



# ANNUAL REPORT 2018-2019

Asia Pacific Hemophilia Working Group



**APHWG**  
ASIA PACIFIC HEMOPHILIA WORKING GROUP

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# FOREWORD

We are pleased to share with you the 2018-2019 APHWG Annual Report, where you will find all the key activities carried out by our association from May 2018 to March 2019.

## ABOUT APHWG

The 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 India, Australia, Malaysia, Japan, China, Hong Kong, Taiwan, Thailand, South Korea, Brunei, Vietnam and Singapore. A steering committee guides the group activities, with a larger working group of clinicians contributing to key projects.

The APHWG is governed by the Steering Committee and functions as an independent, non-incorporated body. It has a Memorandum of Understanding (MoU) with World Federation of Hemophilia (WFH) for collaboration in all its educational programs and for helping APHWG to manage its funds.

## 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 hemophilia (PWH) at Hemophilia Treatment Centres (HTCs) in the AP region.

## Steering Committee Members

The members of Steering committee are as below:

Dr Alok Srivastava (Chair)	India
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 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

Our key areas of focus are Education and Training, Scientific data generation and publication, and Data Registries.

Three working group committees have been set up as below:

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

## ACTIVITIES IN 2018-2019

A brief summary of the various activities between May 2018-March 2019.

### NEW MEMBERS OF THE STEERING COMMITTEE

The Steering Committee discussed the need to include more representatives from the countries and invited Dr. Darintr Sosothikul from Thailand and Dr. Jameela Sathar from Malaysia to be part of the steering committee to which they have accepted.

### TRAINING & EDUCATION

APHWG has conducted three workshops in coordination with WFH and local host institutions.

#### 1. Management of Musculoskeletal Complications in Haemophilia Workshop.

From November 12-18 2018, 23 participants from 9 countries gathered to participate in the workshop on the Management of Musculoskeletal Complications in Haemophilia at Christian Medical College Vellore, India. Physiotherapists, Orthopedic surgeons and Physical Medicine Rehabilitation specialists were part of the workshop.

The workshop proved to be a great opportunity to learn about contemporary approaches in MSK management in Asia Pacific Region which will enhance access to improved services for the People with Haemophilia (PWH). The training faculties were Dr. Judy Ann John, Dr. Aby Abraham, Dr. Alok Srivastava, Mrs. Merlyn Tilak, Mrs. R Andriya and other health team members from Christian Medical College Vellore, India.



## 2. Comprehensive Care of Haemophilia Workshop.

With the vision of improving care for people with haemophilia and other hereditary disorders in the Asia Pacific Region, the APHWG organized a workshop on Comprehensive Care of Haemophilia for physicians & nurses at the National Pediatric Hospital (NPH), Phnom Penh, Cambodia from 18-20<sup>th</sup> March, 2019.

The workshop was organized in collaboration with the World Federation of Hemophilia (WFH) and the National Pediatric Hospital, Cambodia.

A total of 27 participants from 11 countries in the Asia Pacific region attended the workshop.

The main training faculties were Dr. Alison Street, Dr. Alok Srivastava, Dr. Joyce Ching Mei Lam, Dr. Pradeep Poonnoose and Dr. Chean Sophal from different institutes/countries of the region. This educational activity was supported by an independent medical educational grant from Shire.



## 3. Basic Coagulation Workshop on Laboratory Diagnosis of Haemophilia

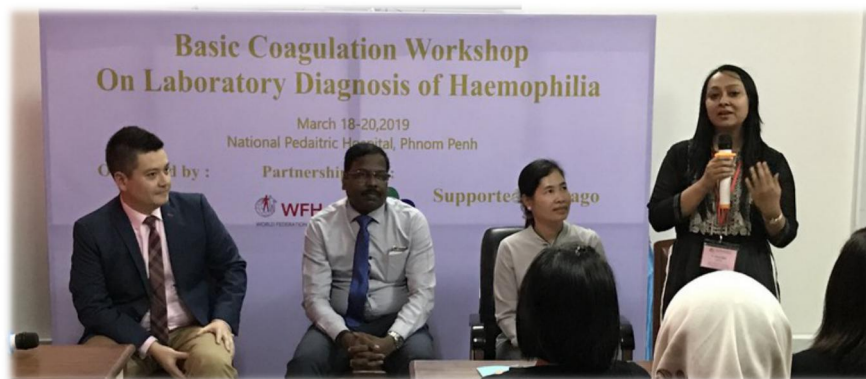
APHWG conducted a three day Basic Coagulation Workshop on Laboratory diagnosis of Haemophilia from March 18-20<sup>th</sup> 2019 at National Pediatric Hospital (NPH), Phnom Penh, Cambodia. The workshop was organized in collaboration with WFH and National Pediatric Hospital (NPH), Phnom Penh, Cambodia.

The aim of the workshop was to offer training to key selected laboratory specialists on the diagnosis of Haemophilia and von Willebrand disease.

A total of 30 Participants from various professional background such as medical laboratory technology, pathology, lab sciences attended the workshop. The participants were selected from 11 countries across the Asia pacific region.

The main training faculties were Dr. Sukesh C Nair, Dr. Rutvi Dave from the Christian Medical College Vellore, India along with technical personnel from the sponsor.

The workshop was supported by Stago Diagnostica.



## PUBLICATIONS

The Asia Pacific Hemophilia Working Group (APHWG) conducted a survey to identify perceived training and educational needs of HTC's in Asia Pacific with a view to providing information that will be helpful for all haemophilia education stakeholders in developing targeted and tailored local and regional educational and training initiatives. The survey was conducted in 2016-17 and targeted HTC's in those Asia Pacific countries affiliated with World Federation of Hemophilia (WFH).

The findings were published in the Research and Practice in Thrombosis and Haemostasis in May 2018, authored by Dr. Joyce Lam, Dr. M Joseph John and Dr. Alison Street on behalf of the steering committee APHWG.

Article access: <https://onlinelibrary.wiley.com/doi/full/10.1002/rth2.12108>



## **HTC DIRECTORY**

With inputs from various sources, APHWG has been putting the effort to list down the HTCs in each country and region in the Asia Pacific, which will be a great resource of information. An exercise to contact each center was taken out and as of September 2018 it has been updated and uploaded in the website of APHWG ([www.aphwg.org](http://www.aphwg.org)). It will require periodic updates.

## **REGISTRY (APBDR)**

APHWG has developed 'Asia Pacific Bleeding Disorder Registry (APBDR)' which is a registry for patients with Hemophilia in AP Region. This registry will be used to collect patient data from Hemophilia Treatment Centres (HTC). Using this system, HTCs throughout the AP region will be able to systematically and consistently collect data and which contributes to improved and measurable patient outcomes, including comparability between centres. The data collection template for APBDR was developed by adapting the Universal-Case Report Form (uCRF) from WFH.

The development and management of those centre registries using APBDR has been contracted by APHWG to the Clinical Data Management Centre (CDMC) at Christian Medical College (CMC), Vellore through an MoU signed on 2nd January 2017.

Until Mar 2019, the CDMC has developed forms, completed test and have developed beta version platform which is ready to accept data from the HTCs. It has already received data forms from one HTC. It has started generating web traffic also on periodic (weekly/monthly) basis.

**APHWG WEBSITE**

The website ([www.aphwg.org](http://www.aphwg.org)) is live since November 2017 and has been updated with training & workshops until March, 2019. The HTC directory has been updated as per the details received.

**SUPPORTING ORGANIZATIONS**

The activities of AHAD-AP are done in collaboration with the World Federation of Hemophilia 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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