ho and Baxter assistant sale manager Ms. Doris Yeo in a Singapore team to visit the Taiwan Hemophilia Care & Research Center. This event was organized by Baxter Healthcare Group.

Hemophilia Care & Research Center (HCRC) is located in Taipei Tri Service General Hospital. The programme was to celebrate the HCRC sixth anniversary and opening ceremony of newly built HCRC. The new HCRC is sponsored by Baxter.

1. Agenda

- Taiwan patient Society overview:
  - To know how the society operates and assist patient's interest.

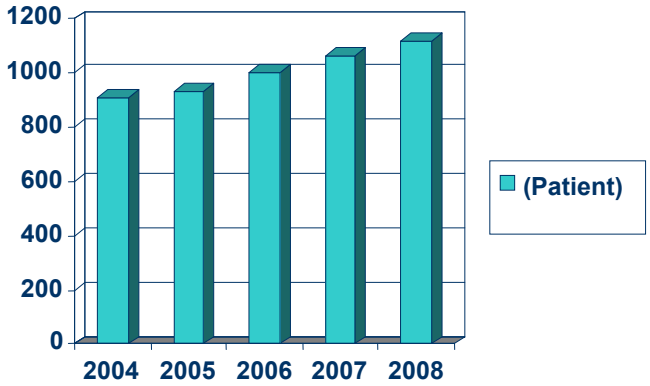
- Hemophilia Care & Research Center sixth anniversary celebration ceremony:
  - Annual review of HCRC activities, appreciation of patients and award for self-infusion, swimming class etc

- Patient activities:
  - To enhance patients' relationship, performance and educational talk on rehabilitative therapy

Below information were provided by Taiwan society, patients and Singapore team.

2. Taiwan Hemophilia Patient

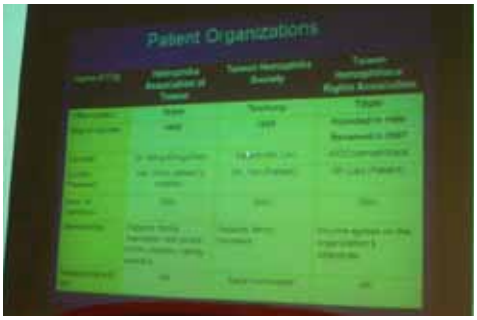
- Taiwan population 23 Million
  - Hemophilia patient (2008): 1,119
  - Patients in each year:
    2004: 908
    2005: 931
    2006: 1003
    2007: 1062



3. Taiwan Hemophilia Patient Organization

There are three Hemophilia Societies in Taiwan:

a. Hemophilia Association of Taiwan (Taipei)
b. Hemophiliacs' Right of Taiwan (Taipei)
(a, b: Using Baxter Recombinant factor)
c. Taiwan Hemophilia Society (Tai-Chong)
(c: Using Bayer Recombinant factor)



4. Taiwan Hemophilia Society Activity

The societies organize different activity yearly, which include:

a. Medical
  - Work closely with hospital doctor and medical team, updating and providing the medical news.

b. Patient's welfare
  - Providing career training and financial support for low income patient etc

c. Counseling
  - Organize seminars, patient care activity, providing individual help to patient if necessary

d. Patient's legal rights and human rights
  - Provide the relevant legal rights and protecting patient's interest

e. Obtaining aid from government and social resource
  - Facilitating patient welfare activity

5. Taiwan Hemophilia Care

Taiwan has excellent health insurance scheme. Under the scheme, hemophilia patients are not only being supported for the cost of anti-hemophilic therapy, but also given priority in treatment and care.

- National Health Insurance Bureau categorize hemophilia as: Rare Severe Disease

- Treatment:
  - All patient are using Recombinant Factor
  - Children are under Prophylaxis treatment

- All patients enjoy privilege of comprehensive health care yearly, which include:
  - Ultra sound, MRI, hematology, orthopedics, dental etc

- Medical expenditure: Fully subsidized by National Health Insurance Bureau

6. How do the hemophilia societies succeed?

Taiwan hemophilia patients used to undertake huge medical expenses. Their success was achieved through effort and unity of the patients, society and medical team for patient welfare.
Below information were provided by the patients.

- Compile existing patient's data, submit to relevant department:
  a. Patient annual treatment expenses
  b. Comparison of income vs. treatment expenses
  c. Patients historical medical treatment record, complication incurred, eg. joint bleeding
- Approach relevant minister: emphasis on the potential new disease and consequences
- Provide hemophilia medical treatment data of other countries ie. Taiwan, Japan, Korea etc. Such data can be obtained from Health care medical supplier

7. **Taiwan Hemophilia Patient Total Annual Medical Expense (x1000NTS)**
Below data was presented by Hemophiliacs' Right of Taiwan. The amount has been converted into Singapore dollar. Below chart shows hemophilia patient expenses were increased annually!

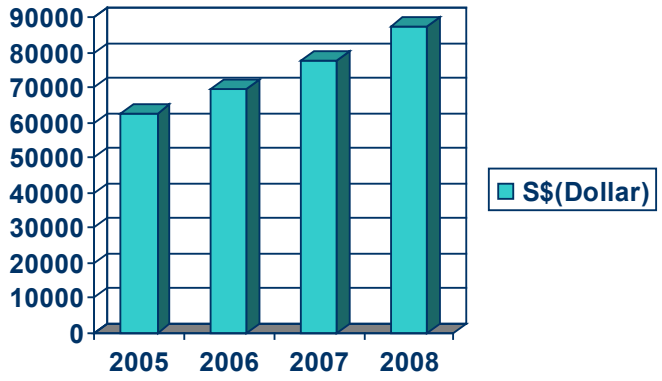
- 2005: 931 patients
  - S$5,941,513 (1,366,548NT)
  - Per patient: **S$63,818**

- 2006: 1003 patients
  - S$6,981,913 (1,605,840 NT)
  - Per Patient: **S$69,610**

- 2007: 1062 patients
  - S$82,683,652 (1,901,724 NT)
  - Per patient: **S$77,856**

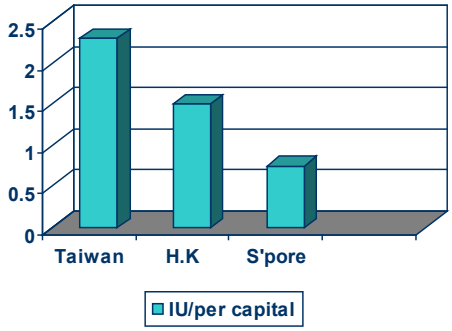
- 2008: 1119 patients
  - S$97,618,695 (2,245,230 NT)
  - Per patient: **S$87,237**

S$1 =NT23



8. **Hemophilia patient annual factor usage per capital**
Calculation: Total IU of factor used / Country population
The chart shows that Singapore anti-hemophilic factor usage is pretty low as compare to Taiwan.

- Taiwan: 2.27 IU
- Hong Kong: 1.5 IU
- Singapore: 0.75 IU



9. **PowerPoint Presentation**
Taiwan patients have been very helpful, below PowerPoint Presentations file were prepared by medical team and sent by Mr. Lee of Hemophiliacs' Right of Taiwan for sharing with Singapore patients.

- Rehabilitative Exercise
- Hemophilia Foot Care
- Medical Treatment for Hemophilia

10. **Other information - Web address**

a. Hemophiliacs' Right of Taiwan
- http://tw.myblog.yahoo.com/hemophiliatw/comments

b. Hemophilia Association of Taiwan
- www.hemoph-assoc.org.tw

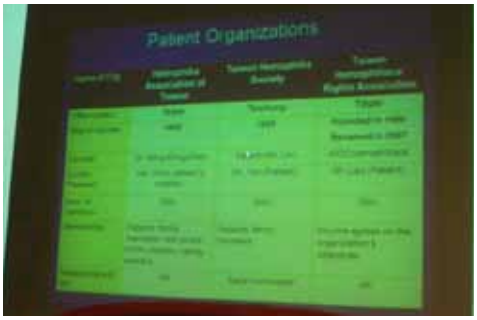
c. Hemophilia Care & Research Center
- http://www.tsghhcrc.org/bbs/index.php

11. **Summary**
The Taiwan trip is fruitful and meaningful; the patients are proactive and positive. I was deeply impressed by the team work of patient, family, society and medical team. The team strives for patients' medical welfare. We hope that Singapore patients will be like Taiwan's; to have better medical care and welfare. This should be our goal for achievement. However, it requires patient and family hard work.

Acknowledgement and information source:
Hemophiliacs' Right of Taiwan, Hemophilia Association of Taiwan, Hemophilia Care & Research Center, Baxter Health Care Group

Reported by: Mrs. Ng (Hemophilia patient: Ng Kheng Chew's mother May)
Date: 19/01/2010

台湾 ---台北血友病防治及研究中心之访
(12/11/2009 – 15/11/2009)

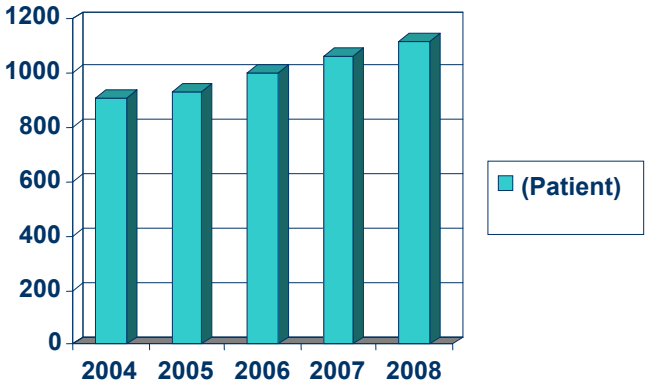


通过百特(Baxter)的邀请与安排, 我以新加坡血友病家属的身份, 同新加坡中央医院血液科医生Dr Ng Heng Joo,高级护士Lillie Ho及新加坡百特销售部助理经理Doris Yeo组成了新加坡团拜访台湾台北血友病防治及研究中心(Hemophilia Care and Research Center).
新落成的血友病防治及研究中心设立在台北三军总医院, 中心设立费用由百特(Baxter)全权支付, 这次拜访活动是基於新中心落成及该中心在三軍總醫院设立六周年庆祝仪式.

1. 日程
(Agenda)
- 台湾血友病协会概要:
  - 了解协会的运做和如何协助患者
- 血友病防治及研究中心(HCRC)成立六周年庆祝仪式
  - HCRC的年度活动, 般奖等
- 病友活动:
  - 加强病友的联系, 娱乐表演, 物理治療運動讲座

以下的资料是与当地协会, 病人及新加坡团交流之后所做的总结, 以供参考:

2. 台湾血友病人数
(Taiwan Hemophilia Patient)
- 台湾人口(2008): 2,300百万
  - 血友病人(2008): 1,119人
  - 其他年度的病人:
    2004: 908人
    2005: 931人
    2006: 1003人
    2007: 1062人



3. 台湾血友病组委会
(Taiwan Hemophilia Patient Organization)
台湾共成立三个血友病协会:
a. 社团法人中华民国血友病协会 (Hemophilia Association of Taiwan) – 会址台北
b. 社团法人台湾血友病浮木济世会(Hemophiliacs' Right of Taiwan) - 会址台北
(a, b: 使用 Baxter 基因工程凝血因子)
c. Taiwan Hemophilia Society - 会址台中
(c: 使用 Bayer基因工程凝血因子)

4. 台湾血友病协会活动概要
(Taiwan Hemophilia Society Activity)
协会使用基金举办各种不同类型活动, 包括:
a. 医疗:
  - 结和各大医院与专业医生与护理人员, 提供最新与最正确的医疗资料

b. 生活
  - 针对病友於就业, 经济提供援助

c. 心理輔导
  - 办理心灵成长活动, 病友联谊活动, 针对个案生活特殊状况进行补助

d. 答辩权益 - 法律与人权
  - 争取应有的权益与提供相关法律权益问题的咨询, 协助

e. 政府与社会资源的协助
  - 透过专案提报, 个案, 加强政府及社会民间福利机构连结

5. 台湾血友病之照顾
(Taiwan Hemophilia Care)
台湾的健保做得非常好, 当地病友不但无需支付凝血因子, 也拥有全面医疗照顾.
- 国家健保局:列血友病为罕见疾病(Rare Disease)
- 治疗:
  - 一律使用基因工程凝血因子(Recombinant Factor)
  - 小孩:提供预防性注射治疗(Prophylaxis treatment)
- 每位血友病人每年拥有全面性检查, 它包括:
  - 超音波, MRI,验血, 关节及牙齿检查等等
- 医疗花费: 全面由国家健保局支付

6. 血友病协会如何争取?
(How the hemophilia societies succeed?)
台湾血友病人原本也需承担庞大的医药费, 他们结合病友, 协会与医生团体的力量极力争取医药福利, 以下是和当地病友交谈后, 记录以供参考:
- 收聚现有患者的数据与资料个案, 呈递给有关部门, 例如:
  - 血友每年度治疗总费用
  - 治疗费用与所得比较
  - 治疗的记录, 出血导致致复杂化, 例如:关节出血等
- 联系相关部长:强调长期出血的后果及重申潜在的新疾病
- 提供其他国家血友病药物治疗数据, 例如台湾, 韩国, 日本. 此资料可从药商取得.

7. 台湾血友病友总年度医疗费用**(x1000NTS)**
(Taiwan Hemophilia Patient Total Annual Medical Expense)
以下资料由台湾血友病浮木济世会(Hemophiliacs' Right of Taiwan)提供, 本人将它换算成新币, 并列出统计表供大家参考. 由表上可知其费用逐年增加.

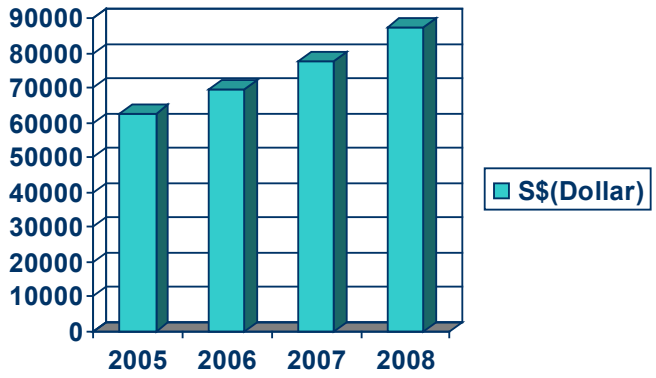
- 2005: 931病人
  - S$5,941,513 (1,366,548NT)
  - **S$63,818 818 (**新币/每病人**)**

- 2006: 1003病人
  - S$6,981,913 (1,605,840 NT)
  - **S$69,610 (**新币/每病人**)**

- 2007: 1062病人
  - S$82,683,652 (1,901,724 NT)
  - **S$77,856 (**新币/每病人**)**

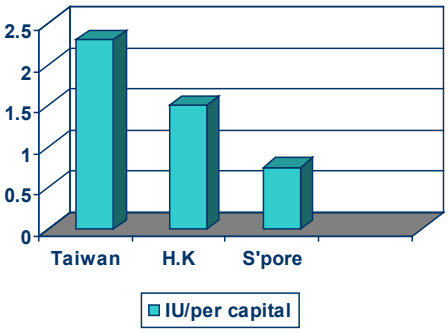
- 2008: 1119病人
  - S$97,618,695 (2,245,230 NT)
  - **S$87,237 (**新币/每病人**)**

1 新币**=23**新台币



8. 血友病人凝血因子每年之用量
(Hemophilia patient annual factor usage per capital)
计算法:凝血因子用量总计/国家的总人口
从表上看来, 新加坡的凝血因子用量十分低和台湾相差甚远.

- 台湾: 2.27 IU
- 香港: 1.5 IU
- 新加坡: 0.75 IU



9. 简报资料
(PowerPoint Presentation)
通过台湾血友病浮木济世会(Hemophiliacs' Right of Taiwan) 理事李先生热切的帮忙, 提供了医疗队所备的简报资料给本地会友们参考:

- 居家物理治疗运动与原则-復健医学部 (Rehabilitation Exercise)
- 血友病之足部保养-物理治疗師 (Hemophilia Foot Care)
- 血友病药物治疗-臨床药学部, 外科加護中心 (Medical Treatment for Hemophilia)

10. 其他网络资讯
(Other information)
a. Hemophiliacs' Right of Taiwan
- http://tw.myblog.yahoo.com/hemophiliatw/comments

b. Hemophilia Association of Taiwan
- www.hemoph-assoc.org.tw

c. Hemophilia Care & Research Center
- http://www.tsghhcrc.org/bbs/index.php

11. 总结
(Summary)
台湾之访, 获益不浅. 当地病友积极及主动. 对於病友, 家属, 协会与医疗队们极力争取血友病人医药福利, 感触万分!这是我们应该努力的目标, 希望新加坡能跟随台湾的脚步, 提升血友病患医疗照顾. 这还需靠本地病友, 家属的努力啊!

鸣谢与资料来源:
Hemophiliacs' Right of Taiwan, Hemophilia Association of Taiwan, Hemophilia Care & Research Center, Baxter Health Care Group

Reported by: Mrs. Ng (Hemophilia patient: Ng Kheng Chew's mother May)
Date: 19/01/2010

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Our First Day in Tri-Service General Hospital, 12 Nov (Thu)...

Dr Chen extending his welcome to the Singapore & China Team. Together with his dedicated colleagues, we were given an overview of the Haemophilia Care & Research Centre in Tri-Service General Hospital.

蔡淑鈴 經理 from中央健保局 (BNHI) gave a presentation on how the Board has been supporting the cost of anti-hemophilic therapy and will continue to stay committed, despite the budget deficit situation that they are facing. Haemophilia patients enjoy privileges similar to patients with severe diseases. They are given priority in treatment and care.

Patients and Nurse demonstrating exercises taught by Physiotherapist

Join these leading authors and publish in *Haemophilia* – view their articles free now at www.blackwellpublishing.com/hae:

Pathogenesis of haemophilic arthropathy
G Rodriendaal, FP Lafeber

Variant Creutzfeldt-Jakob disease: risk of transmission by blood transfusion and blood therapies
JW Ironside

The obstetric and gynaecological management of women with inherited bleeding disorders - review with guidelines produced by a taskforce of UK Haemophilia Centre Doctors' Organization
CA Lee, C Chi, SR Pavord et al.

Congenital platelet disorders: overview of their mechanisms, diagnostic evaluation and treatment
CPM Hayward, AK Rao and M Cattaneo

Quality of life is associated to the orthopaedic status in haemophilic patients with inhibitors
Scalone L, Mantovani LG, Marinucci PM, et al.

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WILEY-BLACKWELL

Forth Coming Events

1. ***Outing: Farm, Factory and Fun***
   Sunday 14th March 2010
   9.00am - 4.00pm

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