



執委會成員：

主 席：蘇子頌
副 主 席：陳達揚、林漢威
文 書：林國東、蔡小琴
財 政：陳綺蓮 康樂：陳景樺
聯 絡：霍偉明、李錦磊
資訊技術：華錫輝
刊物編輯：華錫輝

本會顧問：

梁乃江太平紳士(醫療顧問)
陳志峰教授(醫療顧問)
凌紹祥醫生(醫療顧問)
袁煦樑醫生(醫療顧問)
成明光醫生(醫療顧問)
李澤荷醫生(醫療顧問)
李志偉醫生(醫療顧問)
袁素芬醫生(醫療顧問)
李婉玲護士(醫療顧問)
畢惠貞律師(法律顧問)
楊楊雁華女士(病人組織顧問)

編者的話 • Letter from Editor

過去，血友病人因為血友病引致的種種生活上的困難、不便，總希望有一日能有一條渠道可以讓他們提出訴求，爭取病人應有的權益和保障。一年前，憑着一班熱心人士的無私支持與付出，香港血友病會順利誕生，令全港血友病人的希望可以成為事實。

香港血友病會快一歲了！去年，我們致力於本地的宣傳工作，加強了與各間醫院、醫管局和其它病人組織的聯系；並積極舉辦各種活動和學習班，改善了血友病人的日常護理常識、促進了他們的身心健康。我們見證着血友病會的成長，血友病會亦見證着我們的成長。踏入二零零八年，本會執行委員會即將進行改組及注入新血，但願新一屆執委會能秉承本會友愛的精神，繼續為服務全港血友病人及其家屬綻放人生光彩。

In the past, patients suffering from Haemophilia have encountered many difficulties & inconveniences in their daily life as a result of their illness. They had been hoping for a long time to find a channel, one which would enable them to increase public awareness regarding their right and social security. Finally, thank to the generous support from a group of enthusiastic people we are very appreciative of, the Hong Kong Society of Haemophilia was established last December, which is no doubt an important milestone for the entire haemophilia community in Hong Kong to strike for better quality of patients' lives.

It is almost time to celebrate the first anniversary of the Hong Kong Society of Haemophilia. During the past year, our work has focused on increasing the general public awareness about haemophilia disease locally in Hong Kong. These publicity events have led to the establishment of a supporting network between various hospitals, Health Authority and other patient groups. Through various activities and classes, our patients have received useful education, henceforth enabling them to improve their knowledge of disease-related daily-life management and their overall qualities of life.

We have witnessed the development of the haemophilia society and patients have also observed our growth in parallel. As we approach year 2008, the society executive committee will seek to re-structure and invite new members to join, with the vision to further expand and improve the society. We trust the new committee group will succeed the loving and caring spirits we serve haemophilia patients and their family, so as to offer their lives the best of our wishes.



遠赴加拿大 參加“世界血友病聯盟”全球論壇

Participation of World Federation of Hemophilia Global Forum 2007, Canada

今年的世界血友病聯盟全球論壇 (World Federation of Hemophilia Global Forum 2007) 於九月二十四至二十五日在加拿大蒙特利爾Delta Centre Ville Hotel舉行，主題是“血液製品的供應和安全”。鑑於論壇內容與本會目標有著密切的關係，本會派了副主席林漢威先生、康樂部負責人陳景權先生和本人前往參與，希望藉此增加本會與國際血友病組織接觸的機會，從而引起外界對本港血友病人的關注。



本會主席蘇子頌先生(右一)、副主席林漢威先生(正中)及康樂陳景權先生(左一)到達論壇會場留影。

出席是次論壇的人士包括來自世界各地的醫學界學者、藥廠代表和病人組織代表。我們除認識了目前最新治療血友病的藥物及其技術的發展趨勢外，更與不同背景的血友病組織打了交道。交流中，他們瞭解了本會去年成立的經過，表示支持之餘，亦送上真摯的祝賀。我們也趁此機會向他們介紹了香港血友病人面對的情況，以聽取他們的意見。

論壇過後，Mr.Robert Leung(世界血友病聯盟亞洲區經理)為我們安排了餘下的行程。我們先拜訪了他們位於蒙特利爾的總部，不但獲贈許多由他們出版的刊物，更獲准使用他們一些刊物上有關血友病的資訊。

Mr.Robert Leung隨後安排我們與加拿大血友病會 (Canadian Hemophilia Society) 的代表見面。在他們的總部，我們暢談了一個多小時。其間，他們介紹了加拿大血友病會成立的歷史和向當地政府爭取使用基因重组 (Recombinant) 藥物的過程，並一一解答了我們會員預設的問題。

最後，我們獲安排到達位於Hamilton的McMaster University Medical Centre。該院兒科血友病主管Professor Anthony Chan和他的同事盛情地招待了我們一整天，除了讓我們參觀醫院外，更為我們準備了一連串的介绍，詳細地講述了他們如何向血友病人提供完善的治療和照顧以及他們獨有的、用來監控省中凝血因子的分配和使用量的先進電腦系統。

在旅途中，我們一行三人學會了如何在長途旅程中照顧自己，如凝血因子的攜帶數量和保存、注射時的過關程序、在飛機上要注意的事項等等。是次旅程不僅讓我們上了寶貴的一課，更重要的是，讓本會向國際病人組織爭取認同踏出了第一步。我們將會在來年的周年大會中，與大家分享旅途所見所聞和當中難忘的經驗。



加拿大血友病會活動發展統籌-Clare Cecchini(正中)與本會代表攝於該會位於加拿大蒙特利爾總部。

Clare Cecchini, the Program Development Coordinator of Canadian Hemophilia Society was taken a photo with our representatives at the headquarter of CHS in Montreal, Canada

The World Federation of Hemophilia Global Forum 2007 was held in Delta Centre Ville Hotel, Montreal, Canada on 24th to 25th September 2007. The main theme was The Safety and Supply of Hematological Products. Since the content of the forum was closely related to the goal of our society, Mr. Lam Hon Wai (Vice Chairman), Mr. Chan King Wah (Recreation leader) and I were nominated to attend the forum. We hope that the close contact with other international haemophilia patient groups would increase the general public awareness of haemophilia patients in Hong Kong.

The participants of the forum include global medical experts, pharmaceutical companies and patient organizations. Apart from learning the newest medication and the most recent development in treatment,

we were able to discuss various topics with Haemophilia organizations of different backgrounds, including the process of our society establishment last year. Apart from showing immense support, they also gave us their best wishes. We also used this opportunity to introduce the issues faced by Hong Kong Haemophilia patients, so as to hear their input and comments towards these issues.

After the forum, Mr Robert Leung (World Hemophilia Network Asia Manager) arranged our subsequent itinerary, which included firstly visiting the Montreal headquarters. Not only were we given many of their published works, we were fortunately given the permission to use some of the haemophilia-related information printed on their publications.

Mr Robert Leung subsequently arranged for us to meet with the representative from Canadian Hemophilia Society. We chatted for more than an hour at their headquarters, during which they introduced the history of the Canadian Hemophilia Society, and how they campaigned for recombinant factors with the local government. They also answered all questions asked by our members

Lastly, we arrived at McMaster University Medical Centre situated at Hamilton. Professor Anthony Chan (Paediatric Haemophilia Supervisor) and his colleagues enthusiastically accompanied us for the entire day. Apart from showing us around the hospital, they also explained to us the holistic approach in the treatment and care for their Haemophilia patients, and the highly advanced computer system used to monitor the distribution and consumption of Anti-hemophilic factor.

During this trip, the three of us learned how to take care of ourselves through the long journey, such as the amount of Anti-hemophilic factor to bring, storage and injection issues, things to be aware of on the plane etc. This trip not only gave us a valuable lesson, but more importantly, we took the first and important step to introduce our society to international patient groups. We will share with everyone our experiences from this journey at our Annual General Meeting in the coming year.



打針學習班 (二) Self-Injection Training Class (II)

不少血友病人礙於欠缺信心、不懂得如何處理針藥或不會找血管等原因，一直不會自行在家注射凝血因子，以致每次發現關節或肌肉有出血癰狀時，即使情況輕微，都得立刻趕往醫院求醫，無疑為日常生活帶來不便。有見及此，本會於今年先後兩次舉行「打針學習班」，讓參加者有機會在專業指導之下，學習正確自行注射因子的方法，衝破生活障礙。

第二次打針班於今年九月二十九日在伊利沙伯醫院舉行。與第一次一樣，我們有幸邀得註冊護士兼本會顧問李婉玲姑娘為導師，詳細講解了注射前要準備的東西(如所需凝血因子、消毒紙、手帶、針筒、「飛機仔」、開藥程序及其注意事項(如要防止開出來的藥太多泡沫，切忌上下搖晃，只宜輕力左右前後移動，又若藥物剛從冰箱拿出來，可先放於室溫地方或暖水一段時間，讓其溫度稍為上升才注射)、注射步驟及其注意事項(如藥針或飛機仔只應以大約20度角進入血管，切忌太斜，否則會刺穿血管)等。李姑娘講解後，便由嘉賓袁煦傑醫生用假手(由藥廠提供)示範靜脈注射的正確手法，再由幾位年青病友即場示範替自己打針。參加者認真學習之餘，也積極嘗試和練習，得着不少。「我的囡囡今次是第一次為自己打針呢！」一位家長高興地說。這位家長心滿意足的表情和她囡囡信心的表現，正是我們舉辦這個活動所最為期望的。

It is not uncommon that haemophilia patients are unsure of the appropriate method of handling injectable medication, have difficulty in finding veins, or even lack confidence in self-injection. Hence, patients seldom apply anti-hemophilic factor injections at home. As a result, they often present themselves to hospitals when minor joint and muscle bleeding occur. No doubt this brings inconvenience to patients and affects their quality of life. In view of this, our society arranged two injection-related education sessions to equip them of the necessary skills. Through these sessions, patients were taught by experienced workers the correct way of injections, in hope to resolve their inconvenient barriers.



本會顧問李婉玲姑娘(左一)及正用假手示範靜脈注射的袁煦傑醫生。

The second injection education session was held at Queen Elizabeth Hospital on 29th September 2007. Similar to the first class, we were honoured to have our society consultant Ms Lee Yuen Ling (Registered Nurse) as our instructor. Preparation details, including anti-hemophilic factors dosages, sterile wipes, tourniquet, injection syringe, and butterfly sets, were fully addressed. Ms Lee demonstrated the re-constitution method of anti-hemophilic factors medication, as well as introducing several important issues, such as how to avoid bubbles during re-constitution, to avoid vial shaking only gently roll or swirl the vial to dissolve the

powder, the refrigerated medication have to be left at room temperature or luke-warm water for a period before infusion, injection methods (e.g. needle injection or butterfly angle at about 20 degrees into the vein, as deep angle insertion may cause venous punctures). Each step was shown clearly to the attendees. Dr HL Yuen was also present as our honorable guest and demonstrated the correct method of venous infusion using a manikin limb (supplied by a pharmaceutical company). This was followed by several young patients performing self injection demonstration. All attendees were fully engaged throughout the event and brought home with them lots of useful information. This is the first time my son performed his own infusion! said by a happy and satisfied parent.



編輯 華錫輝 • Editor: Tony Wah

乒乓球活動 Ping Pong Activity

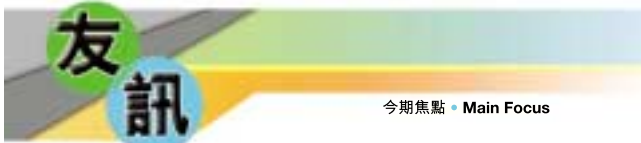
暑假正是舒展身心的時候。為了讓會員意識到運動的重要性，本會於今年八月，一連四個星期六在旺角市政大廈舉行了乒乓球活動。當天參與者有男有女，有老有少，其中更不乏乒乓高手。他們精湛的球技，令我們大開眼界。初接觸乒乓球的小朋友，在大哥哥的悉心指導之下，不但有機會學習各種乒乓秘技，更不愁沒有人逗他們玩耍呢！陪同子女參加的家長也趁此機會交流一翻，彼此分享人生經驗。適量的運動對血友病人是異常重要的。肌肉強化了，關節自然也不會容易受傷。透過今次活動，參加者不但意識到運動的重要性，彼此之間的友誼也在不知不覺中鞏固起來。本會將在明年繼續舉辦這些體育活動，且務求多元化，以讓更多會員可以參與。

Summer holiday is the best time to get physically active. In order to promote the importance of exercise to our members, we organized ping pong activities at Mongkok on all Saturdays in August this year.

Participants included people of both genders and all ages, within which there were experienced players. Their skills impressed all participants. Children who have never played were taught how to play ping pong by older patients. Parents who had accompanied their children used this opportunity to chat and share their experiences.

Modest amount of physical activity is important to haemophilia patients. Strengthened muscles helps prevent joint injuries. Through these events, the participants not only realized the importance of exercise, but also had their friendship with one another strengthened. Our society will continue to hold these exercise-related activities in the coming year, and will strive to include a variety of activities, so as to increase the number of participants.

主席 蘇子頌 • Chairman: Sunny So



總結經驗 • 昂首向前

執筆撰此文之前，我曾經猶豫應否寫這篇文章。想了幾天，我覺得今次太極班之取消並非失敗之事，反而是一個很好的機會，讓我們檢討及總結這次取消太極班的原因，令我們日後籌劃更加適合會員的活動。

外國多份文獻指出，太極有助增加關節炎患者下肢的肌力及平衡。澳洲血友病組織也推廣太極給血友病患者，改善他們的關節問題，他們印製了DVD作教材，本會透過顧問醫生獲得此DVD，更邀請了香港註冊物理治療師教授此套太極，因此便決定推廣太極至本港的血友病患者。剛巧跟瑪麗醫院兒科教授及病人資源中心聯絡，醫院可提供場地及設施，因此便決定在瑪麗醫院舉行太極班。

儘管經過瑪麗醫院病人資源中心張貼海報於有關病房及部門，以及陳志峰教授的熱心呼籲下，只有一位病房護士及一位病人報名參加。因此我遲不得已地取消此活動。其後與執委、陳教授及病人資源中心姑娘作出檢討，分析取消原因：

(一) 有執委認為瑪麗醫院地點太遠，而且本會的會員大多集中在新界及九龍區，減低他們參加的興趣。

(二) 太極對血友病患者的好處是長遠性的，與打針針不一樣，此類運動班對本會會員並非急切性。

(三) 太極對患者父母的吸引力低，所以他們不會帶同子女參加。

(四) 據了解，瑪麗醫院已經有職員太極班，並且已舉辦至高級程度。在相同類型的活動競爭下，本會的太極班的吸引力便降低了。

(五) 經過瑪麗醫院多番商討，本會的太極班是以免費形式讓有興趣的人士參加，因此影響了他們即時報名參與的意欲。

在日後舉辦活動時，我們應該多做資料搜集，看看是否有同類的活動正在舉行，而且要選擇方便的地點。運動班宜有高度的趣味性及會員涵蓋範圍大，讓家長與子女可以一起參加。

Summary from Vice Chairman

Before I picked up my pen, I contemplated whether I should write this article. I thought for a few days, and realized the cancellation of the Tai Chi class is not such a bad thing. It gives us a chance to discuss and summarise the reason for the class cancellation, and will give us a better idea for planning future activities for our members.

副主席 林漢威 • Vice Chairman Henry Lam

執委會退修營 — 檢討過去 展望未來

Summary report of the Executive Committee Camping - Review and Prospect

成立一個組織實不容易，但要維持一個組織的積極運作，甚至完成它的最終使命，就更加不容易了。二零零七年快將過去，今屆執行委員會任期將滿，為了讓來年新一屆執行委員會可以延續創會精神，本年度執委會成員參加了一次退修營，從中總結一年經驗，檢討過去，並為未來工作定下目標，做好準備。

這次退修營於十月二十七日至二十八日在瑪嘉烈醫院舉行，並獲得香港復康會社區復康網絡註冊社工王劍豪先生擔任主持。王社工透過各種互動遊戲，讓我們意識到各人認清自己、目標清晰、方向明確、進度一致、合作無間、溝通充足都是一個成功組織所必須具備的元素。例如，在一個要透過理解不同文字線索去解決問題的集體遊戲裏面，有人帶領遊戲、有人從旁協助、有人給予意見、有人埋頭苦幹、有人默默耕耘……最終透過協商、交流把問題解決。這就反映了由於各人有各人的特點，在一個團體裏面，如果每人都可各依所長，在適當崗位做好本份，往往能發揮團體的最大效能。又如，在一個要“用最短時間順序將球傳送各人”的遊戲裏面，由於每個人對同一句話可能有不同的側重點，要事半功倍，往往需要打破隔膜，坦誠溝通。最後，我們更在王社工的協助之下，為本會未來三年立下遠景。現粗略將當日所得總結如下：

- 透過各種傳播媒介(如報章、雜誌、互聯網、電視)，進一步提升本會知名度，讓社會公眾對血友病有足夠認識
- 緊密與各政府部門(如醫管局、社會福利署、教育署)溝通，提出多關注血友病患者的訴求，以解決他們生活上的不便
- 極力向醫管局爭取提高血友病患者的醫療和藥物水平，如患者由兒科轉往成人或老人科的銜接問題、預防性治療的具體落實、在港設立類似外國的專門照顧血友病患者的醫療中心的可行性問題
- 加緊與世界各地其它血友病組織(首先中國內地、澳門及台灣)接觸、交流和合作，以增加更多渠道獲得治療及照顧血友病病人的最新資訊
- 與社會福利署、復康會或相關部門合作，提供專業心理輔導予血友病患者，尤其兒童及青少年，促進病友身心健康
- 爭取全港七成血友病患者成為本會會員
- 吸納更多熱心青年病友參與本會會務，進一步鞏固本會內部力量，團結一致，為共同目標進發

It is not an easy task to establish an association, and it is even more challenging to maintain the running and complete the set goals of an association. The year 2007 is almost drawing to an end, and our current committee members will soon hand over their work to new committee members of year 2008. In order to enable smooth hand over and continual effective workings of the association, our committee members attended a review camp to summarise the work achieved in year 2007. During this camp, future goals and objectives were discussed.

The review camp was conducted on 27 October 2007 in Princess Margaret Hospital. We were glad to invite Mr Terence Wong, Hong Kong rehabilitation social network worker, to act as the commentator. Through interactive games, Mr Wong enabled us to recognize important factors required to achieve success in running an association, such as understanding more about ourselves, setting correct targets and directions, achieving effective communication with each other. One example is interactive role play in scenarios, where group members act as leaders, assistants, helpers, brain storm-ers etc. By way of discussion, everyone in the group came up with a final decision. This reflects that to serve the association to the very best, everyone must play their own role effectively and to their maximum potential. The game to pass the ball in the shortest amount of time fully illustrated the importance of close cooperation and communication with each other. Finally, we set our three years long term goals under the guidance of Mr Wong. These are shortly summarized as follows:

- To promote the publicity of the association via various media channels (e.g. newspaper, magazines, internet, TV), so as to increase public awareness of haemophilia.
- To work closely with government bodies (e.g. Health Authority, Social Welfare Dept., Education Dept.), in order to further raise the needs and concerns of haemophilia patients.
- Strongly reflect the urgent needs to increase government support on both medical work and medications. For example, to ensure the smooth transition from pediatric department to adult or geriatric department, prophylactic treatment details and confirmation, set up of haemophilic medical treatment centre.
- Build close linkages with various haemophilia patient groups in the world (firstly, China, Macau and Taiwan). Through interaction and cooperation, we aim to set up means to receive the latest development in haemophilia management.
- Through cooperating with social welfare, rehabilitation & other relevant departments, we aspire to provide professional psychological assistance to haemophilia patients, especially for children and teenagers.
- To recruit at least 70% of haemophilia patients in Hong Kong as active members of the society.
- To attract more teenage patients to become volunteers and to actively participate in the workings of the society.

編輯 華錫輝 • Editor Tony Wah



未來活動 • Coming activities:

活動名稱 Activities	日期及時間 Date & time	地點 Venue	備註 Remarks
第二屆會員大會 The 2nd Annual General Meeting	二零零八年 一月二十七日(星期日下午二時至四時) 27 Jan 2008 (Sunday 2-6pm)	伊利沙伯醫院D座地下多用途活動 Multi-function room, G/F, Block D, Queen Elizabeth Hospital, Kowloon	費用全免 Free of charge (有興趣者請填妥終真的參加表格 Interested parties please fill in the application form attached)

血友話你知 Medical Update

血友病的預防性治療

重型血友病患者經常會因頻密的關節出血而導致慢性關節病。這不僅令他們的關節活動能力受到損害，影響日常生活，亦同時加深了醫療機構為治療這些關節病人所帶來的額外醫療負擔。研究顯示，血友病人慢性關節病的成因往往是由於未能接受足夠的凝血因子替代治療。因此，醫學界不少學者都提倡為血友病人提供預防性的凝血因子替代治療，希望減低血友病人罹患關節病的風險。

“預防性治療”主要有以下兩種方式：

- 一級預防：指在“2歲之前而從未發生過任何關節出血”或“任何年齡而在關節受到損害之前（即發生最多1次關節出血）”就開始長期、連續的預防治療。
- 二級預防：不符合一級預防的標準而進行長期、連續的預防治療。（這裏“連續”是指為患者設定每年52週的預防治療直至成年而患者亦實際上每年接受至少46週的預防治療）

臨床證據表明一級預防能夠防止年輕的重型血友病患者發生慢性關節病。根據國際矯形外科的研究結果，瑞典、英國及德國的患者都因使用一級預防得到預防效果，引證了這個結論。在法國、荷蘭以及瑞典的其他一些實驗研究，經過對比不同的治療方法，也得出了相似的結論。

在瑞典，多年以來一級預防已經成為重型血友病患者的標準治療方案。根據藥物動力學研究，每位患者的治療劑量和間隔時間雖會有所不同，但治療目的都是維持體內凝血因子VIII及IX的水平在1%以上，從而使出血傾向得到有效控制。除了減少出血機會外，一級預防治療亦可明顯縮短重型血友病患者的住院時間，並減少就診日間護理的次數。大多數經過一級預防的患者，其外科檢查和影像學關節評分都維持於正常水平。

因此，學者們得出結論：在第一次發生關節出血後，越晚進行預防治療，將來發展成為關節損害的風險越高。很多權威的國際醫療及衛生組織，如World Health Organization, World Federation of Hemophilia, United States National Hemophilia Foundation, Canadian Hemophilia Society都建議要為重型血友病人提供一級預防性治療。

當慢性關節病形成後，二級預防治療仍可減慢病情的惡化，達至舒緩病徵和改善關節功能的效果。

落實全港適齡血友病患者及早進行“預防性治療”並不只為血友病人的健康想的，更是顧及到醫管局需要節省開支的問題。一旦“預防性治療”得到全面推行，血友病人因關節出血或性關節病而求診的數字將可減少，醫院的負擔自然也可相應地得到舒緩。所以，預防性治療方法其實是對未來進行投資，確實需要有關當局對此進行認真的考慮與研究。

Long-term Prophylaxis

Most of the physical, psychosocial, and financial disabilities that affect patients with severe haemophilia are the result of recurrent hemarthrosis and chronic arthropathy. Substantial evidence suggests that the development of chronic arthropathy is related to insufficient factor concentrate replacement therapy. Over the past decades, experts from various countries have advocated the use of long-term prophylactic factor replacement in this group of patients in order to reduce the frequency of hemarthrosis and hence to prevent chronic arthropathy. Recombinant factor concentrates, with a theoretical superior safety with respect to transmission of infection, may increase the acceptability of prophylaxis to parents and patients.

There are two types of long-term prophylaxis:

- **Primary prophylaxis:** defined as long-term continuous prophylactic treatment initiated prior to the age of 2 years and before any clinically evident joint bleeding or prior to the onset of joint damage (presumptively defined as having had no more than one joint bleed) irrespective of age.

- **Secondary prophylaxis:** defined as long-term continuous prophylactic treatment that does not fulfill the stringent criteria for primary prophylaxis.

In this context, continuous means an intention to treat a patient with prophylaxis for 52 weeks per year until adulthood and with that patient actually having received prophylactic treatment for at least 46 weeks per year.

Clinical evidence demonstrates that primary prophylaxis can prevent haemophilic arthropathy in young patients with severe haemophilia A or B. This was shown in patient populations in Sweden, Great Britain, and Germany, in addition to an international orthopedic outcome study. Similar conclusions were reached in studies that compared different treatment regimens conducted in France, the Netherlands, and Sweden.

In Sweden, primary prophylaxis has been standard practice for many years in cases of severe haemophilia. Dose and dose intervals are individualized for each patient through pharmacokinetic studies. The goal of maintaining a FVIII or FIX level greater than 1% is used as a guideline to achieve satisfactory control of the bleeding diathesis. Inpatient hospital stays, outpatient, and daycare visits were significantly reduced in individuals with severe haemophilia on primary prophylactic regimens. Clinical studies have shown that the orthopedic and radiological joint scores do not deteriorate with time in most patients treated with a primary prophylaxis regimen.

Data strongly indicate that in order to prevent haemophilic arthropathy, effective prophylaxis should be started before, or at the latest immediately after, the first joint bleed in patients with severe haemophilia. The longer the start of prophylaxis is postponed after the first joint bleed, the higher the risk of developing arthropathy. Many national and international authorities, including World Health Organization, World Federation of Hemophilia, United States National Hemophilia Foundation and Canadian Hemophilia Society have recommended primary prophylaxis as the optimal treatment for severe haemophilia A and B patients.

In patients who have already developed chronic arthropathy, secondary prophylaxis can help to reduce symptoms, improve functional status and slow down further deterioration of the affected joints.

The implementation on prophylaxis for patients with haemophilia not only helps to reduce the frequency of bleeds and the development of arthropathy in haemophilia patients, but also, in the long run, helps decrease the medical expenditure on arthropathy case related to haemophilia. Thus, all prophylactic measures are in fact investments for the future. Concerning institutions like the Hospital Authority should take serious consideration into the studies and implementation of such measures, so as to benefit both the haemophilia community and our society.



血友之聲 Voice from Haemophilia Patients

無知

從小已經感覺到，無知是一個很大的罪惡。在小二的某天，我如常在課堂享受著我最愛的健教科。在好奇心如常的驅使之下，眼睛如常的左右掃瞄一下周圍的朋友在幹什麼，發現今天的明星就是我。但是幹癩這些眼神真的像在動物園看珍禽異獸時的眼神呢？奇怪得有點不爽。到了小息的時候，朋友們都很快衝去小賣部買東西，當然我也如常的飛奔到小賣部，希望能在止課前可以享用一下美食。發現朋友見到我就移開身子去第二條隊伍排隊去了，是不是我又做了什麼錯事？我打了他們一頓？我咬了他們一口？

懶理他們，還是快快的買完就坐在校外的大樹下食個爽。或者是我食得太像暴龍，我的朋友們在遠遠的看著我食東西的怪相。小時候的耳朵真靈，加上順著風向的聲音，我聽到原來是他們在說我壞話。

「他有病呢。」「什麼？真的嗎？」「會傳染的吧？」「不會吧？我很怕呢。」「嘿！怪物！怪物！」「不要這樣說啦，他是我們的朋友，但是他的確有病……」「會傳染的，不要接近他！」「是啊！」

超難聽的接著下去，但是我已經聽不到，心裡面感受到的只是一種莫名奇妙的痛苦。奇怪在，我只對我某個好朋友說過我的病，為什麼要告訴給其他人知？我明明不想其他人知道我的事的，因為我覺得自己與人家不同，就算成績不錯，還是有其他層面上的不同。幸好幾個月之後我就要搬家了，以後都不會回到這個鬼地方。

在新的小學渡過了三年的時光。小二時的陰影還是揮之不去，從來都沒有對過朋友甚至老師提及過我的病，手冊上都只是寫「因手痛，腳痛入院」加一張病假紙就了事。朋友常問我有什麼問題令我不能上學，「沒有啦，手痛了啦。」

「那，你手上包著紗布的是什麼啦？」「嗯……擦傷而已。」

從小到大都心直口快。有一堂是我班主任的堂課，我還記得那天的堂課自修就好，坐在教師桌前的我在專心的做功課等待回家的鐘聲響起。老師突然好奇心起：「為什麼會時常不上學？是不是被什麼病纏著啦？」一句，「其實我有血友病的。」兩句，沒事。第三句老師就對大家說：「同學們聽好！這位同學有病，你們不要碰到他，碰到他，傷了很難止血的。明白沒？」這一句就令我的朋友在這兩年裡面不敢跟我玩遊戲。

我很我的口快，但我沒有恨我的病。因為我知道如何令自己玩的時候不會傷。換一個角度，但我的母親不相信，或許我表達能力是我比較差的一項吧。

小學這麼多年都沒有去過體育課，中學也是。只不過兩者的分別是，小學我循規蹈矩，中學時，就算我媽一如往年的寫信給老師說只許我做柔軟體操也好，我就會跟老師說一聲：「我能做的我會做，不能做的我會不做，請給我選擇。」當然我差不多每課都有參與啦。隨著年紀的長大，發覺我的身體比小學時的好多了，我會問自己：「為什麼我不能做運動？」我漸漸知道，從小在周圍給我的訊息都有一些不能言喻的問題存在。大家都可以說我反叛，我會覺得自己在測試自己的能力是不是真的這麼不濟。

發現，我真的可以做運動的，自己僅安全就一切可以。那時並未有現在新的血友病會，當然，亦未接觸到更新的血友病資訊啦。

與同病相憐的友人們談及，分享，大家互相的解決生活上的問題，令我更感覺到知識的重要。

後來的小學生活裡面，我開放地提及我的病，將醫生所提供的血友病資訊無一遺漏地告訴我老師和熟悉的朋友知道，有問必答。他們了解了多，就不會避諱，更加不會歧視你，傷害你。

家人從前常叮嚀：「不要去，不要做，因為你有病。」，但是只要父母知多些，讓他們知道血友病人並不是一塊豆腐，就能令他們放心，亦令血友病人不會受到太多「關心的煩惱」。

到了現在，不是賣花讓花香，參加了這個血友病會，讓我感受到自己知道的事原來是這麼的少，不停的新資訊在轟炸我的腦袋，亦令我如何怎樣和血友病共處。

從前，在我叛逆的中學時代裡面，有位老師這樣講過：「無知是一種罪惡，未來的恐懼是因為無知，只有增加知識，才可以洗淨自己的罪，為未來帶來光明。」我想，我明白了。



您也希望與全港血友病友分享面對血友病的經驗和感受，彼此互動互勉嗎？無論您是血友病人、其家屬或朋友，都歡迎投稿。您的心聲，將會是彼此的一份鼓勵、一份支持和我們繼續向前的一份動力。不要吝嗇您的熱誠和創意了，成為下期的血友之「星」吧！

投稿細則：

- 作品以文字或圖畫表達均可
- 文字作品散文、詩詞不拘，中英均可，字數宜不超過1000字
- 作品請郵寄至香港血友病會九龍橫頭磡宏禮樓地下，「香港血友病會」收，信封註明「血友之聲」投稿
- 所有作品概不予發還
- 本會保留作品增刪、改寫、刊登之最終權利

Ignorance

I have realized that ignorance is criminal since I was little.

One day in 2nd grade, I was enjoying my favourite health and physical development class as usual. I looked around to see what my friends were doing, and realized I was the celebrity for today. But how come the look on their faces and in their eyes resembled looking at beasts and creatures at the zoo? It didn't feel right.

When there was a recess break, I was amongst the children to run to the canteen, in hope that we can finish all the delicious snacks before class began again. I then realized my friends had abandoned me and moved towards a different queue when they saw me approach. Did I do something wrong? Did I hit them? Did I bite them?

I didn't care, I quickly bought my food and ate it under a big tree outside the school building. Perhaps I looked like a dinosaur, because my friends were watching my every move from afar. My ears were very sensitive, and as the wind was blowing my way, I finally realized they were talking about me.

He s got some disease, What? Really?, Can we catch it?, Oh no, I m scared, What a monster!, Don t say that, he s our friend & but he really has some disease, It s infectious, don t go near him!, Yes, yes & .

There were much harsh words to follow, but I already gave up on listening. My heart was literally in pain. The funny thing is, I only told one of my best friends about my illness, how come he s told everyone else? I didn't want anyone else to know about it, because it makes me different from other people.

Even though my school results are not bad, this still puts me in a different category to other people. Thankfully, we moved house a couple of months later, and we never came back to this horrible place. (I spent the next three years at my new primary school. I could still remember the agonising recollections of 2nd grade, hence I never told my friends, or even my teachers about my illness. My handbook often bore the simple words of I have to attend the hospital due to limb pains, plus a medical certificate, no questions asked. My friends often asked me why I was absent so frequently, I would reply Nothing much, just some pain in my arms. Then how come you have a bandage around your arm? Oh that & I accidentally scraped it .

Since little, I seldom think thoroughly before speaking. I remember that day I was in my home teacher s class. It was a self-study class, and I sat in front of my teacher concentrating on my homework whilst waiting for the end-of-school bell to ring. My teacher suddenly asked Why are you often absent from school? Are you sick? . I actually have Hemophilia . My teacher then said to the class Please listen everyone. This student have an illness. Don t touch him. If you push him, he may bleed heavily and may be difficult to stop. Understand? This informal address led to my friends abandoning me in the next two years. (I hate letting my tongue slip. But I don t hate my illness. Because I know how to avoid injury when I play. My mother don t believe me though, perhaps my expressive speech is not my forte.

I never attend physical education classes in both primary and high school. The difference between the two is that I strictly followed the rules in primary school. During high school, although my mother wrote to my teacher every year to allow me to do gentle gymnastics, I usually say to my teacher I will do what I can do, and won t do what I can t do. So please let me choose . Of course I participate in almost every class. As I grow up, I realize that my health is much better than when I was young, and I ask myself Why can t I participate in sports? I have slowly come to realize that the information relayed to me since I was young are unclear and muddled. Everyone may say I am rebellious, however I tend to question whether I am actually as dreadful as they say.

I finally realize that I can actually do sports. I just have to be more careful with everything I do. At that time, there was no Haemophilia society, nor was there any method to access updated Haemophilia information.

Through chatting and sharing our experiences with one another, I have come to appreciate the importance of updated knowledge.

In the following high school days, I openly talk about my illness and share other relevant information my doctors provide with my friends and teachers. I always try my best to answer all questions. I have come to realise that the more they understand, the more they will not avoid the topic, and in turn will not discriminate you or upset you.

Family have always said Don t go, don t do, because you have an illness . However, the more our parents know, the more they will realize Hemophilia patients are not pieces of tofu. This will make them more at ease, and hence reduce the love and caring stress experienced by patients.

I never realized I knew so little until I joined the Haemophilia society, where additional knowledge have allowed me to enhance my communication with other patients.

One of my teachers once said in my rebellious high school days Ignorance is criminal, fear is due to ignorance, the only way to be acquitted of our crime is to increase our knowledge, to bring light to the future. I think I understand.



香港血友病會

第二屆會員大會

一年之計在……新年！！

日期： 2008年1月27日 (星期日)

時間： 下午二時至六時

內容： 執委會選拔、有獎遊戲、茶點招待等

地點： 伊利沙伯醫院D座地下多用途活動室

費用： 全免

查詢電話： 9515 1039 (霍先生) 或 9724 1987 (黎太)

報名方法： 郵寄報名表至本會以下地址: 九龍橫頭磡村宏禮樓地下香港血友病會收

截止報名日期： 2008年1月13日(以郵戳為準)

溫馨小提示： 如果閣下選擇續會，本會將在大會當日收取續會費用 - 會員\$50元；友誼會員\$50元，多謝合作。

AGM

香港血友病會第二屆會員大會 (請以中文填寫表格，多謝合作)

姓名	會員	非會員	會員編號
1.	<input type="checkbox"/>	<input type="checkbox"/>	
2.	<input type="checkbox"/>	<input type="checkbox"/>	
3.	<input type="checkbox"/>	<input type="checkbox"/>	
4.	<input type="checkbox"/>	<input type="checkbox"/>	

通訊地址: _____

電郵地址: _____

聯絡電話:(手提電話) _____ (住宅) _____

如閣下選擇續會，請在空格裡加上✓號。

入會 / 續會表格 Membership Application / Renewal Form



香港血友病會
Hong Kong Haemophilia Society
會員申請 / 續會表
Membership Application / Renewal Form

本會專用 For Office Use Only
會員編號: Membership No:

會員資格 (請在適當位置加上 ✓ 號) Membership Subscription (Please tick the appropriate items)

會員申請 New Application / 續會 Renewal

會員類別 Membership Type	詳細資料 Details
<input type="checkbox"/> 基本會員 Full (<input type="checkbox"/> 病人 Patient / <input type="checkbox"/> 病人親屬 Patient s relatives) \$50	病人姓名 Name of patient: 關係 Relationship:
<input type="checkbox"/> 友誼會員 Associate (其他人士 Others) \$20	友誼會員 (其他人士) Associate (Others) \$20

你有興趣成為 執行委員會議列席者 / 本會義工 ?

Would you like to attend the ex-committee meeting / be a helper?

個人資料 Personal Information

姓名 Name (與身份證相同 as in HKID): (英文 English) _____ (中文 Chinese) _____

身份證號碼 Hong Kong Identity Card No: _____ 性別 Gender: 男 Male / 女 Female

出生日期 Date of Birth (年 yyyy / 月 mm / 日 dd): _____

通訊地址 Correspondence Address: _____

聯絡電話 Phone: (手提電話 Mobile) _____ (住宅 Home) _____ (傳真機號碼 Fax) _____

電郵地址 E-mail address: _____

病人病歷資料 Medical History of the patient

所屬醫院 Hospital: _____

病症 Diagnosis: 缺乏第八凝血因子 Factor VIII Deficiency / 缺乏第九凝血因子 Factor IX Deficiency /

其他 Others: _____

付款方法 Payment

請附上劃線支票，抬頭註明香港血友病會，支票背面寫上會員姓名及聯絡電話號碼，把填妥的會員申請表及支票郵寄到香港血友病會九龍橫頭磡宏禮樓地下 (封面註明：會員申請 / 續會)

Payments should be made with CROSSED CHEQUE ONLY payable to Hong Kong Haemophilia Society with you name and contact telephone number on the back of the cheque. Send the completed form and cheque to Hong Kong Haemophilia Society, G/F, Wang Lai House, Wang Tau Hom Estate, Kowloon, Hong Kong (Re: Membership Renewal / Application).

支票號碼 Cheque Number: _____ 發票銀行 Bank of the Cheque: _____

聲明 Declaration

本人聲明以上資料及其他附加資料全部屬實及正確。本人同意遵守香港血友病會會章的內容。

I declare that all the above information and all substantial documents are true and correct. I agree to abide by the Charter of Hong Kong Haemophilia Society

日期: _____ 簽署: _____

鳴謝 Acknowledgement:



香港血友病會
The Hong Kong Society
for Haemophilia
以血為友
Living with Haemophilia Matters

Baxter



Bayer HealthCare
Bayer Schering Pharma

Wyeth

(特別鳴謝 Bayer HealthCare 協助參與今期友訊的製作。 Special thanks to Bayer HealthCare to assist in the publication of this newsletter.)