

HAEMOPHILIA SOCIETY OF SINGAPORE





THE FUTURE OF GENE THERAPY

DR JOYCE LAM
Senior Consultant
KK Women's and Children's Hospital

ONLINE (PLATFORM)
19 MARCH, 2022
1PM - 2PM

PLEASE EMAIL YOUR QUERIES TO
HAEMOPHILIA.YOUTH.SG@GMAIL.COM

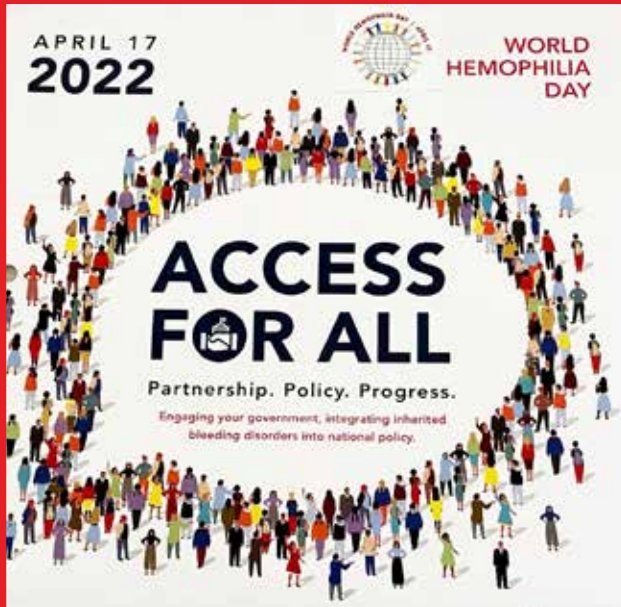
APRIL 17
2022

WORLD
HEMOPHILIA
DAY

ACCESS FOR ALL

Partnership. Policy. Progress.

Engaging your government, integrating inherited bleeding disorders into national policy.



ANNUAL REPORT

2021
-
2022



8 | 9 October 2021

Virtual
20TH AUSTRALIAN CONFERENCE
ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

EMBRACING A CHANGING WORLD



WFH 2022
WORLD CONGRESS



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CONTACT INFORMATION**Registered Address**

Block 704 Bedok Reservoir Road
#01-3622
Singapore 470704

Mailing Address

Farrer Road P O Box 0273
Singapore 912810

Key Bankers

DBS Bank
Maybank Singapore Ltd
CIMB Bank

Auditors

TKNP International

TREATMENT CENTRES**Singapore General Hospital**

Staff-in-charge : Yeam Shin Yen
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

MANAGEMENT COMMITTEE

| Name | Designation Appointment * | Date of Last Appointment | Attendance at meetings | |
|-----------------------|---------------------------|--------------------------|------------------------|-------------|
| | | | Physical:5 pax | Virtual:All |
| Chee Chun Woei | President | 26 Sep 2021 | 5/5 | 2/2 |
| Dr Gan Kim Loon | Vice-President | 26 Sep 2021 | 5/5 | 2/2 |
| Wee Ai Choo | Honorary Secretary | 26 Sep 2021 | 5/5 | 2/2 |
| See Ek May | Asst. Hon. Secretary | 26 Sep 2021 | 5/5 | 2/2 |
| Lim Keok Kung, Freddy | Honorary Treasurer | 26 Sep 2021 | 5/5 | 2/2 |
| Ang Har Boon | Committee Member | 26 Sep 2021 | N.A. | 0/2 |
| Ng Teck Hiang | Committee Member | 26 Sep 2021 | N.A. | 2/2 |
| Tan Gek Cheng | Committee Member | 26 Sep 2021 | N.A. | 2/2 |
| Dr Tan Hooi Hwa | Committee Member | 26 Sep 2021 | N.A. | 1/2 |
| Tan Kai Em | Committee Member | 26 Sep 2021 | N.A. | 2/2 |

Elected at * the 26 September, 2021 Annual General Meeting

ABOUT**HAEMOPHILIA SOCIETY OF SINGAPORE**

Haemophilia Society of Singapore is a voluntary organisation that was registered under the Charities Act on 17 September, 1986. It was set up 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 World Federation of Haemophilia.

The Society's main service to its members is to provide subsidies for members' treatment costs at three 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

Unique Entity Number (UEN)

S85SS0047A

Charity Registration No

00374

Society Registration No

ROS 105/85



PRESIDENT'S MESSAGE



The pandemic has forced a new paradigm into our lives. It has changed the way we work. It has changed the way we communicate. We have adopted tools and accepted as norms, that pre-pandemic would have met with resistance. It has also changed our consumption patterns. Food and grocery delivery services and online shopping enjoyed unprecedented boom.

To many companies and businesses, Covid is a curse. Yet to others, it created a unique opportunity to flourish.

The same challenges faced charities and societies like ours. The Haemophilia Society of Singapore had to change the way it operates. New tools such as video conferencing platforms for meetings and talks were adopted. Just like companies that saved millions of dollars by conducting meetings virtually across borders, the Society too learnt of these tools' efficacy.

The World Federation of Haemophilia (WFH) undaunted by the Covid-19 pandemic, saw countries around the world celebrate 2022's World Haemophilia Day which falls on April 17 every year. Singapore held a Zoom celebration to mark the occasion, organized by the three hospitals, namely Singapore General Hospital, National University Hospital and KK Children's Hospital. The global bleeding community also had the opportunity to participate both virtually and in person at the WFH 2022 World Congress in Montreal in May 2022. We, in Singapore, can look forward to the 2024 World Congress to be held in Kuala Lumpur, Malaysia.

Fund raising had always been a challenge for lesser known organization like ours. The pandemic's biggest impact to the Haemophilia Society of Singapore was curtailing its ability to raise funds. Before the pandemic, one of the major fund raising events was the Charity Film Premiere. The lockdown stopped that. It also impacted traditional donors making donations harder to come by.

In face of this, other means to fund raise came about. Two parents of members helped put the Society on corporate programmes such as Benevity and Charities Aid Foundation America; another member rallied his family, friends and neighbours for his Charity Bake Sale while some students from Singapore Chinese Girls' School sold masks to fellow students to help the haemophilia cause. The Society is grateful for all their efforts and that had given us the encouragement to persevere in trying times.

Chee Chun Woei

President
Haemophilia Society of Singapore

The pressure to meet the treatment subsidies of haemophilia members which amount to more that \$250,000 per year is an ever-pressing one. Almost the entirety of funds raised every year is expended on treatment subsidies. The funds raised benefit the members directly since the Society is helmed by a team of dedicated volunteers, with no paid staff.

The Society is fortunate to have received a grant from SymAsia Foundation Limited during the year to help alleviate our financial situation. Also thanks to all the generous hearted donors, our Project Calendar 2022 achieved an all time high of over \$150,000!

We acknowledge the generosity of SymAsia Foundation Limited and also the contribution of Mrs Wee Ai Choo, who had been behind Project Calendar since 2011 and seeing it become a major fund raising source for the Society.

For financial year 2021/2022, the Society raised \$504,295.30 of which expenditure amounted to \$323,900.96 resulting in a healthy surplus of \$180,394.34 overcoming the deficit of the previous year. This would not have been possible without the support of the many kind donors, organisations and pharmaceutical companies.

Since the Society's inception in 1986, both the quality of life and treatment for members with haemophilia, have improved considerably. Going forward, members' support and active participation are sought in order for the Haemophilia Society of Singapore to stay relevant and deliver value. May this quote by

“
Do more than belong : **participate**
Do more than care : **help**
Do more than believe : **practice**
Do more than be fair : **be kind**
Do more than forgive : **forget** „
Do more than dream : **work**

William Arthur Ward provide ' food for thought ' :

Lastly, I would like to thank all past and present ExCo members who have contributed selflessly their time and resources, especially the stalwarts who have served tirelessly the past 35 years - Dr Tan Hooi Hwa, Dr Gan Kim Loon and Mrs Wee Ai Choo. Also to the healthcare professionals at Singapore General Hospital, National University Hospital and KK Children's Hospital, thank you for your invaluable care of patients with haemophilia.

Together may we strive for a better tomorrow for Singapore's haemophilia community.



YEAR IN REVIEW : CALENDAR OF EVENTS

COMMUNITY: SINGAPORE CHINESE GIRLS' SCHOOL



Five Secondary Four students (4PR) from Singapore Chinese Girls' School's Business Academy initiated the 'MasksbyBaez' Project from February to May 2022 to raise funds for the Haemophilia Society of Singapore.

The Project Team sold masks of various designs in two on-line phases – firstly to fellow students and secondly to students from other schools and members of the public. The price was \$5.00 for 10 masks.

The team experienced some delivery setback with the China lockdown and the masks supply was disrupted in April. Fortunately the problem was overcome and the team's project ended on a positive note with a commendable sum of over \$1000 raised!

The five Biz team members were thanked for their hard work and for supporting the haemophilia cause.

Top Row (L – R) : Natalie Teng, Nadia Lim and Keira Wee

Front Row (L – R) : Jodie Lim and Li Wanru

LOCAL : HAEMOPHILIA EVENTS



(I) A virtual talk by Dr Joyce Lam, Senior Consultant at KK Women & Children's Hospital titled 'The Future of Gene Therapy' was held on 19 March, 2022.

Dr Lam shared some updates on the haemophilia treatment landscape and also on the future of gene therapy. While gene therapy offers the chance of a "once-off" cure, potentially allowing patients to lead a normal life, it is still at the clinical trial stage where its long-term out-comes are yet to be determined.

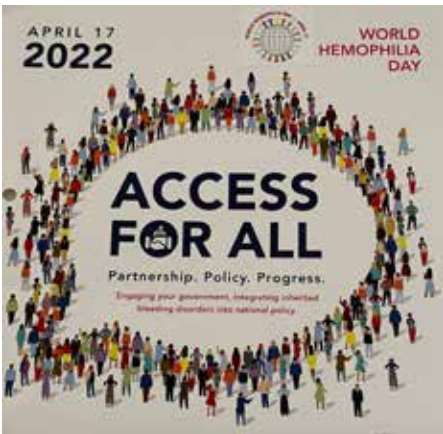
(II) Singapore's 'Haemophilia Day Celebration' was held on 16 April, 2022 via Zoom. The occasion was jointly organized by KK Women & Children's Hospital, Singapore General Hospital, National University Hospital and Haemophilia Society of Singapore.

The programme covered talks from financial aid to caring for joints, plus some fun quizzes.

The 'celebration' was well-received by those who participated. A big thank-you to the organisers for bringing the haemophilia community together on this Haemophilia Day.



WORLD HAEMOPHILIA DAY



World Haemophilia Day

17 April, 2022 is World Haemophilia Day. The Theme this year was "Access for All: Partnership. Policy. Progress. Engaging your government, integrating inherited bleeding disorders into national policy".

"World Haemophilia Day is a day for people who have been affected by a bleeding disorder....But we can't forget that governments play a critical role. It's important that they recognize bleeding disorders and assist people who have a condition in their countries." Cesar Garrido, WFH President

This important event is about bringing the global bleeding disorders community together, to raise awareness and bring haemophilia and other bleeding disorders to the attention of policymakers and bring about more equitable access to care and treatment.

While the Covid-19 pandemic continues to affect the world, we must give support to the worldwide efforts and emerge stronger as a community to achieve our shared vision of "Treatment for All".

WFH 2022 WORLD CONGRESS

The 2022 World Congress was held in Montreal, Canada on 8 – 11 May, where both face-to face and virtual sessions were available.



The Congress was a great success, with thousands of attendees taking part in person and virtually over four days. An exciting programme by the experts

and eminent health professionals covered latest haemophilia developments and issues and provided a wealth of up-dated information.

The Congress presented a great opportunity for the global bleeding community to share experiences, to catch up with "old friends" and to make new ones.

For those who missed the Montreal Congress, World Federation of Haemophilia hope to see you at the next Congress in Kuala Lumpur, Malaysia in 2024.



MAKING NEWS

Managing bleeds under new treatments - Suzanne O'Callagan

With new haemophilia treatments for adults and children available now across Australia, the 2021 Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders was a great opportunity to discuss how the new treatments impact on bleeding episodes and how to manage bleeds when they occur.

The benefits of the new treatments have been welcome, but there is no doubt that the changes involved can be substantial.

What have these changes meant to individuals? Jane Portnoy, Haemophilia Social Worker at the Ronald Sawers Haemophilia Centre in Melbourne, opened the session with a snapshot of experiences among adults and children with haemophilia cared for by Haemophilia Treatment Centres (HTCs) in Australia.



Jean Portnoy

Jane pointed out that experiences can vary: for many on prophylaxis it was a huge relief not to have to infuse into a vein and infuse so often; others were more cautious and wanted to wait to get ready to start the new treatment; and some have experienced disappointment when the new treatment did not work out for them. There were challenges with learning the new processes for administering the treatment, but it also offered more opportunities – to travel, to be with friends and family, to take on new sports and activities.

BLEEDS MANAGEMENT

Understanding and managing bleeds with extended half-life and non-factor therapies such as Hemlibra is also a new territory. Dr Julie Curtin is HTC Director at the Kidz Factor Zone at Westmead Children's Hospital, Sydney and provided an expert and very accessible walk through the science and the issues.

Extended half-life factors (EHLs) :

Dr Curtin explained that although EHLs can reduce the number of infusions, every person reacts a little differently and this needs to be measured in the individual through pharmacokinetic (PK) studies. Other important factors in an individual's treatment plan:

- The patient's bleeding phenotype
- Their activity levels, including participation in sport.

If patients using EHLs have a breakthrough bleed, the bleed treatment may include the EHL. Treating serious bleeds can involve a more complex treatment plan and close monitoring of factor levels is critical.

Non-factor products – Emicizumab (Hemlibra): outlining the action of emicizumab, Dr Curtin explained that it worked like Factor VIII, bringing together Factor IX and Factor X to continue the clotting pathway.

- It has a very long half life and provides steady drug levels in the blood
- But it is harder to measure the equivalent Factor VIII activity in the blood
- Unlike prophylaxis with factor, there is no peak in effect after a dose
- Treatment for breakthrough bleeds requires factor replacement therapy
- A different type of testing needs to be used to monitor Factor VIII levels when the patient is being treated with emicizumab, which is important in a breakthrough bleed or injury or with surgery.

MANAGING INJURIES AND BLEEDS

Although the new treatments have reduced the risk of injury and the number of bleeds, injuries and bleeds still occur. In the Q&A that followed, physiotherapist Ali Morris and the haemophilia nurses Joanna McCosker and Beryl Zeissink outlined some of the issues for people with haemophilia on new treatments and were joined by Dr Julie Curtin in a panel discussion.

INJURIES, TREATMENT AND RECOVERY

KEY POINTS

New treatments may reduce the risk of injury of muscle bleed/joint bleed

BUT

No new treatments speed up 'natural healing' time once an injury or bleed has occurred

Pain resolution ≠ Recovery



Alison Morris

Ali Morris is the Senior Musculoskeletal Physiotherapist at Perth Children's Hospital and her experience brought a real sense of how the issues play out for young people.

She pointed out:

- When an injury or bleed has occurred, no new treatment can speed up natural healing'
- Resolving pain isn't the same as recovery
- Recovery will involve a treatment plan and respect for the time that the healing process takes.

Ali walked through some key aspects of rehabilitation—the process of healing and decisions involved in returning to sport and activity safely

When Should You Contact Your Haemophilia Treatment Centre (HTC)

- If you have a planned dental / surgical procedure
- If you have uncontrolled bleeding from any part of your body
- If you have been in an accident
- If you have sustained a trauma to any part of your body
- If you are in pain from an injury or swelling and restrictions in movement
- If any symptoms / pain gets worse or does not go away with pain relief.

PERSONAL STORIES

A powerful part of the session was hearing from people with haemophilia and parents about their experiences with the new treatments.

For Lenny non-factor therapy was an exciting and a very welcome change: infusing only once a week, collecting his treatment product from a pharmacy, the independence of being able to administer his own treatment instead of relying on his family, and so many new aspects to his life – finishing his university degree and looking for employment, singing with a community choir and doing volunteer work in the community.

Leah gave a parent's perspective. Her small daughter has severe haemophilia and had experienced both an extended half-life therapy and a non-factor therapy. Although she is very active, her daughter has started primary school with very few bleeds and hospital admissions. Leah commented that it is harder now to know how to recognize a bleed, so they err on the side of caution. "We feel really fortunate to live in this era and in this part of the world – because we know not everywhere has access to these treatments. She can live, she can go to school, every party doesn't end up in a hospital admission, like it used to."

Bruce is in his 70s and gave an account of his treatment experience with extended half-life factor for prophylaxis as an older man. Prophylaxis had made a great difference to controlling his bleeds, but for Bruce one of the greatest positives of moving from standard prophylaxis to a longer acting factor was the condition of his veins – treating only once every six days instead of three times a week. He also felt freer traveling, with a much smaller volume of treatment product to carry with him.

This article is reproduced from NATIONAL HAEMOPHILIA, a publication of Haemophilia Foundation Australia.



KEY PROGRAMMES

There are just over 200 people in Singapore registered with haemophilia, mostly males, though women can carry the genetic alteration causing haemophilia. Haemophilia is usually inherited, but one-third of those affected are without any known family history.

Effective treatment for haemophilia is available, but as yet there is no cure. Treatment is very costly and many encounter difficulties meeting the costs. Aid from the Society is rendered to all its members regardless of background, to help alleviate the heavy financial burden.

The key programmes offered by the Society range from treatment subsidies, educational talks, parents' support, fund raising activities and more.

• Treatment Subsidy



Anston's self-infusion

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 \$1200 to \$400, depending on products used, for youth/adults and children respectively. The funds raised by the Society are used mainly to fund this programme.

• Welfare Fund

The Society provides assistance to members with haemophilia facing financial hardships. Requests for aid are approved by the Committee when warranted. Regular reviews are conducted and long term dependency discouraged. Members may be referred to other social agencies for more appropriate help if required.

• Educational Awards



Tan Yu Fei Secondary School Recipient

These awards are given annually to encourage our school going members to value the importance of education. The awards are based on academic performance and the monetary rewards range from \$200 for primary schools to \$600 for junior colleges/polytechnics/ITE.

For 2021, five awards were given to members from primary (1), secondary (2) and JC/Poly (2).

• Seminars / Talks

Seminars and talks are organized to impart knowledge of haemophilia and to share latest developments from specialists locally and overseas. An on-line Zoom talk by Dr Joyce Lam on 'The Future of Gene Therapy' was organized on 19 March, 2022.

• Support Group

A Chat Group was initiated to keep parents in touch with one another to share regarding children's bleeds and concerns. It enabled parents to obtain moral support too from one another.

• Home Therapy

Six year old Anston Tan has been on home therapy since he was three years old, thanks to his father's determination to learn self-infusion. Mr Tan practised with the nurses and doctors and they encouraged him not "to give up" even if it meant "poking" Anston several times initially as it was difficult to locate his veins.



Anston's father assisted by grandfather

Those hard times are over and Anston now receives his infusion readily with grandfather assisting his father.

• Fund Raising Events

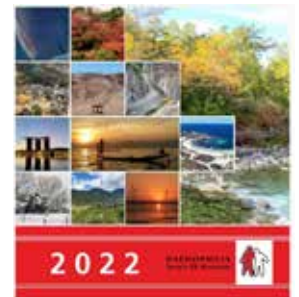


Outreach Effort

'Lend a Helping Hand to Haemophilia' Campaign was launched by Aminah & Fawzie Bessaih in July 2021. They have a five year old son with a similar bleeding disorder. They were thanked for raising \$3435 for the Society.

* **Project Calendar 2022** was the Society's only major fund raising activity owing to the Covid-19 pandemic.

The Society records its thanks to the sponsor, the seven photo-graphers namely Diep Anna, Gan Daniel, Huynh Selena, Lim Brenda, Lim Cheng Wee, Lim Young Boon and Sim Morene, for sharing their beautiful photographs and the many others who generously donated and who helped with calendar sales. With all their combined effort, Project Calendar 2022 achieved an all time high of over \$150,000 – which exceeded all our expectations!



Charity Bake Sale

A Charity Bake Sale in December offered a wide variety of cookies and helped raise some \$4000 for the Society.



Tray of Ondeh-Ondeh cookies

Thank you Chun Woei and family for baking all those yummy cookies!



To end on a happy note, thanks to Mr Pirabu and ROSEC Team from Linde Gas Singapore who nominated Haemophilia Society to receive the donation raised by staff via Charities Aid Foundation America, the Society was able to receive the amount of \$13,618 in April 2022.



“ FROM BOYS TO NSmen “ ... sharing their National Service journey are ...



Jarrett Tay

I am Jarrett Tay who was conscripted into the Singapore Armed Forces (SAF) on 14 February, 2019 until February 2021. When I was preparing to enlist, I had my share of apprehensions and many thoughts crossed my mind – “will I survive the two years? How will I be treated in National Service?”

Following the routine medical check-ups, I underwent both Basic Military Training and Administrative Support Assistant course for two months. I did not encounter any problems during the Basic Military Training. It provided me the opportunity to meet new people and expand my social network. I even met some of my school friends in my Platoon! I found time to learn Military terminologies while in National Service.

Soon after, I was posted to HQ PERSCOM in CMPB as an Ops Monitoring Assistant. My tasks included taking minutes, filing documents, doing excel work and fulfilling the diverse tasks given by superiors. There was always a backlog of work and that meant working outside office hours and at times on weekends too. Some officers made my life very “difficult” and I had to cope both physically and emotionally. I decided to take a positive outlook as my experience would prepare me for working life in future. The NS experience would make me more resilient! Amidst the stressful situations, I learnt valuable lessons imparted to me by both senior and junior officers, where a listening ear or shared positivity made a difference and improved my office life. Aside from the office, my volunteer work at the NTUC Silverlace Centre, value-added to my NS experience.

One of my initial concerns when in NS was that I have haemophilia. That made me “different”.....However I soon realized that every soldier posted to BMT School 5 also had an underlying medical condition that deemed him unfit for normal BMT—that relieved my anxiety. We were all “similar” and my army mates and I bonded as a true blue “Band of Brothers “ with a close relationship that saw us through some hardships together.

While my NS journey for the two years was not always smooth sailing, I was also enriched with other valuable lessons for my future pursuits. For those joining NS, stay positive and your NS experience may be better than you expect.



Ng Kheng Chew

I am Ng Kheng Chew. Let me share some insights of my National Service experience and the challenges faced in my NS journey.

I was enlisted into the Singapore Armed Forces from August 2019 – August 2021. For us in Singapore, National Service (NS) is mandatory for every male citizen or PR, even for persons with haemophilia. The thought of enlistment appeared intimidating to me. “How would I with Haemophilia handle this NS phase of my life? What would be in store for me?”

Before enlistment, I went through the required medical check-ups to determine my PES (Physical Employment Standards). As one with haemophilia, I was grouped under PES E. However because of my limited physical abilities, I was excused from physical activities for BMT (Basic Military Training). I was also not required to stay in-camp and that enabled me to better manage my haemophilia condition when infusions were required.

Following the completion of BMT, I was posted to be an “Admin Support Assistant “ – in army terms – an administrative clerk. My day-to-day job involves clerical work in an office environment. This was best for me as there were minimal bleed risks that I encountered. There were however difficulties and challenges that I faced in the course of my clerical duties. These ranged from demands by superiors to tasks involving co-ordination and communication. My NS exposure had certainly improved my communication and critical thinking skills which would prove useful in my future endeavours.

NS can be daunting for any persons with haemophilia and it must be equally daunting for parents too. While my NS experience may not be representative of what other haemophilia members may go through, I would like to assure those yet to join NS, not to be afraid, but rather to see it as a positive learning experience.

I am Tan Kai Ern sharing my NS experiences from the perspective of someone with Haemophilia. I completed my full two years of National Service (NS) on 1 October 2021. Initially I dreaded the thought of entering NS as it felt

like a huge waste of time which disrupted the momentum of my studies. I was also unsure of what I would gain from NS. As it was a compulsory journey for me, I decided to approach NS with a more positive mindset and to learn whatever I could from those two years in the army. At worst it was a two year break from school....

Before NS started, there were a series of health checks to go through. These were to ascertain our fitness levels and to determine our Physical Employment Standards (PES) which ranged from PES A – combat fit to PES F, medically unfit for any form of service. Being a haemophiliac, I was under PES E, suitable for combat service support vocations which basically meant clerical work.

I was OOC (Out of Course) for my BMT (Basic Military Training) due to an unfortunately timed wrist injury. I was fortunate to have superiors at that time who were understanding and caring. They allowed me to pursue my own endeavours and even provided books for me to read.

I was then sent to ASA (Administrative Support Assistant) training which was like school, with classes to attend and tests to take. What was taught was mainly applicable for the military set-up and prepared me for the subsequent posting to Artillery HQ manpower branch. There my main task was recruitment of regulars and arranging interviews for applicants. I had to also help maintain the databases for officers and scholars within that formation.

The job itself was fairly dry and mundane. It was having to work under a “notoriously difficult superior” that affected my daily office operations. Fortunately for me, she was posted out to another camp and I had some relief! Aside from that, I made many new friends at my work place and those friendships shared added meaning to my NS journey.



Tan Kai Ern and mother

With the onset of the Covid-19 pandemic, my time in NS was disrupted as the Army’s response was to implement cohorting which meant I only had to return to camp for two to three days per week instead of the usual five days.

Upon looking back at my NS journey, my initial ‘dread’ was unfounded. Thanks to NS, the friendships made over the two years left me with some fond memories of my NS days. My NS experience also helped me to gain the soft skills which I did not have. My haemophilia condition did not adversely affect my time in NS and I was able to maintain a balance between my health and my duties. I have matured too in that two years and am more aware of what I want to make of my life going forward. My NS journey had proven worthwhile after all.



Jervis Tham

I am Jervis Tham, currently still serving my National Service. I enlisted for National Service in April 2021 and will complete my two years in April 2023. Before my enlistment, I did not have much expectation of my time in NS – just be there to fulfill my mandatory two years of compulsory service and definitely it was not an experience I could expect to ‘enjoy’.

During the routine medical check-ups, as one with haemophilia, I was placed under PES E and assigned to do clerical work. I am presently in Administrative Service. Aside from my desk bound duties, I have my share of physical tasks like helping to carry things, assist with deliveries of files, documents to other sections and so forth. Thankfully I did not experience any related bleeding problems so far.

My NS mates are aware of my haemophilia condition and it made no difference to them as they accepted me for who I am. That was a plus point as I made many friends from among them and that made my NS life, both bearable and enjoyable thus far.

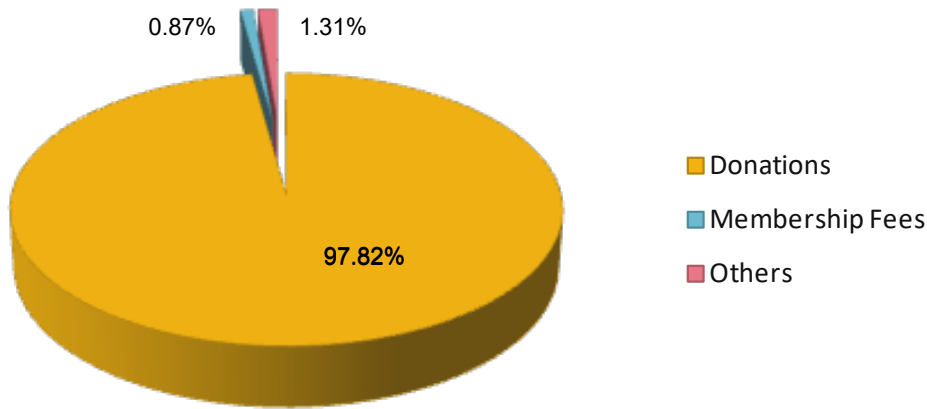
As I entered NS at the height of the Covid-19 pandemic, the normal NS routine was disrupted. I had to work from home on some days. However with the recent lifting of restrictions, it was back to normal work routine for me : 8 am – 5.30 pm Mondays to Fridays. I commute daily to my camp as I was not required to stay in.

I still have almost another year to go, but my NS experience thus far has been manageable. For all those enlisting soon, be positive and optimistic. You may find NS less daunting than you imagine.



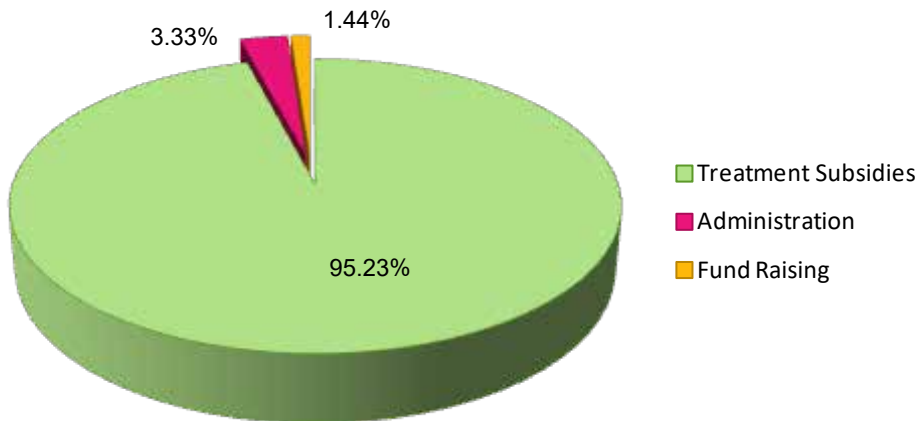
FINANCIAL INFORMATION SUMMARY

Breakdown of Total Income 2021/2022



| | | |
|-----------------|--------------|--------|
| Donations | \$493,280.45 | 97.82% |
| Membership Fees | \$4,390.00 | 0.87% |
| Others | \$6,624.85 | 1.31% |

Breakdown of Total Expenses 2021/2022



| | | |
|---------------------|--------------|--------|
| Treatment Subsidies | \$308,448.97 | 95.23% |
| Administration | \$10,776.34 | 3.33% |
| Fund Raising | \$4,675.65 | 1.44% |

OUR DONORS

INDIVIDUALS

| | | | |
|------------------------|------------------------------|-------------------------------|--------------------------|
| Achu | Kee Peisi | Ng Jim | Tan Hwee Hoon |
| Alwar Muralitharan | Keh Wei Ling | Ng Joie | Tan Hwee Lay |
| Ang Har Hui, Ivy | Khong May Yue | Ng Nancy | Tan Ka Sek, Doreen |
| Ang Kang Hai, Alex | Khoo Bee Keng (Dr) | Ng Peik Lan, Mary | Tan Kai Ern |
| Ang Zhaoxi, Glen | Khoo Mei Ying, Grace | Ng Shuh Fang | Tan Kok Hui |
| Bedmar Ernesto | Ko Chia Hui | Ng Shuh Fen | Tan Lai Ean |
| Bessalh Fawzie | Koh Cheong Boo, Rodney | Ng Teck Hiang | Tan Lai See |
| Bharatharun Ramasamy | Koh Qian Wei | Ng Zhen Yang | Tan Li Jiuan |
| Bong Kwee Wee | Kong Wan Loon, Alan | Oei-Kim | Tan Li Lian, Olga |
| Cahyadi Jeffrey | Kua Hui Eng | Ong Chun Sim, Jason | Tan Mei Mei |
| Chan Chen Yi | Kumar Saravanan Vignesh | Ong Connie | Tan Ru Shi |
| Chan Kok Siong | Kumar Vivek Pravin D | Ong Deng Yuan, Nicholas | Tan Siew Tin, June |
| Chan Mee Kiang, Dora | Kuperan Ponnudurai (Dr) | Ong Laureen | Tan Sue-Ann, Jacelyn |
| Chan Sai Mun | Lam Ching Mei, Joyce (Dr) | Ong Lee Fong, Maggie | Tan Tat Chu |
| Chee Jing Jye (Dr) | Lam Soo Lay | Ong Wei Chuah, Bervyn | Tan Wee Bee |
| Chee Lee Chin | Lau Paik Wah, Irene | Ong Yee Yong, Max | Tan Wei Tong |
| Chen Wei Ching | Lee Chai Luan, Connie | Pac Thor Nan Whee | Tan Wilson |
| Cheng Yao | Lee Hiap Huat | Pan Ai Juan | Tang Ying Wei |
| Chew Boon Ping, Wayne | Lee Jun Hin, Kenneth | Pan Ai Lian | Tay Eileen |
| Chew Hwee Koon | Lee Kok Leong | Pan Cheng Lui | Taye Mervyn |
| Chew Yeow Yong | Lee Qian Yi, Michele | Pan Yue | Teo Ah Cheo |
| Chia Hee Chye | Lee Siew Wai | Pang Hee Yap, Jake | Teo Chen Wei, Terence |
| Chia Ming Wen, Jeremy | Lee Van Sa, Michelle | Phua Seok Kian | Teo Doris |
| Chia Tian Weng | Leiw Jean | Phung Meei Lin | Teo Keng Ming |
| Chiang Poh Leong | Leong Siew Fong | Poh Beow Kiong (Dr) | Teo Soo Ling, Catherine |
| Chiang Sau Lin, Flora | Lerh Pei Qi, Yvonne | Poh Boon Keong | Teoh Yi Boon |
| Chin Mee Ee | Li Dong | Poh Po Jie, Shandy | Tey Siew Ling |
| Chng Gek Cheng | Liau Suzanne | Poh Soon Leong | Tham Jervis |
| Chng Gek Siang | Liew Hock Meng | Poh Zi How | Thien Pik Yuen, Valerie |
| Chng Thee Ing | Lim Ah Lay, Judy | Poh Zi Yang | Tien Melanie |
| Chong Fui Tze | Lim Brenda | Qian Liwen (Dr) | Toh Chuan Seng |
| Chua Lay See | Lim Carine | Quay Chew Eng | Toh Qiao Lin |
| Chua Meng Pin | Lim Chiew Ying | Quek Shao Kin | Toh Seck Gee |
| Chua Poh Kiang | Lim Chon Wei, Edwin | Quek Tong Hwa | Tong Boon Chye |
| Chua Seok Fen | Lim Danny | Quek Young Boon | Vaz Gerard |
| Chua Seok Khim | Lim Eunice | Rivault Florence A. | Vijayakanth Jayapal |
| Clarke Louise | Lim Freddy | Salimbogat Innumerable N.Liza | Wee Ai Choo |
| Eng Meng Chor | Lim Huey Yuee | Samir Filali | Wee Alison |
| Fjeldstad Christina | Lim Huyi Ling | Saw Cheng Hin | Wee Clinton |
| Foo Bao Jiun | Lim Kai Chuan, Richard | Say Alison | Wee Derek |
| Foo Joo Pin (Dr) | Lim Shew Keng, Lisa | Seah Choo Meng | Wee Lester |
| Foo Suan Pin | Lim Sok Ngin | See Bee Bee | Wee Shiang Ning |
| Fung Eric | Lim Teck Chai, Danny | See Bee Pheng | Wong Chen Liong |
| Fung Hao Shia | Lin Hoe Ngoh, Lillian | See Beng Teck (Dr) | Wong Chi Lun, Allan |
| Gan Bee Keen | Lin Shimin | See Chun Wei, Jonathan | Wong Chin Loong |
| Gan Kim Loon (Dr) | Ling Leong Siung | See Ek May | Wong Josephine |
| Goh Boon Hong | Loh Chin Seng | Seng Boon Kheng (Dr) | Wong Kwang Han |
| Goh Chye Har, Cecilia | Loh Shu Ching | Seng Nerine | Wong Mae-Ling, Stephanie |
| Goh Hua Hiang | Loo Leong Mei, Ada | Seow Jen Yi | Wong Ngai Hua |
| Goh Kim Cheng | Lotfi Hadjkali Riad | Sheyo Fie Fie | Wong Peng How, Alan |
| Goh Koon Tho | Low Chee Kok | Shi Qiqi | Wong Seng Nguong, Steven |
| Goh Meng Hwee, Samuel | Lua Ee Laine | Shuai Shiyu | Wong Sharon |
| Goh Siew Lian, Agnes | Lye Susan | Sim Hua Kiew | Wong Xiao Lee |
| Goh Sok Eng | Lyen Kenneth (Dr) | Sim Jun Yan, Javern | Wong Yang Ping |
| Goh Sor Cheng | Marc Tomlinson Bruno | Sim Victor | Woo Chu Sin |
| Guo Yanyan | Marcel Dulat Johan | Sin Guan Heng | Yap Boon Kim, Pamela |
| Gunawan Yasin | Menard Isabelle | Siti Ruziya bte Nasir | Yap Zi Qi |
| Hans Rahmann | Mok Chee Keong | Soh Aruna | Yeap Shin Yen |
| Heng Chee Chou | Muhd. Izzat bin Abdol Rahman | Soh Lai Yee | Yeo Chin Loo |
| Heng Edmund | Nah Zhu Hui, Lea | Soh Sai Sim, David | Yeo Chung Hwa |
| Heng Jia Xuan | Neo Eng Hoe | Soh Siew Hong, Jenny | Yeo Meini, Madeleine |
| Heng Siang Thiam | Ng Andrew | Solaiman Theresia | Yeo Philip |
| Ho Kwong Soon, Bernard | Ng Boon Serh | Song Yet Lee | Yip Owen Kyle |
| Ho Pui Kuan, Emily | Ng Chin Ang | Soon Aston | Yong Helen |
| Ho Sau Kuen | Ng Dih Hann, Simon | Sulianto Hauliono | Yong Kuek Siong (Dr) |
| Huay Kwok Meng | Ng Hian Fong, Michael | Tan Boh Cheng, Iris | Yoong Lee Yoo |
| Huynh Selena | Ng Hui Fen | Tan Chun Long | Yuriada bte Yusoff |
| Ilangovan, C. K. | Ng Hui Lin, Jacqueline | Tan Hong Beng | Zheng Xingyi, Ray |
| Kan Kam Kheen | Ng Hwee Hoon, Adeline | Tan Hooi Hwa (Dr) | |
| Kee Boon Lan, Amanda | Ng Jia Wei | | |

ORGANISATIONS

| | | |
|---|--------------------------------------|---------------------------------|
| Charities Aid Foundation America | Koon Seng Plumbing & Trading Pte Ltd | Singapore Chinese Girls' School |
| CSL Behring Pte Ltd | Linde Gas | SymAsia Foundation Limited |
| Ernesto Bedmar Architects | Loyang Tua Pek Kong Temple | The Divine X'change Ltd |
| Eshcol Pharmaceutical Group (Singapore) Pte Ltd | Reuben Meyer Trust Fund | THL Holdings Pte Ltd |
| Estate of late Lim Choon Huat | Roche Finanz AG | |



CODE OF GOVERNANCE: EVALUATION CHECKLIST FOR HAEMOPHILIA SOCIETY OF SINGAPORE

Submission Form for Governance Evaluation Checklist (Basic Tier)

Please note that this checklist is based on the Code of Governance (2017).

Instructions: Please fill out the boxes. Input the explanation if the selection is non-compliance for each field. Applicable to charities with gross annual receipts or total expenditure **from \$50,000 to less than \$500,000.**

| S/N | Code Guidelines | Code ID | Response <i>(select whichever is applicable)</i> | Explanation <i>(if Code guideline is not complied with)</i> |
|-----------------------------|---|---------|---|--|
| BOARD GOVERNANCE | | | | |
| 1 | Induction and orientation are provided to incoming governing board members upon joining the Board. | 1.1.2 | Complied | |
| | Are there governing board members holding staff ¹ appointments? (skip items 2 and 3 if "No") | | No | |
| 2 | Staff does not chair the Board and does not comprise more than one third of the Board | 1.1.3 | | |
| 3 | There are written job descriptions for the staff's executive functions and operational duties, which are distinct from the staff's Board role. | 1.1.5 | | |
| 4 | The Treasurer of the charity (or any person holding an equivalent position in the charity, e.g. Finance Committee Chairman or a governing board member responsible for overseeing the finances of the charity) can only serve a maximum of 4 consecutive years. If the charity has not appointed any governing board member to oversee its finances, it will be presumed that the Chairman oversees the finances of the charity. | 1.1.7 | Complied | |
| 5 | All governing board members must submit themselves for re-nomination and re-appointment, at least once every 3 years. | 1.1.8 | Complied | |
| 6 | There are documented terms of reference for the Board and each of its committees. | 1.2.1 | Complied | |
| CONFLICT OF INTEREST | | | | |
| 7 | There are documented procedures for governing board members and staff to declare actual or potential conflicts of interest to the Board at the earliest opportunity. | 2.1 | Complied | |
| 8 | Governing board members do not vote or participate in decision making on matters where they have a conflict of interest. | 2.4 | Complied | |

| HUMAN RESOURCE AND VOLUNTEER² MANAGEMENT | | | | |
|--|--|-------|--------------|--|
| 9 | The Board approves documented human resource policies for staff. | 5.1 | Not Complied | Not Applicable. The Board are all not paid and there are no paid staff. |
| FINANCIAL MANAGEMENT AND INTERNAL CONTROLS | | | | |
| 10 | There is a documented policy to seek the Board's approval for any loans, donations, grants or financial assistance provided by the charity which are not part of the charity's core charitable programmes. | 6.1.1 | Not Complied | Not Applicable The Charity's documented policies are only for its core charitable programme |
| 11 | The Board ensures that internal controls for financial matters in key areas are in place with documented procedures. | 6.1.2 | Complied | |
| 12 | The Board ensures that reviews on the charity's internal controls, processes, key programmes and events are regularly conducted | 6.1.3 | Complied | The Society has its Operation Manual in place for the management of the Society. |
| 13 | The Board approves an annual budget for the charity's plans and regularly monitors the charity's expenditure. | 6.2.1 | Complied | |
| | Does the charity invest its reserves (e.g. in fixed deposits)? (skip item 14 if "No") | | Yes | |
| 14 | The charity has a documented investment policy approved by the Board. | 6.4.3 | Complied | |
| FUNDRAISING PRACTICES | | | | |
| | Did the charity receive cash donations (solicited or unsolicited) during the financial year? (skip item 15 if "No") | | Yes | |
| 15 | All collections received (solicited or unsolicited) are properly accounted for and promptly deposited by the charity. | 7.2.2 | Complied | |
| | Did the charity receive donations in kind during the financial year? (skip item 16 if "No") | | No | |
| DISCLOSURE AND TRANSPARENCY | | | | |
| 17 | The charity discloses in its annual report — (a) the number of Board meetings in the financial year; and (b) the attendance of every governing board member at those meetings. | 8.2 | Complied | |



| | | | | |
|----|--|-----|----|--|
| | Are governing board members remunerated for their services to the Board? (skip items 18 and 19 if “No”) | | No | |
| 18 | No governing board member is involved in setting his own remuneration. | 2.2 | | |
| 19 | The charity discloses the exact remuneration and benefits received by each governing board member in its annual report. OR The charity discloses that no governing board member is remunerated. | 8.3 | | |
| | Does the charity employ paid staff? (skip items 20 and 21 if “No”) | | No | |
| 20 | No staff is involved in setting his own remuneration. | 2.2 | | |
| 21 | The charity discloses in its annual report — (a) the total annual remuneration for each of its 3 highest paid staff who each has received remuneration (including remuneration received from the charity’s subsidiaries) exceeding \$100,000 during the financial year; and (b) whether any of the 3 highest paid staff also serves as a governing board member of the charity. The information relating to the remuneration of the staff must be presented in bands of \$100,000. OR The charity discloses that none of its paid staff receives more than \$100,000 each in annual remuneration. | 8.4 | | |

Notes:

- ¹ Staff : Paid or unpaid individual who is involved in the day to day operations of the charity, e.g. an Executive Director or administrative personnel.
- ² Volunteer : A person who willingly serves the charity without expectation of any remuneration.

Declaration

I declare that my charity’s / IPC’s governing Board has approved this Governance Evaluation Checklist and authorised me to submit on its behalf. All information given by me in this checklist submission is true to the best of my knowledge and I have not willfully suppressed any material fact. The full responsibility for providing accurate and updated checklist information will rest with my charity’s / IPC’s governing Board

CONFLICT OF INTEREST DECLARATION
HAEMOPHILIA SOCIETY OF SINGAPORE

As required by the new compliance procedure, all members of the Management Committee of the Haemophilia Society of Singapore disclose on an annual basis that they do not have any conflict of interest with regard to rendering their voluntary service to the Society