

**MINUTES OF THE 44TH ANNUAL GENERAL MEETING
OF THE HEMOPHILIA SOCIETY OF MALAYSIA
HELD AT DEWAN AL' HAMBRA, NUR LEMBAH ECO PANGSUN RESORT
HULU LANGAT, SELANGOR
ON SATURDAY, 16TH DECEMBER 2023**

1. INTRODUCTION

As the emcee, Mr. Ilham started at 10.30am by greeting, thanking, and welcoming all exco members, parents, patients, volunteers, supporters, as well as participants of the Hemophilia Camp 2023 to the 44th Annual General Meeting (AGM) for the Hemophilia Society of Malaysia (HSM) that had been held at Dewan Al' Hambra, Nur Lembah Eco Pangsun Resort, Hulu Langat, Selangor. This meeting was attended by 58 people in total, including 24 non-HSM members and 34 members.

2. OPENING ADDRESS BY THE PRESIDENT

Mr. Edwin thanked to all exco members, HSM members, Medical Providers and World Federation of Hemophilia to join the 44th Annual General Meeting (AGM) for the Hemophilia Society of Malaysia (HSM). Mr. Edwin hope that there will be more participation in HSM's future events.

Mr. Edwin presented an extensive overview of the activities conducted by HSM throughout the year 2023. The events included both local and international programs, demonstrating the organization's commitment to fostering a global presence. Emphasis was placed on the active participation of HSM delegates in various training sessions and events, showcasing the organization's dedication to continuous learning and development.

Mr. Edwin informed the attendees about the opening of registrations for the WFH's PACT Advocacy Academy program. He highlighted the significance of the program by referencing Mr. Adryon's participation in the previous year. This served as a tangible example of the program's value and relevance to HSM members, encouraging further participation.

Mr. Edwin discussed the upcoming WFH World Congress scheduled for April in Madrid, Spain. He underscored HSM's success in securing a seat for youth fellowship at the event, indicating the organization's active involvement and influence on the global stage. Additionally, he briefly touched upon the anticipation for the WFH 2026 World Congress to be held in Kuala Lumpur, Malaysia, setting the stage for future international engagements.

Mr. Edwin outlined the future directions of HSM, focusing on key pillars such as collaboration, involvement, common values, member empowerment, and data-based initiatives. These strategic areas reflect the organization's commitment to growth, unity, and leveraging data-driven approaches for effective decision-making.

Mr. Edwin expressed a hopeful vision for the future, envisioning comprehensive care and numerous opportunities for individuals with hemophilia. This forward-looking perspective

emphasizes HSM's commitment to making a positive impact on the lives of those affected by hemophilia. Mr. Edwin concluded by providing HSM's contact information for any inquiries or purposes. This ensures that members have a direct and accessible channel to seek information or clarification on any matters related to the organization.

3. CONFIRMATION OF MINUTES OF THE 43RD ANNUAL GENERAL MEETING

Mr. Ilham then invited the Secretary, Mr. Azfar Azhar, to verify and confirm the minutes of the 43rd Annual General Meeting report. The minutes of the previous AGM was confirmed by Mr. Jimmy Koh and seconded by Dr. Ahmad Qabil.

4. ANNUAL REPORT OF THE EXCO MEETING FOR THE YEAR 2022

Please refer to Attachment 1.

5. REPORT OF THE UNAUDITED ACCOUNT FOR YEAR 2022 & PROPOSED BUDGET FOR THE YEAR 2024

The emcee invited Mr. Azraf Azhar to present the Audit Report for 2022 and Proposed Budget for 2024. The Audit Report had been proposed by Mdm. Norhana and seconded by Mr Azizul.

6. MATTERS ARISING

The Emcee moved to next agenda which is arising matters and open to all attendees to ask question. Mr. Azizul inquired about the eligibility criteria for a cash award related to academic contributions. The qualification for the cash award includes patients with hemophilia throughout their lifetime, covering academic levels from PT3, SPM, STPM, diploma, and degree. Mr. Azizul sought clarification on whether the cash award should be applied every two semesters. Mr. Azfar responded affirmatively, stating that any inquiries or concerns can be directed to Mdm. Intan.

Dr. Qabil suggested inviting more members from across Malaysia to participate in the organization's activities. Mr. Azfar acknowledged the merit of the proposal but highlighted concerns about the associated costs. While acknowledging the idea, he mentioned that it is currently in the planning stage.

Mdm. Ros highlighted that the stock of factor concentrates in HKL can only be obtained within a week due to issues related to cost, decreasing stock levels, increased patient numbers, and weight gain among patients. Mr. Edwin explained that tender processes were affected during the pandemic period, and there were challenges to continue, with hopes for resolution by January or February this year. HSM expressed hope that the issue would not adversely affect patients, and Mr. Azfar explained that there are stock issues not only for hemophilia but also for other medical conditions. Discussions with the director from the Health Ministry have taken place, and efforts are being made to stock up, with acknowledgment that it may take some time.

SN Fuzarimah shared that every year, a budget is allocated for hemophilia, covering prophylaxis and on-demand treatment. However, she mentioned the challenge of having to allocate funds to cover factor costs, which are exceptionally high.

Mr. Azfar discussed various questions and suggestions from emails. Firstly, he mentioned ongoing studies for new treatments in Malaysia. Secondly, there is a proposal for a family day

with a budget available for sponsorship. Thirdly, a senior camp was suggested. Additionally, a patient from Kelantan proposed a workshop in the region. Lastly, there's consideration for home delivery of factor products, with Tapah Hospital having implemented it, while Ampang Hospital briefly did once during the pandemic period but was not continue due to cost concerns.

Mr. Ilham thanked for all suggestions and comments and HSM will try the best to implement whichever program that are leading to better treatment for all patients. In addition, HSM will provide more awareness activities for treaters, parents and patient to receive more knowledge because it is very important to all of us to have the right information.

7. CASH AWARD PRESENTATION

The Emcee invited Mr. Edwin and Mr. Hazri to deliver four cash awards to Hemophilia Patients as they succeed in their academic:

- Wan Iqmal Hakimie Wan Rasna Shahman achieved 3.75 in his 5th semester of Bachelor of TESL, IPG Kampus Pendidikan Islam, Bangi.
- Ahmad Fahim Che Johari completed his Bachelor of Creative Technology (Honours) at Universiti Malaysia Kelantan with 3.27
- Amierul Hakimie Luqman Yusli achieved 3.35 in his 4th semester of Bachelor of Law (LL.B) at the National University of Malaysia.
- Afzar Azhar Zainol Azhar achieved 6As in SPM.

8. ADJOURNE MEETING

Mr. Ilham adjourned the meeting at 1.30pm

Prepared by:



(AZFAR AZHAR BIN ZAINOL AZHAR)
Secretary
Hemophilia Society of Malaysia

Approved by :



(GOH TOKE YEN)
President
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