



# APSHG Newsletter

(Vol. 2 | Issue 2 | December 2021)

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## Country Report on Rare Disease

Rare disease is identified as any illness that affects a small percentage of the population and is frequently debilitating. There are about 6000 to 8000 rare diseases worldwide and most of them are associated with genetic disorders.

Here we report the result of a survey that was conducted on the current development of rare diseases in selected country of the Asian Pacific region.

**Thailand**

*Reported by: Thanyachai Sura and Duangrurdee Wattanasirichaigoon*

1. In your country can you find the local information on rare diseases in social media?

Social media: Yes

2. What is the population in your country in 2021?

Population: 69.8 M

3. Is there a Rare Disease Support Group in your country?

Rare Disease Support Group:

- Thai Rare Disease Foundation – <http://thairdf.org>
- <https://www.facebook.com/Thai-Rare-Disease-Foundation>

4. Is there a national policy/law/act for the rare diseases in your country?

National Policy/ Law/ Act:

- UHC (NHSO) - Rare Disease Policy
- National Drug Policy Committee (Essential Medicine included) – Working Committee on Rare Disease Medicine
- The Medical Council of Thailand – Subcommittee on Genomic Medicine

5. Can you provide a brief commentary regarding rare diseases in your country?

Six aspects of Rare Disease Policy:

- Definition: 10,000 for RD and 1,000 for ultra RD.
- Health Service System for specific RD under UHC benefit package.
- Pharmaceutical Management System.
- Information System: National Data Registry.
- Research system including HTA.
- Financing system including alternative financing.

### **Taiwan**

*Reported by: Yin-Hsiu Chien*

1. In your country can you find the local information on rare diseases in social media?

Social media: Yes

2. What is the population in your country in 2021?

Population : 23,451,837 (2021)

3. Is there a Rare Disease Support Group in your country?

Rare Disease Support Group:

<http://www.tfrd.org.tw/tfrd/>

4. Is there a national policy/ law/ act for the rare diseases in your country?

National Policy / Law/ Act:

National Drug Policy Committee (Essential Medicine included) – Working Committee on Rare Disease Medicine

5. Can you provide a brief commentary regarding rare diseases in your country?

Rare disease shall refer to diseases with prevalence rate lower than 1 in 10,000; and recognized through review by the Review Committee.

### **Philippines**

*Reported by: Catherine Lynn Silao, Mercy Laurino and Eva Cutiongco-de la Paz*

1. In your country can you find the local information on rare diseases in social media?

Social media: -

2. What is the population in your country in 2021?

Population: <https://worldpopulationreview.com/countries/philippines-population>

3. Is there a Rare Disease Support Group in your country?

Rare Disease Support Group: <http://www.psod.org.ph/>

4. Is there a national policy/law/act for the rare diseases in your country?

National Policy / Law/ Act:

<https://doh.gov.ph/node/5509> Republic Act No. 10747 | Department of Health website

(doh.gov.ph)

### **Indonesia**

*Reported by: Sultana MH Faradz, MD, PhD*

1. In your country can you find the local information on rare diseases in social media?

Social Media: Yes

- <https://www.penyakitlangkaindonesia.org/page/about-us>
- [https://instagram.com/indonesiararedisorders?utm\\_medium=copy\\_link](https://instagram.com/indonesiararedisorders?utm_medium=copy_link)
- <https://m.facebook.com/groups/indonesiararedisorders/?ref=share>
- [https://www.instagram.com/p/CW-lxaqFmBo/?utm\\_medium=share\\_sheet](https://www.instagram.com/p/CW-lxaqFmBo/?utm_medium=share_sheet)

2. What is the population in your country in 2021?

The population of Indonesia in 2021 was 276,361,783.

3. Is there a Rare Disease Support Group in your country?

Yayasan MPS dan Penyakit Langka Indonesia

Address: Graha Dirgantara Building, Unit F. Lot D, GF Floor. Jl. Protokol Halim Perdana kusuma No. 8,

Jakarta 13610 Email: [info@penyakitlangkaindonesia.org](mailto:info@penyakitlangkaindonesia.org)

<https://www.penyakitlangkaindonesia.org/page/about-us>

### **Malaysia**

*Reported by: Zilfalil Bin Alwi*

1. In your country can you find the local information on rare diseases in social media?

Social Media: Yes

Facebook:

- (<https://www.facebook.com/MalaysianRareDisordersSociety/>)
- <https://www.facebook.com/Malaysia-Lysosomal-Diseases-Association-101898083240617/>
- <https://www.facebook.com/MalaysiaMetabolicSociety/>

Website:

- Malaysian Rare Disorders Society (MRDS) (<http://www.mrds.org.my/>)
- Malaysia Lysosomal Diseases Association (<https://www.mymlda.com/>)
- Malaysia Metabolic Society (<https://mms.org.my/>)

2. What is the population in your country in 2021?

Population: 32,673,142 (2021) (Department of Statistics Malaysia)

3. Is there a Rare Disease Support Group in your country?

Rare disease support group:

- Malaysian Rare Disorders Society (MRDS)
- Malaysia Lysosomal Diseases Association
- Malaysia Metabolic Society

4. Is there a national policy/law/act for the rare diseases in your country?

National Policy/ Law/ Act:

Malaysian Orphan Medicines Guideline

2020 (<https://www.pharmacy.gov.my/v2/en/documents/malaysian-orphan-medicines-guideline-2020.html>)

5. Can you provide a brief commentary regarding rare diseases in your country?

The criteria for inclusion of a disease in the Malaysian Rare Disease List are:

- There are or have been confirmed patients in Malaysia
- The disease affects fewer than 1 in 4,000 people in Malaysia\*
- The disease is a severe condition
- Its inclusion is approved by the national advisory committee\*\*

\* *Based on expert opinions and on local epidemiologic data where available*

\*\* *National Rare Disease Committee*

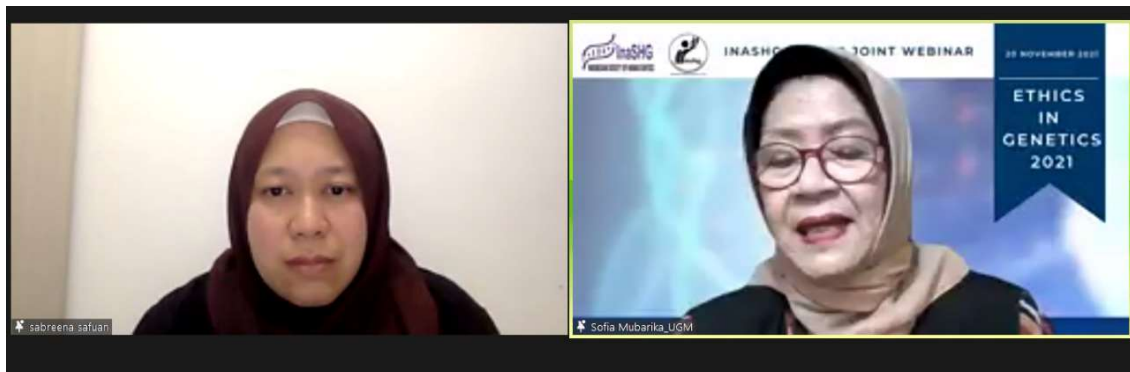
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## JOINT WEBINAR ON HUMAN GENETICS

### Malaysian Society of Human Genetics (MSHG) and Indonesian Society of Human Genetics (InaSHG)

The Joint Webinar on Human Genetics is a collaboration effort between the Malaysian Society of Human Genetics (MSHG) and the Indonesian Society of Human Genetics (InaSHG). The first webinar was conducted on 20 November 2021 from 10.00 AM until 12.00 PM. The topic for the first webinar was Ethics in Genetics.

Prof. Dr. Tri Wibawa from the Universitas Gadjah Mada, Indonesia and Dr. Sabreena Safuan from the Universiti Sains Malaysia, Malaysia were invited to share their expertise as the guest speakers for the session. Prof. Dr. Tri Wibawa talked about the Ethical Aspects of Genetics Disease from the Clinical and Research Perspective while Dr. Sabreena emphasized on the Important Ethical Consideration of Using Animals in Genetics Research. A total of 120 participants from both Malaysia and Indonesia joined the webinar via the Zoom platform.





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Published by  
Asia-Pacific Society of Human Genetics (APSHG)  
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