FEBRUARY 28

Rare Disease Day

Rare Disease Day is held on the last day of February to raise awareness for rare diseases and improve access to treatment and medical representation for patients and their families.

What is a Rare Disease?

Rare Disease is described as a disease that affects fewer than 200,000 people in the United States, affecting 30 million people in the United States.
According to the NIH, about 7,000 – 10,000 rare diseases affect humans, many of which have no treatment.

What are Characteristics of a Rare Disease?

Characterized by a broad diversity of disorders and symptoms that vary not only from disease to disease but also from patient to patient suffering from the same disease.

Relatively common symptoms can hide underlying rare diseases leading to misdiagnosis and delaying treatment. There are often no existing effective cures.

Challenges

- Lack of scientific knowledge and quality information about the disease
- Social and financial burdens – lack of access to treatment and care
- Common symptoms can hide underlying diseases, misdiagnosis is common
- Equity for people living with rare disease is equitable access to diagnosis, treatment, health, social care, and opportunity

Statistics

- There are 6000+ rare identified diseases.
- Collectively the number of people with a rare disease is equivalent to the population of the world's third largest country. 300 million people worldwide are living with a rare disease.
- 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral) allergies and environmental causes or rare cancers.
- 70% of genetic rare diseases start in childhood.
- There are an estimated 200 rare cancers.

References
Rarediseaseday.org

APIAHF
ASIAN & PACIFIC ISLANDER AMERICAN HEALTH FORUM