MINUTES OF THE 46th ANNUAL GENERAL MEETING

HEMOPHILIA SOCIETY OF MALAYSIA

HELD ONLINE VIA ZOOM MEETINGS
ON SUNDAY, 28TH DECEMBER 2025

1. INTRODUCTION

As the emcee, Mr. Afzar and Mr. Irfan started at 10.00am by greeting, thanking, and welcoming all exco members, parents, patients, volunteers, supporters to the 46th Annual General Meeting (AGM) for the Hemophilia Society of Malaysia (HSM) that had been held online via Zoom Meetings.

2. OPENING ADDRESS BY THE PRESIDENT

Edwin commenced the session with a warm opening speech, acknowledging the efforts of the organizing committee and expressing appreciation for everyone's presence. He extended heartfelt gratitude to all individuals and organizations who supported the team throughout the year, particularly the sponsors for their generous contributions.

Edwin presented a comprehensive overview of HSM's activities for 2025, with notable activities including Hemophilia Boys Camp in January 2025, Super Senior Camp for people with hemophilia above 30 years old in November 2025, as well as HSM's participation in the International Session at the 14th China Rare Disease Summit in Wuhan, China in September 2025 represented by Timothy Achan on behalf of HSM.

Edwin notes that 2025 is a year of preparation and outreach, with HSM officially completing its PACT Program initiatives that started in 2020, which enhanced HSM's presence throughout Malaysia via the establishment of Regional Champions and strengthened HSM's leadership through 4 graduates who successfully completed the PACT Academy Program. He cites that with the closing of the PACT Program chapter, HSM has readied itself for the upcoming World Federation of Hemophilia (WFH) 2026 World Congress, to be held in Malaysia on April the same year.

The latest bulletin/newsletter was showcased, summarizing the year's milestones, events, and community stories. Edwin encouraged everyone to share it widely and to contribute actively to future editions by submitting articles, updates, or photos from state-level activities.

Edwin then addressed the challenges currently faced by HSM, namely the inconsistent supply of treatment factors from 2024 has finally stabilized during the year, however he urges the hemophilia community for its continued support to ensure hemophilia is listed for potential healthcare financing. Limited financial donations due to policy changes in partner organizations have affected the scale and frequency of HSM's programs, to which HSM shall source for other means of donations and sponsorship in the coming years. Edwin also stressed the need for proactive engagement with medical professionals to ensure succession planning and that HSM will always maintain a channel for communications within the medical community.

Lastly, Edwin shares the future direction of HSM, which will emphasize on having more engagements and workshops in Sabah and Sarawak, improving relationships with stakeholders and medical professionals to ensure sustainable healthcare, strengthening HSM's communication channels via social media and group chats, as well as more focus on the development of hemophilia youth and women with bleeding disorders.

3. CONFIRMATION OF MINUTES OF THE 45th ANNUAL GENERAL MEETING

The emcee then invited the Secretary, Mr. Azfar Azhar, to verify and confirm the minutes of the 45th Annual General Meeting report. The minutes of the previous Annual General Meeting was confirmed by Madam Norhana and seconded by Dr. Siah.

4. ANNUAL REPORT OF THE EXCO MEETING FOR THE YEAR 2024

Mr Azfar Azhar proceeded to present the Annual Report 2024 for verification and confirmation, of which was confirmed by Mr Taqrir and seconded by Madam Norhana. For more details, kindly refer to Attachment 1.

5. TREASURER'S REPORT 2024: UNAUDITED ACCOUNT FOR YEAR 2024 & PROPOSED BUDGET FOR THE YEAR 2026

The emcee invited the Treasurer, Mr. Amierul Hakimie to present the Treasurer's Report 2024, which comprises Unaudited Report for 2024 and Proposed Budget for 2026.

Mr. Amierul Hakimie had estimated that total income for 2026 will stand at approximately RM102,000 in conjunction with the upcoming WFH 2026 World Congress, to which he proposed for approval of HSM's projected expenses of approximately RM101,650. The report has been approved by Madam Norhana and seconded by Mr Taqrir.

6. CASH AWARD PRESENTATION

The Emcees announced the four cash awards recipients for Hemophilia Patients who have achieved academic success, as follows:

- Ahmad Ammar Mohd Fakhizan achieved 4.00 CGPA in Electrical & Electronic Engineering course from Kolej Matrikulasi Kejuruteraan Kedah

- Amierul Hakimie Luqman Yusli achieved 3.48 CGPA in Bachelor of Laws (LLB) (Hons) course from Universiti Kebangsaan Malaysia (UKM)

- Mohd Fakharuddin Zakaria achieved 3.30 CGPA in Bachelor of Estate Management course from Universiti Teknologi MARA (UiTM)

- Ahmad Iqmal Hamat Radzuan achieved 3.43 CGPA in Bachelor of Business in Insurance course from UKM

7. WFH 2026 WORLD CONGRESS

The Emcees invite Edwin once more to share exciting news on the upcoming World Congress, which will be held in Malaysia and is the first congress in 12 years to be hosted in Asia Pacific since Thailand's World Congress. Edwin shares that the date and venue have been officially confirmed, with the Congress to be held in KLCC Convention Centre from 19 April 2026 to 22 April 2026. He also shares that some delegates who are attending GNMOT Training shall arrive earlier to Malaysia on 17 April 2026.

The Opening Ceremony will be held on Monday from 7.00 am to 8.00 am, which will feature traditional performances and speeches from various VIPs. The Congress will feature poster presentations from patients

and doctors across the globe, as well as trainings and sharing sessions on various topics. Notably, Edwin mentions that there will be no networking session or dinner provided throughout or after the Congress.

Edwin proceeds to introduce the important members WFH and International Conference Services (ICS), the company in charge of logistics, marketing and flow management of the Congress, as well as the various committee boards that will play important roles during Congress. The main Congress committee which oversees the entire event will be co-chaired by representatives from Malaysia, namely Dr Veena and Mr Taqrir.

Edwin states that the participation goal of this World Congress is targeted to exceed 2,000 participants, from 144 NMOs worldwide. As for the responsibilities of HSM, HSM shall seek to procure sponsors who are non-pharmaceutical companies and provide aid during the event, if necessary. Edwin hopes that more Malaysian patients and caregivers can register in this historic event to provide a channel for the Malaysian hemophilia community to understand and advocate for better treatment.

Lastly, Edwin explains participation fees and possible subsidies that can be provided by HSM, which includes Airbnb accommodation for Sabah and Sarawak participants as well as 20 complimentary admission tickets on first-come-first-served basis. Edwin encourages the members of HSM to take the opportunity and contact him for those interested in the free admission tickets.

8. MATTERS ARISING

The Emcee moved to next agenda which is arising matters and open to all attendees to ask questions through the Zoom chat message function. Among the questions and answers provided are as follows:

- New treatment: Explained by Dr Veena and Edwin, currently available treatment includes factor replacement therapy as well as Gene therapy which is still experimental. Edwin takes the opportunity to urge attendees to register for Congress to understand more on this topic as it will be covered comprehensively during the Congress.

- Bonding with members from rural regions: Attendees raised concerns on the differing situations and lack of communication channels in non-KL centric regions, to which Edwin and Azhar encourage the newly established Regional Champion chapters and local community leaders to come up with their own initiatives and activities, as well as utilize online platforms such as Zoom and WhatsApp to communicate with HSM so that they can receive support in terms of hospital recommendations, contacts for professional trainers as well as financial support to an extent.

- Inquiry on CPR for hemophilia patients: Confirmed by Dr Siah, hemophilia patients should receive CPR immediately should the situation arises, and there are no additional steps to be performed other than factor replacement after the patient has been resuscitated (if necessary).

- Volunteers for World Congress: Edwin confirms that the maximum number of volunteers is capped at 50 pax, whereby HSM will reach out to NCSM for professional volunteers. Edwin recommends that HSM members should attend as regular participants as volunteers will be too busy to fully engage in the Congress activities.

- How to improve our advocacy efforts: Shakir clarifies that those who wish to help improve the hemophilia community must present themselves as not just a consumer of medical products but an active advocate who is compliant with treatment plan in order to present a credible opinion to medical

practitioners. Shakir also urges attendees to adhere to the treatment plan provided to them as HSM has received multiple complaints from doctors on non-compliance.

- How to ensure factor supplies for patients overseas: Jointly answered by Dr Veena and Shakir, to obtain factor supplies while overseas, a potential method could be to enter clinical trials or purchase insurance coverage to help source the medicines. Otherwise, the best method would be to return to Malaysia and restock with a letter of justification from doctors on the factor stock (in case of aviation issues), which is more cost effective since factor is subsidized in Malaysia.

- Availability of Hemlibra / Emicizumab for all patients: Current tender is for patients with inhibitors and children of up to 6 years old, meant as a means for prophylaxis for these patients. Dr Veena explains that it is currently not possible to be administered for all patients due to pricing, however the tender team is working on procuring extended half-life factor concentrates instead.

Edwin then invites our HSM Exco representatives, Mr Jonathan and Mr Timothy, from Sabah and Sarawak respectively to give speeches about their activities and achievements in their regions.

Timothy thanks the committee for welcoming him and explains that while there is less activity in Sarawak due to low reception from the local government, he and the Sarawak team are actively participating in various other activities to start traction to improve the presence of the Sarawak hemophilia community.

Jonathan thanked HSM and its continuous support towards the Sabah region, and outlines the initiatives by the Sabah Chapter, which includes expansion of treatment centers in hospitals, as well as teaching doctors how to perform infusions.

9. ADJOURNE MEETING

The emcees adjourned the meeting at 12.20pm.

Prepared by:	Verified by:	Confirmed by:
(ADRYON KOH JIA HAO) Assistant Secretary Hemophilia Society of Malaysia	**(AZFAR AZHAR BIN ZAINOL AZHAR)** Honorary Secretary Hemophilia Society of Malaysia	**(GOH TOKE YEN)** President Hemophilia Society of Malaysia