

Association for Haemophilia and Allied Disorders-Asia Pacific



ANNUAL REPORT 2019-2020



AHAD-AP

ASSOCIATION FOR HAEMOPHILIA AND ALLIED DISORDERS - ASIA PACIFIC

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FOREWORD

We are pleased to share with you the 2019-2020 AHAD-AP Annual Report, where you will find all the key activities carried out by AHAD-AP from April 2019 to March 2020.

About AHAD-AP

The AHADAP, previously known as APHWG was convened in 2014, and consists of clinicians managing haemophilia from countries and regions across the Asia Pacific region. Countries and regions currently represented include Australia, China, Hong Kong, India, Japan, Malaysia, Singapore, South Korea, Taiwan, Thailand and Vietnam.

A steering committee guides the group activities, with a larger working group of clinicians contributing to key projects.

Over the last 3-4 years AHAD-AP has evolved gradually and has conducted several training workshops, published the Asia Pacific Principles of Haemophilia Care and created a format for outcomes data collection.

Mission

To improve care for people at risk for haemophilia and other hereditary bleeding disorders in the AP Region.

Our Objectives

- To address the educational needs of the region and conduct relevant training activities.
- To develop and publish scientific documents relevant to and necessary for improving haemophilia care in the Asia Pacific Region.
- To help develop an outcome data registry, suitable for collection of data on individual people with haemophilia (PWH) at Haemophilia Treatment Centres (HTCs) in the AP region.

Governance

The AHAD-AP is governed a Steering Committee led by appointed Chair, as well as different standing committees and functions as an independent, incorporated body. The AHAD-AP has a collaboration agreement with the World Federation of Hemophilia, an NGO affiliated with the WHO, so as to coordinate with them and supplement their activities in the region. Financial administration is being managed under a memorandum of understanding with the WFH.

Whilst the group aims to work in collaboration with societies such as the World Federation of Hemophilia (WFH), and Asia Pacific Society of Thrombosis and Haemostasis (APSTH), it is not formally under the auspices of any of the Haematological organisations.

Steering Committee Members

The members of Steering committee are as below:

Dr Alok Srivastava (Chair)	India
Dr Eun-Jin Choi	South Korea
Dr Scott Dunkley	Australia
Dr Hishamshah Ibrahim	Malaysia
Dr Joseph John	India
Dr Joyce Lam	Singapore
Dr Sukesh Nair	India
Dr Jameela Sathar	Malaysia
Dr Ming-Ching Shen	Taiwan
Dr Midori Shima	Japan
Dr Darintr Sosothikul	Thailand
Dr Alison Street	Australia
Dr Jing Sun	China
Dr Huyen Tran	Australia
Dr Raymond Wong	Hong Kong
Dr Renchi Yang	China

WORKING GROUP COMMITTEES

Three working group committees have been setup under the guidance of the Steering Committee. Current leads and members of these groups are listed below

Publications & Scientific Committee	Co-Chairs- Scott Dunkley and Midori Shima Members- Huyen Tran, Joseph John, Raymond Wong, Tadashi Matsushita
Education & Training Committee.	Co-Chairs- Alison Street and Sukesh Nair Members- Joyce Lam, Jing Sun, Jameela Sathar and Clarence Lam
Registry Committee	Co-Chairs- Alok Srivastava and Hishamshah Ibrahim Members: Shashi Apte

ACTIVITIES IN 2019-2020

A brief summary of the various activities between April 2019-March 2020.

NEW MEMBERS OF THE STEERING COMMITTEE

The Steering Committee discussed the need to include more representatives from the countries and invited Dr. Ming-Ching Shen from Thailand and Dr.Eun-Jin Choi from South Korea to be part of the steering committee to which they have accepted.

NEW PROGRAM MANAGER

With the exit of Mr. Vivek Singh as the Program Manager of AHAD-AP in the month of April 2019, the exercise to recruit a new Program Manager was initiated and the vacancy was advertised. Shortlisted candidates underwent the process of a written evaluation and a personal interview and Miss. Toshirenla Aier was selected and commenced the role of the Program Manager from the month of November 2019.

TRAINING & EDUCATION

AHAD-AP has planned three workshops to be conducted in the first quarter of 2020 but due to the Covid-19 pandemic, it was put on hold and gradually shifted to the virtual platform in the last quarter of 2020.

REGISTRATION

The process to register as a legal entity was initiated. The name of the association was re-branded as Association for Haemophilia and Allied Disorders-Asia Pacific and the constitution was drafted based on the EAHAD model which was reviewed and refined by the steering committee AHAD-AP. Few legal firms were contacted in Singapore and Goodwins Law Corporation was selected to aid the association in the process of the registration. The process is expected to be completed by mid-2019.

PUBLICATION

On behalf of the AHAD-AP, an oral presentation by Dr. Alison Street on “Asia Pacific Haemophilia working Group- Its role in enhancing Haemophilia Care” was selected to be presented during the WFH World Congress planned from June 14 to 17,2020. Due to the covid-19 concerns the summit has been canceled and the paper will be presented as an iposter in the virtual summit planned in the same month.

WEBSITE

The existing website of APHWG was running on a static mode and with the change in the name of the association and the need to upgrade it, the process to develop and design a new website of AHAD-AP was initiated in the month of February 2020.

HTC Directory

The periodic verification and update of the HTC directory was initiated in the month of January 2020, whereby all existing HTCs in the directory were contacted to check the data relevancy as well as update with a few additional details. The directory is updated with the basic services available at each center and can be accessed by all on the website of AHAD-AP.

REGISTRY (APBDR)

The ‘Asia Pacific Bleeding Disorder Registry (APBDR)’ has been made available to all HTCs.

FOLLOW UP OF CAMBODIA WORKSHOP

As one of the action item for the workshop conducted by AHAD-AP, a 12 month post workshop follow up of Cambodia workshop (CCH) was carried out. Follow up form were shared with all the participants who has attended to assess the impact of the workshop and the challenges faced in their own place of work. The results were analyzed and taken into consideration for designing and refining future educational activities of AHAD-AP.

SUPPORTING ORGANIZATIONS

The activities of AHAD-AP are done in collaboration with the World Federation of Hemophilia (WFH) and have been supported by project grants from Takeda Pharmaceuticals, Roche and Stago till date.

All financial transactions have been managed through the World Federation of Hemophilia, so far.

CONTACT US

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