



**ASSOCIATION FOR HAEMOPHILIA  
AND ALLIED DISORDERS-ASIA  
PACIFIC**

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**2020**

**ANNUAL REPORT**

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## ABOUT AHAD-AP

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Association for Haemophilia and Allied Disorders-Asia Pacific (AHAD-AP) previously known as Asia Pacific Haemophilia Working Group, was formed in 2014 by a group of health care professionals involved with haemophilia care from the Asia Pacific region.

Our goal is to enhance care for people with haemophilia and other hereditary bleeding disorders in the region through education, training, research and advocacy. AHAD-AP has been established as a legal entity incorporated in Singapore from 2020.

During the past years, AHAD-AP has conducted multiple training workshops, published the Asia Pacific Principles of Hemophilia Care and created a format for outcome data collection. Various other activities are also planned.

### 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 by a Steering Committee led by appointed Chair, as well as three standing committees.

## ACTIVITIES (2020)

A brief summary of the activities of AHAD-AP between April 2020-December 2020.

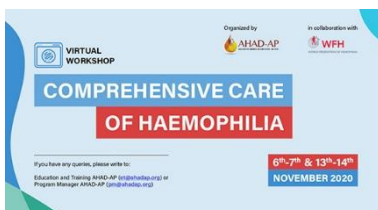


### 1. TRAINING and EDUCATION:

There were three workshops organized by the Education and Training Standing Committee for the year 2020.

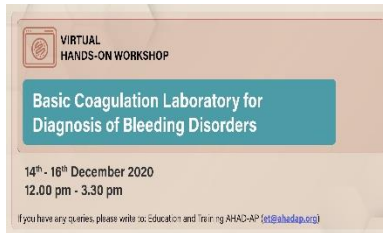
- Musculoskeletal Management of Haemophilia, Virtual Workshop:** With the aim to offer training to key selected specialists on the assessment and management of MSK complications in haemophilia, a virtual workshop on Musculoskeletal Management of Haemophilia was organized from 12-16<sup>th</sup> October 2020. This workshop was conducted in collaboration with Christian Medical College (CMC) Vellore India and World Federation of Hemophilia (WFH).

The course lead was Dr. Judy Ann David from the Department of Physical Medicine and Rehabilitation, CMC Vellore, India. All the other faculties were from the same institution.



- Comprehensive Care of Haemophilia, Virtual Workshop:** The AHAD-AP in collaboration with the World Federation of Hemophilia organized a 4 days virtual workshop on Comprehensive Care of Haemophilia to bring together multi-disciplinary health professionals from the Asia Pacific region, to share experiences, learn together and develop skills in the care of Persons with Haemophilia (PWH). The workshop was held on 6-7<sup>th</sup> and 13-14<sup>th</sup> November, for three hours a day.

Dr. Alison Street, Co-chair of the Education and Training Committee was the course lead.



- **Basic Coagulation Laboratory for Diagnosis of Bleeding Disorders, Virtual Hands-on Workshop**

With the above aim, a virtual hands-on workshop on Basic Coagulation Laboratory for Diagnosis of Bleeding Disorders was held from 14-16<sup>th</sup> December 2020, in collaboration with Christian Medical College Vellore, India.

The course lead of the workshop was Dr. Tulasi Geevar from the Department of Transfusion Medicine & Immunohematology Christian Medical College, Vellore India. Other faculties were Dr. Sukesh C Nair, Dr. Rutvi Dave and Mr. G Surender Singh from the same institute.

The feedback received for all the three workshops were generally positive.

## WORKSHOP FIGURES



68  
Participants

10  
Countries



121  
Participants

18  
Countries



32  
Participants

9 HTC's

### SPONSORS

The educational activities were supported by an unrestricted grant from Takeda and Roche

## 2. INCORPORATION OF AHAD-AP

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The AHAD-AP, previously known as the Asia Pacific Haemophilia Working Group (APHWG) was incorporated as a legal entity in Singapore as of 30<sup>th</sup> July 2020.

## 3. APPOINTMENT OF AN AUDITOR AND COMPANY SECRETARY

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In compliance with the Companies Act of the ACRA in Singapore, the association was required to appoint a local firm of public accountants as auditors of the Company within 3 months as well as a qualified company secretary within 6 months from the date of incorporation.

In consultation with the local legal team, two potential names were identified and being considered for further discussion and engagement with AHAD-AP.

## 4. BANK ACCOUNT OF AHAD-AP

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Financial administration till date is being managed under a memorandum of understanding with the World Federation of Haemophilia. With the establishment as an independent entity, the AHAD-AP has initiated the process of opening a bank account in Singapore and which is expected to be completed by mid-2021.

## 5. NEW WEBSITE OF AHAD-AP

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The process to develop, design and host a dynamic website for AHAD-AP was initiated under the guidance of a few of the Steering Committee members in the month of February 2020. The project was completed in the month of July 2020 and made live to the users. The new website is [www.ahadap.org](http://www.ahadap.org)

## 6. PUBLICATION

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On behalf of the AHAD-AP, an abstract on “Asia Pacific Haemophilia working Group- Its role in enhancing Haemophilia Care” was presented as an iPoster by Dr. Alison Street during the WFH Virtual Summit held on June 14-19 2020.

The abstract was also published in ‘Haemophilia’ (The Official Journal of the World Federation of Hemophilia)

## 7. HTC DIRECTORY

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AHAD-AP has been putting the effort to list down the HTCs and its basic information across the region. With the aim to make the directory as a tool will be vital for both the health care provider and the patient, the directory is compiled and updated from various sources and AHAD-AP is grateful to all who has given their input in compiling and updating the directory of HTCs.

At present, the directory has details from 17 countries and regions across the Asia-Pacific.

The process of verification and update is an ongoing process.

## 8. REGISTRY

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Documentation of demography, diagnosis and outcomes data is critical for good management of people with bleeding. The AHAD-AP therefore encourages such documentation at each HTC using a standardized format for data collection and has made the platform APBDR (Asia Pacific Bleeding Disorder Registry) available to all who are interested.

A twitter account was created for AHAD-AP to enhance the presence of AHAD-AP in the social network.

## 9. CONNECTION

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## FINANCES

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AHAD-AP's financial year is 1<sup>st</sup> April-31<sup>st</sup> March.

Financial administration till date is being managed under a memorandum of understanding with the World Federation of Haemophilia.

The activities of AHAD-AP have been supported by project grants from Takeda Pharmaceuticals and Roche.

## FUTURE ACTIVITIES

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1. **AHAD-AP ACADEMY:** The AHAD-AP is in the process of creating an Academy ePlatform providing members with premium and complete access to educational resources including webinars, courses, recorded presentations and talks of the different workshops for FREE.
2. **AHAD-AP Annual Meeting:** The AHAD-AP will be hosting the 1<sup>st</sup> Annual Meeting in collaboration with the Indian Association for Haemophilia and allied Disorders (IAHAD) on 16<sup>th</sup> & 17<sup>th</sup> September 2021
3. **Expansion of the existing Standing Committees:** To expand the membership of three standing committees of AHAD-AP and represent the different countries in the region, it is proposed to include more members from the region.

## GOVERNANCE

The Association for Haemophilia and Allied Disorders-Asia Pacific is currently managed by a Steering Committee led by appointed Chair, as well as different standing committees.

### STEERING COMMITTEE

|                                   |                |                       |            |
|-----------------------------------|----------------|-----------------------|------------|
| <b>Dr Alok Srivastava (Chair)</b> | <b>Vellore</b> |                       |            |
| <b>Dr Eun-Jin Choi</b>            | Daegu          | Dr Ming-Ching Shen    | Chuanghua  |
| <b>Dr Scott Dunkley</b>           | Sydney         | Dr Darintr Sosothikul | Bangkok    |
| <b>Dr Hishamshah Ibrahim</b>      | Kuala Lumpur   | Dr Alison Street      | Melbourne  |
| <b>Dr Joseph John</b>             | Ludhiana       | Dr Jing Sun           | Ghuangzhou |
| <b>Dr Joyce Lam</b>               | Singapore      | Dr Huyen Tran         | Melbourne  |
| <b>Dr Tadashi Matsushita</b>      | Nagoya         | Dr Raymond Wong       | Hong Kong  |
| <b>Dr Sukesh C Nair</b>           | Vellore        | Dr Renchi Yang        | Tianjin    |
| <b>Dr Keiji Nogami</b>            | Nara           |                       |            |
| <b>Dr Jameela Sathar</b>          | Ampang         |                       |            |



**STANDING COMMITTEES**

Three Standing Committees have been setup under the guidance of the Steering Committee.

Current leads and members of these groups are listed below

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

**AHAD-AP OFFICE**

|                        |                        |
|------------------------|------------------------|
| <b>Program Manager</b> | <b>Toshirenla Aier</b> |
|------------------------|------------------------|

## ORGANOGRAM

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**ASSOCIATION FOR HAEMOPHILIA AND  
ALLIED DISORDERS-ASIA PACIFIC**

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 www.ahadap.