

ASIA PACIFIC HEMOPHILIA WORKING GROUP (APHWG)

ANNUAL REPORT
2017-18



www.aphwg.org

CONTENTS

FOREWORD	1
MISSION	1
ABOUT APHWG	1
STEERING COMMITTEE & WORKING COMMITTEES	1-2
OBJECTIVES	2
ACTIVITIES IN 2017-18	2-5
<i>RECRUITMENT OF PROGRAM MANAGER</i>	2
<i>SURVEY OF EDUCATIONAL NEEDS OF HEMOPHILIA TREATMENT CENTERS WITHIN ASIA PACIFIC</i>	3
<i>PRINCIPLES OF CARE (PoC) DOCUMENT</i>	3
<i>TRAINING AND EDUCATION</i>	3-5
REGISTRY	6
APHWG WEBSITE	6
BUDGET	7
ACKNOWLEDGEMENTS	7
CONTACT US	7

Foreword

We are pleased to publish our first report from the Asia Pacific Hemophilia Working Group (APHWG) which summarizes our activities from foundation to April 2018.

We are keen to work with all agencies within the Asia Pacific (AP) region committed to development of clinical care for persons with hereditary bleeding disorders and welcome approaches, support and feedback.

Mission

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

About Us

The APHWG was convened in 2014, and consists of clinicians managing hemophilia 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.

Steering Committee Members

The members of Steering committee are as below:

Dr Alok Srivastava (Chair)	India	Dr Joyce Lam	Singapore
Dr Alison Street	Australia	Dr Midori Shima	Japan
Dr Hishamshah Ibrahim	Malaysia	Dr Raymond Wong	Hong Kong
Dr Huyen Tran	Australia	Dr Renchi Yang	China
Dr Jing Sun	China	Dr Scott Dunkley	Australia
Dr M Joseph John	India	Dr Sukesh Nair	India

The key areas of focus of the APHWG are education and training, scientific publications, and an outcome registry.

Three Working Committees have been set up to address these areas:

1. Publications & Scientific Committee

Co-Chairs	Scott Dunkley and Midori Shima
Members	Huyen Tran, M Joseph John, Raymond Wong

2. Education & Training Committee

Co-Chairs	Alison Street and Sukesh Nair
Members	Joyce Lam, Jing Sun, Jameela Sathar and Clarence Lam

3. Registry Committee

Co-Chairs	Alok Srivastava and Hishamshah Ibrahim
Members	Shashi Apte

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.

ACTIVITIES IN 2017-18

Recruitment of Program Manager

APHWG recognised the need for a Program Manager reporting to the Steering Committee to coordinate its activities. The position was advertised on the internet with a detailed job description and terms of reference. APHWG received approximately 200 applications and finalised the recruitment through a round of written evaluation and an interview. Mr Vivek Singh, who has 13 years of experience in working with NGOs in healthcare, including those with an international focus in the region, was selected. He commenced duties in July, 2017.

Survey of educational needs of hemophilia treatment centers within Asia Pacific

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

[The report has been accepted for publication in Research and Practice in Thrombosis and Hemostasis](#)

Principles of Care (PoC) document

WFH and EAHAD have previously published PoC and general treatment guidelines. Publication of these documents allows them to be used for guidance and advocacy of improved haemophilia care. A similar document, relevant to Asia Pacific countries was required for the same purpose. In our region, Australia and New Zealand have carried out benchmarking exercises, based on local PoC documents to identify potential areas of improvement. Similar evaluations, using an AP model of care could be accomplished by individual countries in the AP region. These identify targets for improvement initiatives within and between individual countries in determining gaps in current care and treatment and the PoC.

The “Asia Pacific Principles of Hemophilia Treatment & Care” document is principally aimed at policy maker and healthcare provider audiences. The content has been supported by peer reviewed literature and established treatment guideline data. It is in essence a concise, aspirational document, presented in a language readily understandable to both laymen and health care workers. The document has been accepted for publication in Haemophilia.

[Please search the article with 10.1111/hae.13425 in Wiley Online Library](#)

Training and Education

APHWG has conducted four workshops in coordination with WFH and local host institutions:

1. Workshop on Laboratory Diagnosis of Bleeding Disorders

With the vision of improving care for people with haemophilia and other hereditary disorders in the Asia Pacific Region, one of its aims is to enhance diagnostic capacity in the region. Towards this end, the APHWG organized a workshop on laboratory diagnosis of bleeding disorders with special focus on haemophilia in collaboration with WFH and the National

Health Laboratory (NHL), Yangon, Myanmar on October 9-11, 2017. The program was supported by Stago Diagnostica. 28 participants from eight countries attended. They were medical laboratory technologists, pathologists, or other laboratory scientists.



2. Workshop on the Management of Musculoskeletal (MSK) Complications in Hemophilia

On November 13-17, 2017, 17 participants (F:7, M:10) from 11 countries gathered to participate in the workshop on the Management of Musculoskeletal Complications in Hemophilia at CMC Vellore, Tamilnadu, India. They were Physiotherapists, Orthopedic surgeons or Physical Medicine Rehabilitation specialists.

They learnt about contemporary approaches in MSK management in AP Region which enhance access to improved services for the People with Hemophilia (PWH).

Workshop participants included representatives from Bangladesh, India, Maldives, Malaysia, Mauritius, Myanmar, Nepal, Sri Lanka Thailand, Syria and Vietnam

The objectives of the workshop included:

- Development of knowledge and skills in the comprehensive assessment and management of MSK complications in Hemophilia.
- Competence in assessment of core outcome measures in Hemophilia.
- Familiarity with disease specific guidelines and recent advances in Hemophilia care.



3. Comprehensive Hemophilia Care Workshop

APHWG organised a Comprehensive Hemophilia Care Workshop in partnership with Chulalongkorn University, Bangkok and WFH at King Chulalongkorn Memorial Hospital, Thailand on January 8-10, 2018.

This model of clinical care is delivered by a team of multidisciplinary healthcare professionals, usually under the direction of a hematologist, to provide acute and chronic care to PWH. The purpose of this workshop was to discuss support and development of appropriate models of integrated chronic disease management, specific to haemophilia, within local healthcare systems. 29 participants from 14 countries comprised of physicians, paediatricians, hematologists and nurses familiar with care of PWH took part in the workshop.



4. Training of Trainers' on Laboratory Diagnosis in Hemophilia

APHWG organised a 5-day Training of Trainers' workshop on Laboratory Diagnosis in Hemophilia at Christian Medical College, Vellore, India on February 19-23, 2018.

The objective of this advanced workshop was to upskill trainers to then conduct laboratory workshops in the AP region, to develop local expertise in laboratory diagnosis and monitoring of bleeding disorders. Quality activities in testing and blood product assessment were also addressed. 15 pathologists, laboratory scientists and technologists from seven countries took part in the workshop.



Activities Review

The Steering Committee will be reviewing outcomes of these workshops as well as funding support in development of the next set of educational activities in line with APhWG objectives.

Registry

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. The aim is to set standard clinical measures to collect on people with hemophilia and other hereditary bleeding disorders.

Based on draft uCRFs, CMC data centre developed Beta version of web based data capture system with rigorous security and privacy standards. Inbuilt validation checks were incorporated in the data management system for completeness and accuracy of the captured data. An extensive user guide was developed to guide the end users at HTCs as to how to access the web-based data capture system by module.

Before deploying the study database for real time data capture, dummy data capture was conducted to ensure the acceptance of study database as per the uCRF. Beta version of the system was implemented and advised to "APHWG – Registry Committee" members for their review and inputs.

Please see the uCRF here - <https://cmc-biostatistics.ac.in/APHWG/crf.php>

Action Plan

The APHWG would like to provide the registry platform for all HTCs to record baseline and outcome data on all PWH being followed at their centers. The minimal data form (MDF) has been adapted from the WFH WBDR and customized to the needs of the AP region. In addition, the HJHS and FISH forms have also been adapted to make entries easier. The data provided will belong to the HTC and used for their own services or analysis till protocols for sharing these data are worked out within the region and outside.

Website

APHWG successfully developed the content and launched its website in Jan 2018. APHWG is now readily available to communicate with the wider audience; general public, patients, caregivers, funders and clinicians looking for training. The website can be accessed at: <http://www.aphwg.org/>

Budget

Baxalta (Shire) has supported APHWG activities through its Educational Grant received on July 31, 2016. Basic Lab workshop of APHWG was supported by Stago Diagnostica.

Acknowledgement

APHWG expresses sincere thanks to its donors; Baxalta (now part of Shire) and Stago Diagnostica.

Contact

Program Manager, APHWG

Email: aphwgcommittee@gmail.com

Website: www.aphwg.org



ASIA PACIFIC HEMOPHILIA WORKING GROUP
(APHWG)

India | Australia | Malaysia | Japan | China | Hong Kong | Taiwan
Thailand | South Korea | Brunei | Vietnam | Singapore