Asia Pacific Society of Human Genetics

APSHG Newsletter

Volume 01 | Issue 01 | December 2020

Message from the President

Dear friends and colleagues,

Welcome to our first biannual APSHG newsletter. As the president of the APSHG, I am honoured to be a part of the Editorial Board of the APSHG Newsletter.

The newsletter is a platform for sharing our society's activities and educational information on health science particularly in the field of Genetics and Genomics. I invite you to contribute articles and Letters to the Editor on matters related to clinical genetics, genetic counseling and scientific research in your area of practice that might be of interest to APSHG members.

In early 2020, our lives and well being was greatly impacted by the COVID-19 pandemic forcing us particularly those working on the frontline of clinical care or providing crucial support, to cope with unforeseen challenges in such unprecedented times. The APSHG is proud of its members and their tireless and resilient work.

I would like to thank those who took part in the 3rd APSHG Summer School in Taiwan on 22 August 2020. It was an amazing virtual meeting adapted to fit the current pandemic situation by our APSHG Taiwanese board members and team.

Your views are very valuable. They will shape the content of future issues. As always, the editorial board will do their best to maintain the quality of the newsletter and strive for improvement with feedback from all members. If you wish to get in touch, email us at apshg@apshg.info.

We, and our respective countries are all against the COVID-19 pandemic. Best wishes and may we all emerge with a renewed appreciation for each other.

Thank you.

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APSHG Newsletter

Board of Editors 2020
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Contents

Featured in this inaugural issue of the Asia-Pacific Society of Human Genetics (APSHG) newsletter is the message from the APSHG president, Professor Thanychai Sura from Mahidol University, Thailand. In his message, Professor Sura discusses the impact of Covid-19 infection on citizens of the Asia-Pacific region and the challenges that we, as members of APSHG, faced in our daily life and practices.

Also featured in this issue is the brief introduction of all the APSHG executive council members to APSHG members thus connecting the elected representatives with the members of their respective countries through the provision of services and advice.

Another key feature in this issue is the article on the history of the APSHG, written by APSHG President Emeritus Professor Lai Poh San. Our society was for mally registered in Singapore on 2006. However, its members have been meeting informally, organizing conferences, collaborating in research and exchanging ideas, as far back as the 1990's. We hope that through the APSHG, the network and linkages will continue to prosper and bring together members from all the countries in the Asia-Pacific region.

Members who are interested in our society will find very informative the articles highlighted in the section Recent Publications on Human Genetics in the Asia Pacific (page 8). If you have any published articles of interest, especially to our society members in the Asia Pacific region, or wish to contribute news, announcements, opinions and knowledge in your area of expertise to the biannual newsletter, you are most welcome to do so. Please email them to me at zilfalil@gmail.com or to any of the editoral board members. These contributions will be published in the June 2021 issue.

I wish to thank all the hardworking members of this newsletter's editorial board for their contributions in getting this inaugural issue published on time. To all APSHG members, we need your feedback and contributions in terms of articles. news, and announcements. We hope to hear from you. Please make yourselves heard and counted.

Prof. Zilfalil Bin Alwi
Editor-in-Chief
APSHG Newsletter

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The History of the Asia-Pacific Society of Human Genetics (APSHG)

Contributed by APSHG President Emeritus Professor Lai Poh-San* (Singapore)
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Early origins

Like many other human genetics societies, the establishment of the Asia-Pacific Society of Human Genetics (APSHG) was driven by a small group of professionals with common interests in understanding genetic diseases and making diagnosis for patients with these conditions.

The origins of the APSHG could be traced back to the early 1990s with a regional network of medical geneticists and researchers mostly from SE Asia countries like Indonesia, Thailand, Malaysia, the Philippines and Singapore, who met regularly to discuss common challenges in studying and managing diseases like thalassaemia and glucose-6-phosphate dehydrogenase (G6PD) deficiencies which were prevalent in the local populations[1].

It is noted that there was a significant role played by Japanese researchers during this time with a number of meeting activities organized with the support of the Japan Society for the Promotion of Science (JSPS) under the auspices of Monbusho, the Ministry of Education, Science, Sports and Culture in Japan. These meetings included the JSPS Seminar on Human Genetics in Perinatal Medicine (1-8 August 1993) in Jakarta, Indonesia; NRCT-JSPS (National Research Council of Thailand-Japan Society for Promotion of Science) Regional Seminar on Medical Genetics and Molecular Biology (27-29 July 1994) in Bangkok, Thailand; International Seminar on Child Health (29-30 September 1995) in Singapore; International Symposium on Human Genetics & Gene Therapy (5-6 February 1999) in Singapore; Seminar on Advances in Neonatology (1-2 March 1999) in Yogyakarta, Indonesia; Asian Symposium in Neonatology: G6PD deficiency and related conditions (8-9 August 2000) in Yogyakarta, Indonesia; Asian Symposium on Inherited Metabolic Disorders (6-9 November 2002) in Kobe, Japan and so on. These gatherings brought stakeholders from different countries together, sowing the seeds for the formation of APSHG.

Under an informal network, the pioneering members convened six big regional conferences in human genetics between 1994 to 2004 with several meetings jointly organized with the Human Genome Organization (HUGO) (Table 1). Subsequently, the drafting of the Society's constitution was followed by the official registration in Singapore on 17 February 2006 with 14 founding members, consisting of two each representing Hong Kong, Indonesia, Malaysia, Philippines Singapore, Taiwan and Thailand (Table 2). The APSHG was then admitted as a full member of the International Federation of Human Genetics Societies (IFHGS) in August 2006. As a member, the APSHG has been consistent in their support of the activities of IFHGS and promoted the International Congress of Human Genetics (ICHG) meetings organized by IFHGS once every five years.

Activities of the APSHG

Since the official incorporation of the Society, more than 7 conferences have been organized in various countries like Malaysia, the Philippines, Vietnam and Thailand. These conferences were usually well participated with attendees from ASEAN countries and beyond such as from Japan, Taiwan, China, Mongolia, India, Sri Lanka, Australia and even the Middle East. The 12th Asia-Pacific Conference on Human Genetics (APCHG) held in Bangkok, Thailand from 8–10 November 2017 was considered special as it represented a tribute to the very 1st APCHG that was held also in Bangkok, Thailand[2]. Besides these conferences, educational activities such as the three summer/autumn schools were held in Hong Kong (2016), Singapore (2018) and Taiwan (2020). Members formed working groups in interest areas like genetic counselling, birth defects, newborn screening, rare diseases, NGS technologies, bioinformatics, population genetics and ELSI, collaborating together to organize workshops and publish joint manuscripts. Additionally, some of our members have recently collaborated and worked on a special publication issue of the American Journal of Medical Genetics Part C that features publications by geneticists in Asia and showcases the rich work in genomic medicine, clinical genetics and genetic counselling in this region[3].

Table 1. Asia Pacific Conferences on Human Genetics (1994 to 2019)[1]

	Date	Venue	Organizers
1st Asia Pacific Conference on Human Genetics	27-29 July, 1994	Bangkok, Thailand	Suthat Fucharoen & Pornswan Wasant
2nd Asia Pacific Conference on Human Genetics	19-23 Sept, 1995	Jakarta, Indonesia	Sangkok Marzuki & Herawati Sudoyo
3rd Asia Pacific Conference on Human Genetics	1-3 Dec, 1997	Kuala Lumpur, Malaysia	M Nizam Isa
Joint 3rd HUGO-Pacific and 4th Asia Pacific Conference on Human Genetics	18-20 Oct, 2000	Shanghai, China	Zhu Chen & Li Jin
Joint 4th HUGO-Pacific and 5th Asia Pacific Conference on Human Genetics	27-30 Oct, 2002	Pattaya, Thailand	Suthat Fucharoen & Pornswan Wasant
Joint 5th HUGO-Pacific and 6th Asia Pacific Conference on Human Genetics	17-20 Nov, 2004	Singapore	Edison Liu and Poh-San Lai
Joint 6th HUGO-Pacific and 7th Asia Pacific Conference on Human Genetics	6-10 March, 2006	Taipei, Taiwan	Yuan-Tsong Chen & Wuh-Liang Hwu
Joint 7th HUGO-Pacific and 8th Asia Pacific Conference on Human Genetics	2-5 April, 2008	Cebu, Philippines	Carmencita Padilla & Eva Cutiongco de la Paz
9th Asia Pacific Conference on Human Genetics	30 Nov-3 Dec, 2010	Hong Kong, China	Stephen Lam
10th Asia Pacific Conference on Human Genetics	5-8 Dec, 2012	Kuala Lumpur, Malaysia	Meow-Keong Thong
11th Asia Pacific Conference on Human Genetics	16-18 Sept, 2015	Hanoi, Vietnam	Dung Chi Vu
12th Asia Pacific Conference on Human Genetics	8-10 Nov, 2017	Bangkok, Thailand	Pornswan Wasant & Thanyachai Sura
13th Asia Pacific Conference on Human Genetics	7-9 Nov, 2019	Manila, Philippines	Carmencita Padilla & Eva Cutiongco de la Paz

Table 2. Founding Members of Asia Pacific Society of Human Genetics (APSHG) in 2006[1]

Hong Kong (China)	Chen Zhu & Stephen Lam
Indonesia	Sangkot Marzuki & Herawati Sudoyo
Malaysia	M Nizam Isa & Meow-Keong Thong
Philippines	Carmencita Padilla & Eva Maria Cutiongco-De La Paz
Singapore	Poh-San Lai & Ivy Ng
Taiwan (ROC)	Chen Yuan-Tsong & Paul Hwu Wuh-Liang
Thailand	Suthat Fucharoen & Pornswan Wasant

Summary
Asia is home to more than 60% of the world's population with amazing resources and human talent. Being a member of APSHG represents an exciting opportunity for contributing towards enabling local Asian communities to embrace human genetics and genomics into research and healthcare needs. The APSHG has grown since its inception and is poised to further develop in this era of genomic and precision medicine. While the unexpected circumstances of COVID-19 have temporarily halted many activities, the APSHG had nonetheless been able to host the third summer school as an online event on 22 August this year. In a post-COVID world, we look forward to new norms when we can physically meet again in the near future and collaborate fruitfully as we have in the past even as we continue to embrace new communication and meeting platforms in the virtual space.

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APSHG Committee Members

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Zilfalil Bin Alwi, MD, PhD, Malaysia

APSHG Committee Members

Thanyachai Sura MD MRCP, is an adult clinical geneticist working in Department of Medicine Ramathibodi Hospital Mahidol University. He organized the training program in medical genetics and molecular medicine for the Royal College of Physicians of Thailand. He is the current president of APSHG.

Dr CHUNG Hon Yin Brian initially trained at HKU (2000-2006) and subsequently at the University of Toronto, the Hospital for Sick Children (2007-2010). He obtained his fellowship of the Canadian College of Medical Geneticists, and later became a founding fellow of the subspecialty of Genetics & Genomics (Paediatrics) of the Hong Kong Academy of Medicine.

Mercy Laurino, MS CGC, PhD is a licensed genetic counselor with 15+ years of clinical and research experience. She was pivotal in launching the genetic counseling master's program at the University of the Philippines-Manila in 2011. She is founding president of the Professional Society of Genetic Counselors in Asia.

Breana Cham, MHSc (Genetic Counselling) is a pioneer genetic counselor in Singapore. In the past decade, she has contributed to the development of the profession through clinical work, research and education. She is a founding member and president-elect of the Professional Society of Genetic Counselors in Asia.

Sultana M. H. Faradz, MD, Ph.D is a Professor of Medical Genetics, at Diponegoro University, Indonesia. She has been trained on Medical Genetics in several countries and obtained her PhD at the UNSW, Australia. She initiated the first MSc program on Genetic Counseling in 2006 and run clinic on Medical Genetics/ Genetics counseling.

Zilfalil Bin Alwi, MBBS, MMed, PhD, is a Professor and consultant Pediatrician & clinical Geneticist at Universiti Sains Malaysia (USM). He received his specialist training (MMed) in Pediatrics from USM and a PhD from University of Aston, United Kingdom. He is the founder and head of the Malaysian Node of the Human Variome Project and the founding president of the Malaysian Society of Human Genetics.

Catherine Lynn T. Silao, MD, PhD, FPPS is a Professor of the Department of Pediatrics, University of the Philippines and of the National Institutes of Health. She is presently the Head of the Molecular Genetics Unit of the NIH-Institute of Human Genetics and is the Program Coordinator of the Master of Science in Genetic Counseling.

Duangrurdee Wattanasirichaigoon, MD, ABMG (1999) is a professor at Mahidol University, Faculty of Medicine Ramathibodi Hospital, with 20+ years of clinical and research experiences in genetics. She has majorly involved in establishing Thai NHSO (UHC)-benefit package for rare disease, and a RCPT-certified fellowship training program in Pediatric Medical Genetics.

Yin-Hsiu Chien, MD, Ph.D., is a pediatrician and medical geneticist with 20 years of clinical and research field, mainly in inborn errors of metabolisms and immunodeficiency. She is the director of the newborn screening center at National Taiwan University Hospital since 2006. She serves as a board member of the Taiwan Human Genetic Society since 2014.

Dr. B R Lakshmi is the Director and Managing Trustee of MDCRC, India, a not for profit organization working in Public Health domain for more than a decade. Her research interests include; Community genetics, Molecular diagnosis, Public genomics, creating working models to identify genetic disorders especially in rural community. She is one of the founding members of Board of Genetic Counseling India (BGCI) and currently the VP of BGCI and an elected Board member at APSHG.

Welcome New Members

We would like to welcome the following new members of APSHG:

Dr Yasue Horiuchi, Japan

Ms Lim Chia Wei, Singapore

Mr Kelvin Chan, Hong Kong

Mr James Massa, USA

Ms Sylvia Kam, Singapore

Dr Hoang Tran Dang , Viet Nam

Dr Sann Lin Ko, Myanmar

How to be a member?

How to become an APSHG member?
Membership is open to those with keen interest in the study of human genetics, including basic, applied and medical genetics.

Categories of Membership:
Regular: Open to persons involved or interested in the study of human genetics in the Asia Pacific region with fully paid membership dues. Regular members have voting rights.

Junior: Open to persons under 30 years of age who are registered full-time students or trainees with fully paid membership dues. Junior members have no voting rights.

Life: Open to Regular members who have paid life membership dues. Life members have voting rights.

Senior: Open to members who have retired from full time employment. These persons should have been Regular Members and have paid annual membership dues for 5 years in total before being qualifying for Senior membership. They will then be entitled to the privilege of Regular members without fee. Senior members have voting rights.

Corporate: Upon recommendation of the Board, the Society may elect organisations that support the aims of the Society to Corporate membership. Each corporate member shall be entitled to nominate not more than two representatives to the Society and these nominees are subject to the approval of the Board. The Corporate members are not eligible to hold office or be members of the Board or to vote. Corporate members cannot use the name or logo of the Society for the purpose of advertisement or for any commercial or non-professional purposes. Corporate members shall seek in writing the written approval of the Board for use of the name or logo of the Society for any professional, education, or other matters. Corporate nominees are subject to similar restrictions imposed on the Corporate members.

Please register online: “Online Registration“

Source: https://www.apshg.info/memberships.html

3rd APSHG Summer School on Human Genetics Report

Reported by Dr. Ni-Chung Lee and Dr. Yin-Hsiu Chien
Department of Pediatrics and Medical Genetics,
National Taiwan University Hospital

Co-organised by the Department of Medical Genetics, National Taiwan University Hospital, Taiwan Human Genetics Society, and Taiwan Association of Genetic Counseling, the 3rd APSHG Summer School on Human Genetics was held on 22 August 2020. Due to the pandemic of COVID-19, the summer school was substituted with a virtual webinar course. The one-day online course offered updated information of genetics/genome in Asia, Clinical dysmorphology, genetic counseling, and technologies of next generation sequencing (NGS). Dr. Poh-San Lai, Dr. Eva Cutiongco-de la Paz, and Dr. Thanyachai Sura were first to present with a talk on "Current status of Clinical Genetics in Asia Pacific area" followed by an update on the clinical recognition of syndromes and counseling by Dr. Brian Chung, Dr. Anne Tsai, and Dr. Meow Keong Thong. After the break, the webinar focused on NGS technology, which was introduced by Christian Gilissen from Nijmegen, Jiaja Xu from Illumina, Zuwei Qian from PacBio, and Dr. Gareth Baynam who spoke from the perspective of diagnosing undiagnosed disease. The webinar concluded with the talk on prioritization of exome data by image analyses and newborn screening by Nicole Fleischer and Dr. Nancy Chien.

Over 190 participants, including 15 countries from the Asia Pacific area, Italy, Mongolia, Netherland, and USA together joined this meeting (Figure 1). We also thank Illumina, PacBio, Yu Jay, and Genomics for supporting this event. The promotional flyer posted on the APSHG, THGS, PSGCA, and TGC websites and social media attracted participants largely made up of physicians and genetic counselors (Figure 2).

Upon the conclusion of the webinar, a survey was conducted among the participants, who ranked all the sessions as above good, very good, and excellent (Figure 3). The most common suggestions for improvement are network connection, technical issues, and the duration of the event. It was suggested that future events be organised over 2 half-day sessions instead of a one-day series of lectures. These suggestions will be taken into consideration for the organisation of the next summer school.

The virtual webinar is the first of its kind in the delivery of APSHG summer school (Figure 4). Although there were internet and technical issues, we thank everyone for their patience throughout the webinar. We look forward seeing more participants in the next summer school, which will be held in 2022 in Thailand as well as providing more educational events on clinical genetics in the Asia Pacific area.

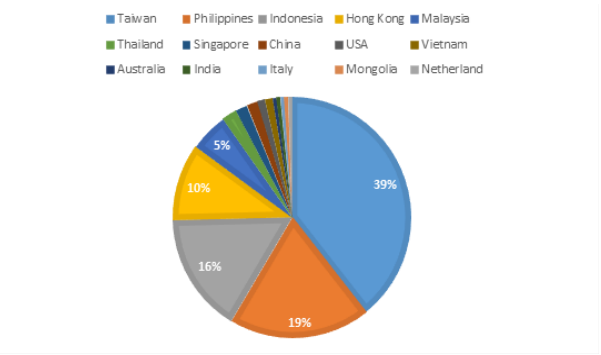

Figure 1. Country of origin of participants

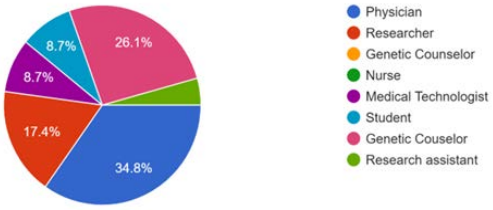

Figure 2

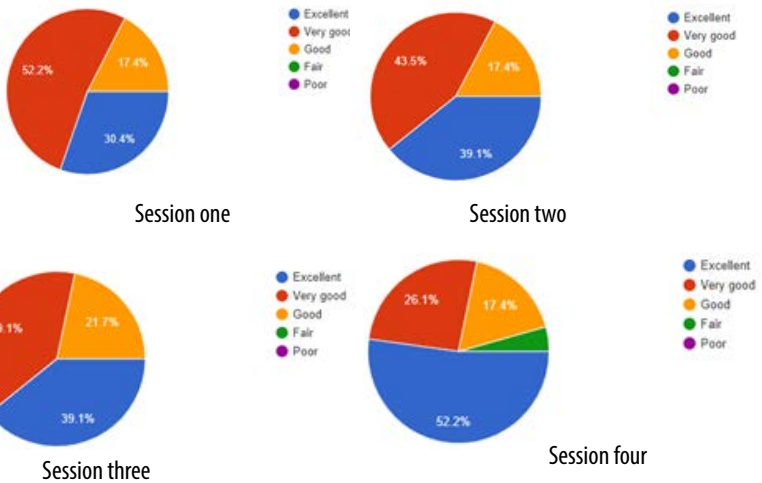

Figure 3

Figure 4.Webinar snapshot

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RESEARCH REVIEW

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Asia Pacific Society of Human Genetics (APSHG) from conception to 2019: 13 years of collaboration to tackle congenital malformation and genetic disorders in Asia

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Abstract

Putting together the reports in this issue that come from a representation of the different countries in Asia presents an opportunity to share the unique story of the Asia Pacific Society of Human Genetics (APSHG), which has provided the authors of many of these articles. This paper, authored by the Past Presidents of the Society, shares glimpses of how medical genetics activities were first organized in the Asia Pacific region and provides interesting corollaries on how under-developed and developing countries in this part of the world had developed a unique network for exchange and sharing of expertise and resources. Although APSHG was formally registered as a Society in Singapore in 2006, the Society has its origins as far back as in the 1990s with members from different countries meeting informally, exchanging ideas, and collaborating. This treatise documents the story of the experiences of the Society and hopes it will provide inspiration on how members of a genetics community can foster and build a thriving environment to promote this field.

KEYWORDS
APSHG, Asia, Asia Pacific society of human genetics, clinical genetics, history of clinical genetics

1 | MEDICAL GENETICS IN ASIA AND THE ORIGINS OF APSHG: A TRIBUTE TO THE PAST

Infant mortality rates in Asia have been on a decline since the Second World War in many countries in Asia in tandem with improvements in access to healthcare, management of infectious diseases and nutritional problems and the implementation of screening programs. In the 1960s, some of the more common single-gene disorders contributing to significant infant mortality and morbidity, particularly in South East Asian countries, were glucose-6-phosphate dehydrogenase (G6PD) deficiency and hemoglobinopathies (Wong, 1965). Neonatal jaundice and kernicterus associated with G6PD deficiency was the leading cause of death for infants in many countries like Singapore until the introduction of neonatal population screening programs which significantly reduced this disease burden (Wong, 1980). Nonetheless, the burden of congenital disorders in this region was still significant with an estimated prevalence of 52.9 per 1,000 livebirths with single gene disorders contributing towards more than 10% of birth defects while chromosomal disorders and malformations accounting for about 4–5% and 63%, respectively (Padilla & Cutiongco-de la Paz, 2016). Among the monogenic disorders, thalassemias also pose a significant disease burden in many countries in Southeast Asia (Fucharoen & Winichagoon, 2011). The early work on this group of disorders include reports on the prevalence of hemoglobin E-thalassemia disease in Indonesia (Eng, Mursadik, Lioe, & Odang, 1956) and the description of 32 cases

All five authors contributed equally and should be considered as joint first authors.

https://onlinelibrary.wiley.com/doi/full/10.1002/ajmg.c.31701

Genetics inMedicine | REVIEW ARTICLE

Medical genetics in developing countries in the Asia-Pacific region: challenges and opportunities

Meow-Keong Thong, MD[1], Yiling See-Toh, MBBS[1], Jamiyah Hassan, MMed(O&G)[2] and Jaffar Ali, PhD[3]

Advances in genetic and genomic technology changed health-care services rapidly in low and middle income countries (LMICs) in the Asia-Pacific region. While genetic services were initially focused on population-based disease prevention strategies, they have evolved into clinic-based and therapeutics-oriented service. Many LMICs struggled with these noncommunicable diseases and were unprepared for the needs of a clinical genetic service. The emergence of a middle class population, the lack of regulatory oversight, and weak capacity-building in medical genetics expertise and genetic counseling services led to a range of genetic services of variable quality with minimal ethical oversight. Some of the current shortcomings faced include the lack of awareness of cultural values in genetic health care, the variable stages of socioeconomic development and educational background that led to increased demand and abuse of genetics, the role of women in society and the crisis of gender selection, the lack of preventive and care services for genetic and birth defects, the issues of gene ethics in medicine, and the lack of understanding of some religious controversies. These challenges provide opportunities for both developing and developed nations to work together to reduce the inequalities and to ensure a caring, inclusive, ethical, and cost-effective genetic service in the region.

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Keywords: medical genetics services; developing countries; Asia-Pacific; challenges; opportunities

INTRODUCTION

Advances in genetic and genomic technology have accelerated the introduction of genetic services into the health-care delivery system in the Asia-Pacific region. As elsewhere in the world, genetic services initially used population-based disease prevention strategies. In the past two decades, as health indices and the socioeconomic status of the Asia-Pacific region improved, genetic service became increasingly clinic-based and therapeutics-oriented. Many health-care systems in the region were unprepared for the needs of a clinical genetic service and have struggled to cope with both communicable and noncommunicable diseases. In addition, the combination of demands from a large emerging middle class population and the lack of regulatory oversight and capacity-building in medical genetics expertise and genetic counseling services have led to a range of genetic services of variable quality with minimal ethical oversight and legal provisions.[1–3]

Developing necessary genetic services is impaired by the lack of accurate data on genetic conditions and inherited disorders because there are few dedicated birth defect registries or rare diseases registries in this region.[4] The pattern and types of genetic diseases in developing countries are quite variable, even within the same geographic region. Physicians and clinical geneticists trained in developed countries may encounter genetic diseases in the local population in their respective countries that they may be unfamiliar with, but which are common diseases in the region, such as citrin deficiency, Barts hydrops, and distal renal tubular acidosis–Southeast Asian ovalocytosis syndromes. Syndromic genetic conditions characterized by subtle physical differences may be particularly challenging if the clinician receives their training in a country with a different ethnic population. While these are issues being addressed in all countries providing genetic services, we will highlight issues specific to Asian countries.

Cultural and socioeconomic perspectives in medical genetics

In developing countries, most genetic services began in the last decade of the twentieth century, usually from academic institutions such as universities and research institutions.[1] These services are usually led by pediatricians who specialized in medical or clinical genetics. The preponderance of pediatricians, like elsewhere in the world, is not surprising

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INTRODUCTION

American Journal of Medical Genetics | WILEY

Development of clinical genetics in Asia

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Abstract

This Special Issue on Clinical Genetics in Asia highlights a collection of articles showing the growth, development, and current status of clinical genetics in Asia. In this Introduction, the Guest Editors share on the themes of this issue to provide useful insights into the rapid growth of genomics and clinical genetics in this region. The contents of this Issue cover a range of topics from the history and development of clinical genetics in Asia to studies on disorders with clinical significance or phenotype differences in the Asian populations to the status of precision medicine. The goal is to provide a glimpse of how significantly the field of genetics in Asia has developed in recent years with the aspiration that this can serve as a catalyst to increase international collaboration and cooperation in combating genetic diseases. We hope that this issue shows Asia's readiness and willingness to be a part of more international conversations about genetics in future.

KEYWORDS
Asia, clinical genetics, introduction, special issue

1 | INTRODUCTION

Asia is the world's largest and most populous continent being home to more 4.5 billion people, representing 60% of the total world population (https://population.un.org/wpp/). As exemplified by the cover of this issue, this landmass extends from the Pacific Ocean in the east and bounded in the north by the Arctic Ocean and on the south by the Indian Ocean while sharing the western borders with Europe. The world cloud image on this cover seeks to depict the furious pace of development in genetics activities that is taking place in this continent. Asia is incredibly diverse with a wide range of cultures, languages, religions, socioeconomic factors, healthcare systems, and healthcare needs. The healthcare needs of such large diverse populations are unique to Asia but should interest healthcare providers worldwide. Asia's recent growth in the world of genetic research and clinical applications provide useful insights on the evolution of precision medicine in its population for other countries that are developing and expanding their healthcare systems. Further, this population is increasingly mobile. The United States Census bureau reports 19.4 million US residents who identify themselves as Asian (Bureu, 2015). This mobility will require physicians worldwide to understand patients from Asian populations and the cultural, socioeconomic background and the medical systems from where they come.

Historically, Asia's participation in the field of genetics has been limited largely due to socioeconomic factors. However, as genetics becomes a more equalized field and with sophisticated equipment becoming more affordable or even in some cases unnecessary, Asia's participation in genetics research and clinical application has increased. Further increasing Asia's participation in this field is the rapidly growing economies in many of the countries. According to the World Bank, extreme poverty in East Asia has dropped from 29.1% in 2002 to 7.2% in 2012 representing hundreds of millions of people rising out of poverty (http://www.worldbank.org/en/region/eap/overview#2). This level of economic growth is unheard of in the modern western world and has rapidly changed the health care considerations of the continent. There are now significantly more opportunities for research and a growing population of patients who are looking for more specialized clinical care. This influx of patients also requires a more diverse body of population genomics data than is currently available.

It should be noted early on at the start that while attempts have been made to be inclusive and provide a comprehensive view of the field of genetics in Asia, several challenges such as the large number of countries involved, the wide ranging field of genetics and the number of contributions out of this continent make this an impossibility.

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RESEARCH REVIEW

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Training in clinical genetics and genetic counseling in Asia

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Abstract

The status of training in clinical genetics and genetic counseling in Asia is at diverse stages of development and maturity. Most of the training programs are in academic training centers where exposure to patients in the clinics or in the hospital is a major component. This setting provides trainees with knowledge and skills to be competent geneticists and genetic counselors in a variety of patient care interactions. Majority of the training programs combine clinical and research training which provide trainees a broad and integrated approach in the diagnosis and management of patients while providing opportunities for research discoveries that can be translated to better patient care. The background on how the training programs in clinical genetics and genetic counseling in Asia evolved to their current status are described. Each of these countries can learn from each other through sharing of best practices and resources.

KEYWORDS
Asia, clinical genetics, genetic counseling, training

1 | INTRODUCTION

Asia is the largest and most populous continent in the world with a total land area of 44,579,000 km^2 or 17,212,000 sq miles (Atlas of the World Including Geography Facts and Flags Worldatlas.com., 2018). According to United Nations estimates, the population of Asia is over 4.5 billion at the beginning of 2018 which is equivalent to almost 60% of the total world population (https://www.un.org). It has been documented that genetic disorders affect 5.32% of births followed up to 25 years of age (Baird, Anderson, Newcombe, & Lowry, 1988); this translates to almost 240 million persons in Asia affected with some form of genetic condition. This staggering number does not capture other diseases with known genetic basis or conditions suspected to have a strong genetic basis.

The medical specialty of clinical genetics provides genetic evaluation, genetic testing, and counseling for individuals or families with,

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Professional Society of Genetic Counselors in Asia (PSGCA) 2019-2022 Leadership

To learn more about PSGCA and become a member, please visit www.psgca.org

History

The Professional Society of Genetic Counselors in Asia (PSGCA) is a special interest group of the Asia-Pacific Society of Human Genetics (APSHG). It was formally launched on September 16, 2015 at the Genetic Counseling Pre-conference Workshop (GCPCW) held at the 11th Asia-Pacific Conference on Human Genetics (APCHG) in Hanoi, Vietnam. Since then, we have hosted the GCPCWs during the 12th and 13th APCHG in Bangkok, Thailand, 2017 and Manila, Philippines, 2019 respectively.

Recent PSGCA events/ participation

- Webinar on *Telegenetics* organized by PSGCA and presented by Ms. Sylvia Mann, who is a leader in telegenetic service delivery, May 2020
- Webinar on *Genetic Counseling services in Asia* organized by Human Genetics Society of Australia (HGSA) and Illumina, presented by Prof Thanyachai Sura and Ms. Juliana Lee, July 2020
- Participation as guest speakers at the 5th Annual e-Conference of Board of Genetic Counseling India by Dr. Mercy Laurino, Ms. Juliana Lee and Prof Sultana Faradz

Publications by PSGCA leadership

- A Report on *Ten Asia Pacific Countries on Current Status and Future Directions of the Genetic Counseling Profession: The Establishment of the Professional Society of Genetic Counselors in Asia*
- *The Global State of the Genetic Counseling Profession*
- *Genetic counseling globally: Where are we now?*

Ongoing efforts and future activities

- Collaboration with Genetic Counselling Society Malaysia (GCSM) and APSHG in the research study, 'The Impact of COVID-19 Pandemic on Genetic Services across Asia'
- 4th Genetic Counseling Pre-conference Workshop in Indonesia, 2022

Upcoming Events

- Malaysia International Genetics Congress, March 15-17 2021, Virtual Conference
- Board of Genetic Counseling - India 6th Annual International Conference, 1st week of July 2021
- 2nd Indonesian Society of Human Genetics Conference, Sept 2-5, 2021, Cirebon, West-Java, Indonesia