

# HAEMOPHILIA

SOCIETY OF SINGAPORE



ANNUAL  
REPORT  
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## CONTENTS

President's Message	1
Highlights of the Year	2
"Advocacy in Action Workshop"	3
Key Programmes	4 & 5
Youth News (I)	6
Youth News (I)	7
Financial Information	8
Our Donors	9
Executive Committee & Contact Information	

## ABOUT US

The Haemophilia Society of Singapore is a voluntary organisation that was set up in 1985 by a group of people with haemophilia, parents, healthcare providers and some interested professionals. It is an Institution of Public Character and an affiliated member of the National Council of Social Service and a member of the World Federation of Haemophilia.

The Society's main service to its members is to provide subsidies for members' treatment costs at government hospitals. This is to alleviate the high costs that members often incur following bleeding episodes. Apart from financial assistance, the Society offers support to parents to help them cope with a haemophilic child, promotes home treatment and keeps members abreast of developments in the area of haemophilia care.

### **Our Mission**

To ensure that every person with haemophilia receive affordable and safe treatment so as to lead productive lives in society.

### **Our Objectives**

- To help people with haemophilia to achieve their potential.
- To look after the welfare of people with haemophilia.
- To assist with treatment costs.
- To promote public awareness and understanding of haemophilia

## PRESIDENT'S MESSAGE



Over the past twelve months, there were significant developments in the area of haemophilia care and community involvement. A chance encounter with Dr Ivy Ng, Chief Executive Officer, SingHealth Services, at a mooncake festival at Singapore General Hospital, set the ball rolling with good news for our haemophilia patients. The treatment situation and high costs incurred for people with haemophilia were conveyed to her and she facilitated subsequent communications with the relevant administrative staff. In November 2014, the Society was informed that the subsidy for the plasma factors at Singapore General Hospital and K K Children's Hospital would be raised from 50% to 65%, bringing it on par with National University Hospital. A big thank you to Dr Ivy Ng and her team for being mindful of the needs of our patients.

At the community level, the Society continued to leverage on more participation to ensure continued support of funding for its treatment subsidies. The Society was fortunate to be named a beneficiary for funds raised by the students of Hillgrove Secondary School in July, the Singapore Island Country Club's May Day Charity Event and the Tote Board's "River with a Heart" event in October 2014. The Society itself launched its "Project Calendar 2015" for fund raising and received support from individuals, companies, Lee Foundation, the Reuben Meyer Trust and its sponsor, Phoon Huat & Co (Pte) Ltd, all of whose help made the Project a success! To all the students, community groups, individuals and companies who have supported our cause, we say a sincere "thank you".

Together, with help from our community partners and donors, the Society raised \$211,048 for the

year 2014/15. Every dollar raised would enable us to do more for the haemophilic community in Singapore. With no paid staff and helmed by a team of volunteers, we expend donations raised mainly on treatment subsidies, which totalled \$205,454.69 for the year.

While we are a small charity, we cannot do less. We face legitimate challenges that need to be overcome. How to raise more funds? How to improve the lives of our haemophilia patients? With a positive mindset, we can cope with the pressure and do the best we can. At the Society level, we must continue to create awareness of the needs of haemophilia patients and strive to achieve the best comprehensive care programme for our members. In our operations, we must remain transparent in order for donors to feel we are worthy of the donation dollar.

Looking ahead, the Society hopes to engage the government on the cost benefits of prophylaxis for its members and easier access to factor replacement. Its members must be more proactive in supporting the Society in its function and for more volunteers to play an active role.

Lastly, I wish to thank the healthcare professionals at the Singapore General Hospital, KK Children's Hospital and National University Hospital for their dedication and care of the patients with haemophilia.

Also to my team of Executive Committee members, for their passion and commitment to the haemophilia cause, my heartfelt thanks.

**Dr Tan Hooi Hwa**  
*President*

*Haemophilia Society of Singapore*

HIGHLIGHTS OF THE YEAR



MP Low Yen Ling, teachers and 5 students with newspaper collection outside flat resident's home

The past year saw the Society involved in community projects and engaged in both social and recreational activities. The Society was fortunate to be one of the beneficiaries of the Hillgrove Secondary School's collection and sale of old newspapers' project. The students and teachers of the school embarked on the fund raising project to raise funds to help others who were disadvantaged. The school presented a cheque for \$9300 to Dr Tan Hooi Hwa, President of the Haemophilia Society, on 12 July, 2014. Dr Tan thanked MP Ms Low Yen Ling,



The students & SG 50 formation



Cheque Presentation

Bukit Gombak CC, the Principal, staff and students of Hillgrove Secondary School for their combined effort and caring spirit to help charitable causes.

The Society was one of the recipients for donations raised by the Singapore Island Country Club's May Day Charity Event. It was also one of six beneficiaries for the first ever "River With A Heart" fund raising event organised by Singapore Pools' i-Shine, a staff volunteerism and outreach programme and Community Chest of Singapore, supported by Tote Board and Lee Foundation and corporate sponsors, Far East Organisation and Singapore River Explorer. The event was held on 28 October, 2014 and raised over \$408,000.



World Haemophilia Day was observed on 18 April, 2015 where haemophilia patients were invited to a talk organised by Singapore General Hospital and KK Children's Hospital. The speaker was Dr Grieg Blamey who spoke on "Integration of Sexual Health & Sexuality into Comprehensive Care of Haemophilia".

Greater awareness of haemophilia was generated through media publicity which featured two of the haemophilia youths on how the bleeding disorder had affected them. Benjamin, with a rare form of haemophilia, was featured with his doctor and Han Xuan, who performed well academically despite the challenges posed by his medical condition, with his lecturer. The Society gained further media exposure with the "Special father-son bond forged" article in a Father's Day feature on 21 June, 2015 where fathers of sons with haemophilia were acknowledged and thanked for their love and care.

The Society benefitted when two of its Committee members attended an all expenses paid "Advocacy in Action Workshop 2015" organised by the World Federation of Haemophilia in Bangkok, Thailand, from 21 -23 May.

The Workshop was aimed at helping patient organisation develop their advocacy skills, to provide the tools for successful implementation of advocacy projects for improved care of people with bleeding disorders. The well organised Workshop provided an enriching experience and valuable insight for Singapore's future directions.



Photo of Dominic and Gerard Vaz

## ADVOCACY IN ACTION WORKSHOP 2015



Group photo of Workshop participants

The Advocacy in Action workshop 2015 conducted by the World Federation of Hemophilia (WFH) was held in Bangkok, Thailand from May 21st to 23rd. Participants of this Workshop were those countries that WFH felt required help with Advocacy. Participants were from Korea, Hong Kong, Indonesia, India, Myanmar, Malaysia, Maldives, Mongolia, Sri Lanka, Singapore, Philippines, Nepal, Vietnam and of course the host nation, Thailand. The Workshop was very well organised by the WFH and they made sure that throughout the Workshop, members from each country were split into different groups so as to be able to interact with participants from all the other countries, to better understand the situation they were facing in their countries and to hopefully learn how to resolve problems in our own country after learning from the experiences of others. The topics that were covered in the first half of the workshop were about the Advocacy in Action program, knowing the environment that you are in, presenting your case with an impact and finally building strong collaborations. These were mainly the tools in which they were teaching - to better equip us to be able to advocate for our needs. The second half of the Workshop was about the participants sharing their own experiences in their countries and trying to resolve the challenges that they faced.



Workshop in Progress

One of the main lessons I learned from this Workshop was that we have to engage the government more proactively so as to be able to get more support from them for our cause. In all the other countries who participated in the Workshop, majority of them had their medicine paid for by their respective governments. However achieving that goal was not without a lot of determination and perseverance. One of the key questions raised during the Workshop was why Singapore, being a first world developed nation, was having problems encountered by a third world country. My response was that because our Haemophilia Society was a voluntary organization, we were constantly preoccupied with raising the much needed funds to assist with subsidies towards treatment costs of haemophilia patients, that it overshadowed the need to engage the government to do more. We also lacked the manpower since the Society was manned only by volunteers.



Grace Vaz &amp; Lester Wee

On a separate note, we were rather fortunate to have the President of the WFH, Mr Alain Weill, join us for this Workshop as he was headed to Vietnam to further help them push for their cause. We managed to spend some time with him and was able to better understand what WFH required from us in order for them to be able to help Singapore.

The experience gained from participation in this Advocacy Workshop had been enriching and provided an invaluable insight for future directions. Together, with support from World Federation of Haemophilia, we, the Haemophilia Society of Singapore and its government can improve the lives of our citizens with haemophilia.

By: Lester Wee

**KEY PROGRAMMES**

There are about 200 people with haemophilia, mostly males, though women can carry the genetic alteration causing haemophilia. Haemophilia is usually inherited, but one-third of people have no previous history.

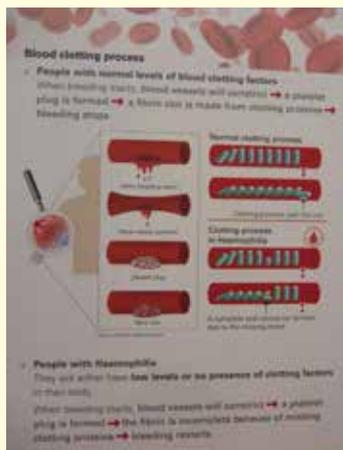
Members of the Haemophilia Society of Singapore comprise babies, toddlers, children, youths, young and mature adults. With today's medical advances, parents and affected sons are able to live more "normal" lives as they learn to overcome the challenges of living with haemophilia along the way. The Society aims to assist its members to have such an independent and fulfilling life.

Effective treatment for haemophilia is available, but as yet there is no cure. Treatment is very costly for those with haemophilia and most working individuals and families would have difficulties meeting treatment costs, especially if they experience frequent bleeding episodes into muscles and joints, which if not properly managed can cause arthritis and joint problems. Aid from the Society is rendered to all its members regardless of financial background, to help alleviate the heavy financial burden.

The key programmes offered by the Society are aimed at addressing the different needs of our members.

**• Treatment Subsidy**

Haemophilia is treated by replacing the missing clotting factor in the blood. This is done by injecting a product that contains the needed factor into the vein. Bleeding stops when enough clotting factor reaches the affected area. The Society assists its members with monthly subsidies to defray part of their treatment costs, capped at \$800.00 and \$400.00 per month for youths/adults and children respectively. The subsidies' programme is the main expenditure item for the Society. Hence all its funds raised are used mainly to support this programme.



"Blood Clotting Process"

**• Welfare Fund**

The Society has in place a welfare fund, with funds specifically designated to provide financial assistance to members with haemophilia facing financial hardships. Members who require financial aid would need to submit their request and aid is approved when the situation warrants it. Regular reviews are conducted and long term dependency discouraged. Members are also referred to other social agencies for more appropriate help if required.

**• Educational Awards**

The Society initiated the Educational Awards programme also known as "Merit Awards" in the year 2000. The awards were to encourage our members in school to value the importance of education, that with education they can improve their lives and reach higher heights.

The awards given at each Annual General Meeting were based on academic performance and categorised under "excellence" and "encouragement". The monetary rewards ranged from \$100.00 for primary schools to \$400.00 for junior colleges / polytechnics / ITE.



"An Educational Exchange....."

This year, 7 awards were given to members from primary (1), secondary (4), ITE (1) and Polytechnic (1).

For those pursuing tertiary studies, there is the Dulcie Wilson Scholarship Fund in memory of the late Mrs Dulcie Wilson, which was set up in 2010. A sum of \$20,000.00 was set aside for this purpose. Grants of \$1000.00 per academic year for a maximum of 3 members were available. No applications have been received to date.

**Seminars / Talks**

Seminars and talks are organised for members of the Society to impart knowledge of haemophilia, to keep members' abreast of latest developments and management of haemophilia from specialists in the field, both locally and from overseas. Talks to members range from caring for joints, importance of dental care to physical activities members can engage in.



Talk by Dr Grieg Blamey

Members attended a talk organised by Singapore General Hospital and KK Children's Hospital on "Integration of Sexual Health and Sexuality into Comprehensive Care of Haemophilia" on 18 April, 2015. The speaker was Dr Grieg Blamey whose talk was both informative and educational.

**Support Group**

The Mothers' Support Group was set up in 2009, primarily to enable mothers with haemophilic sons to obtain moral support from one another and to share their experiences in managing their sons' conditions. Gatherings at fellow members' homes allow for bonding over a shared problem and where self-infusion is demonstrated and home treatment advocated. Mothers and sons are encouraged to learn self-infusion for prompt treatment of bleeding episodes.



self-Infusion

Photo by courtesy of Haemophilia World October 2014.

**Activities / Outings**

The Society would like to thank Grifols Singapore and VC Travel Pte Ltd for their kind sponsorships of outings for members to River Safari and SEA Aquarium during the months of September and November 2014. Members had an enjoyable time at both these places.



Group photo of S.E.A. Aquarium participants.

In March 2015, the Society arranged for members to visit "Alive Museum Singapore". The Illusionary Entertainment Museum from Korea, where art form comes to life, was found to be both fun and interesting for members.



"Band Performance – 'Alive Museum, Singapore'

**Two of our youths, 17 year old Benjamin Tang and 20 year old Choo Han Xuan, were featured in the 'New Paper' in April and May 2015 respectively. We share the news' features with you.**

## YOUTH NEWS (I)



Benjamin Tang & Dr Koh Pei Lin  
Photo from New Paper 13 May, 2015

His father is a taxi driver, his mother, a housewife.

And when it comes to the cost of treatment that their son, student Benjamin Tang, is undergoing, their monthly household income is barely enough to cover the \$20,000 a month.

Fortunately, selfless donors are helping Benjamin's family shoulder his medical expenses. They requested to remain anonymous.

Benjamin, 17, suffers from haemophilia with inhibitors, a complication of the genetic disorder which is passed from his mother's side of the family.

His body is missing a "tiny factor" needed to form a blood clot, but the antibodies in his blood starts to fight against the proteins used in the treatment, preventing it from fixing any bleeds.

His doctor, Dr Koh Pei Lin, a consultant in the division of Paediatric Haematology-Oncology at the National University Hospital (NUH), said Benjamin needs to inject eight vials of FEIBA ( Factor Eight Inhibitor Bypassing Agent ) once or twice a day, depending on the severity of bleed, until it stops bleeding. "Sometimes up to five days," she said. "He is having on-demand therapy, that is, he needs injections only when he has a bleed, as preventive therapy will be too expensive."

Benjamin, who will be starting his term at Ngee Ann Polytechnic next week, is grateful for the financial assistance.

## BENJAMIN TANG - " Dealing with blood disorder "

He was only six months old when he had multiple bruises on his chest. "My parents took me to a TCM practitioner. He took one look and told them something wasn't quite right and advised them to take me to the hospital," he recalled.

A month later, Benjamin suffered a swollen knee due to bleeding. Doctors had to give him Factor VIII injections to replace the missing protein to stem the blood flow.

Benjamin's situation, however, worsened after he turned a year old. He developed severe complication of haemophilia, in which his body started to produce antibodies that fight against his treatment. They prevent the jabs from stopping his bleeds, rendering Factor VIII treatment useless, explained Dr Koh.

The New Paper believes that there are only five boys in Singapore with this rare condition, Benjamin included.

In 2009, when Benjamin was 10, Dr Koh tried immune tolerance induction therapy on him, to get his body to accept Factor VIII. Unfortunately, it failed and "it meant he could never go back to being treated with Factor VIII," said Dr Koh, who also heads the Paediatric Intensive Care Unit at the hospital.

Dr Koh now turns to what is called bypassing agents. Instead of replacing the missing factor, they go around the inhibitor and help the body form a clot to stop the bleeding.

Benjamin needs to inject FEIBA once to twice a day.

"Previously, the Factor VIII treatment was subsidised, but with bypassing agent, there is no subsidy as this is a non-standard treatment since this is a very rare disease," Dr Koh said.

Benjamin is determined to learn more about his disorder and will be studying pharmaceutical science at the polytechnic.

*\*This article appeared in the New Paper on 13 April, 2015.*

## YOUTH NEWS (II)



Han Xuan &amp; his pet dog.

## “ Every cut spells d a n g e r ” .....

While minor cuts and injuries pose little threat to the average person, they can be life-threatening to Choo Han Xuan. The 20 year old was born with haemophilia, a rare bleeding disorder in which the blood does not clot normally.

Han Xuan told The New Paper that while an average person may take at most a day for the blood coagulation to complete, he has to wait for as long as a week, especially when injuries are more serious.

This means he has to be careful to avoid getting himself injured.

He also has to stay away from physically demanding activities and sports.

Han Xuan, will be graduating from Temasek Polytechnic next week with a close to perfect grade point average (GPA), said he had to miss school and rest at home for days, or even weeks, each time he was injured. He recounted a time when he had to be away from school for three weeks because he was suffering from spontaneous bleeding near his abdomen area. “The doctor said it was dangerous because bleeding at the abdomen can affect the other organs,” said Han Xuan.

His absence from school caused him to lag behind in his schoolwork, but thankfully he had the support of his lecturers, who helped when he was struggling to catch up. One of them was his lecturer-cum-careperson, Dr Jomer Bo.

Dr Bo, 40, who was in charge of Choo Han Xuan’s welfare, closely monitored his condition and academic performance. When he had to be absent from school, Dr Bo made sure he could catch up with his peers by giving him extra consultations.



Choo Han Xuan (left) with his Temasek Polytechnic lecturer, Dr Jomer Bo

His lecturer’s support, combined with his positive learning attitude and hard work, led him to perform well despite the challenges posed by his medical condition.

Han Xuan, who completed his diploma in veterinary technology in February, attained a GPA of 3.84 out of four. He was inspired to pursue a course in veterinary technology because of his passion for animals. “I have loved animals since I was young. I wanted to be a vet at first,” Han Xuan said. He soon realised, however, that the job may not be suitable for him after he tried performing animal operations. He had to restrain the animals and hold them down during surgery. However, some of the animals were strong and difficult to subdue. “They would struggle and, at times, bite. Sometimes, I got injured while struggling with the animals. It was a physically demanding task,” he said.

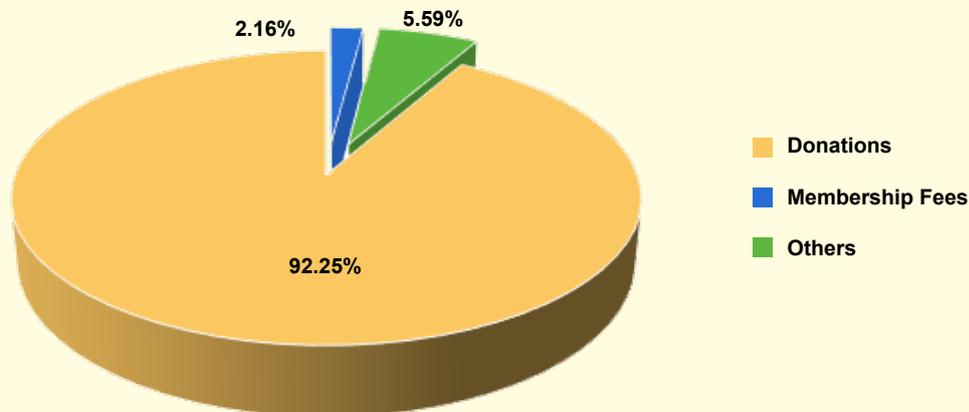
He is now looking at jobs which involve biomedical research in laboratories. His interest in animals is part of the reason he wants to do biomedical research.

“Animals are actually very useful for research studies and trials. So as a researcher, I will still have lots of opportunities to come across animals and work with them,” he said.

*\* This article appeared in The New Paper on 13 May, 2015  
Photo: LIANHE ZAOBAO*

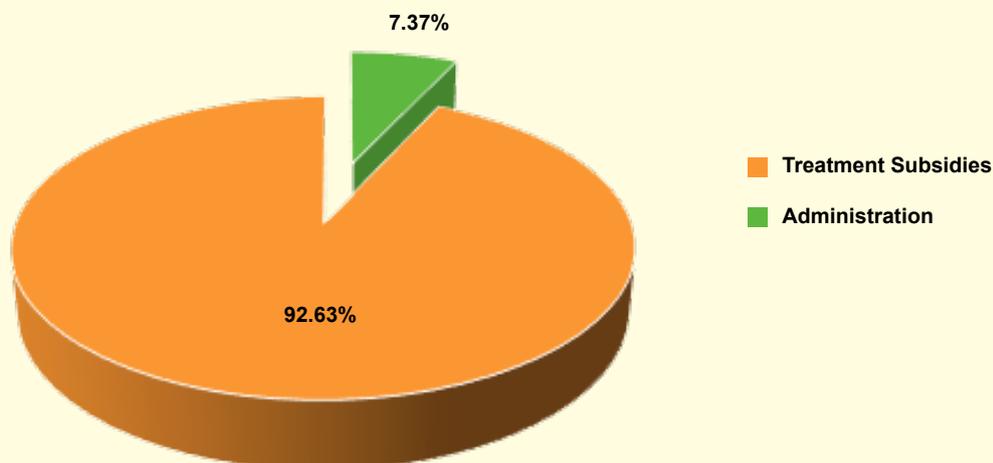
**FINANCIAL INFORMATION SUMMARY**

**Breakdown of Total Income 2014/15**



Donations	\$186,656.00	92.25%
Membership Fees	\$4,370.00	2.16%
Others	\$11,312.00	5.59%

**Breakdown of Total Expenses 2014/15**



Treatment Subsidies	\$205,454.00	92.63%
Administration	\$16,339.00	7.37%
Fund Raising	NIL	0%

*Please see insert for Financial Statement 2014/2015*

## OUR DONORS

## INDIVIDUALS

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Hillgrove Secondary School	Singapore Island Country Club
KIF TCS Pte Ltd	Singapore Pools Pte Ltd
Lee Foundation	Reuben Meyer Trust Fund

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Vice-President  
Honorary Secretary  
Assistant Honorary Secretary  
Honorary Treasurer

**Name**

**Dr Tan Hooi Hwa**  
**Dr Gan Kim Loon**  
**Wee Ai Choo**  
**Ng Teck Hiang**  
**Lim Keok Kung, Freddy**

Committee Members:

**Ang Har Boon, Anthony**  
**Poh Soon Leong**  
**See Ek May**  
**Wee Shen Wei, Lester**  
**Vaz Grace**

*\* Elected at the 28 September 2014 Annual General Meeting*

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64490289 ( Dr Gan KL )

Charity Registration No: 00374  
Society Registration No : ROS 105/85  
Unique Entity No: S85SS0047A

Website: [www.haemophilia.org.sg](http://www.haemophilia.org.sg)

**Key Bankers**

DBS Bank  
Maybank  
CIMB Bank

**Auditors**

TKNP International

**Treatment Centres**

**Singapore General Hospital**

Staff-in-charge : Wahidah  
Telephone No. : 63213844

**National University Hospital**

Doctor-in-charge : Dr Koh Pei Lin  
Telephone No. : 67725030

**KK Women's & Children's Hospital**

Staff-in-charge : Lim Chiew Ying  
Telephone No. : 63926343

**Annual Report Editorial Committee**

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