AWARENESS

RARE DISEASE DAY

The 28th of February marks Rare Disease Day, which aims to raise awareness for rare diseases and highlight the challenges faced by people living with rare diseases worldwide.

According to the National Organization for Rare Disorders, there are over 6 000 rare diseases affecting more than 300 million people globally.

A disease or disorder is defined as rare when it affects a handful of people (fewer than one in 2 000 in Europe and fewer than 200 000 people in the USA).

Eighty per cent of rare diseases have identified genetic origins. Others are the result of infections, allergies or environmental causes.

Common problems:

- Often, no effective cures exist for rare diseases, which adds to the pain and suffering patients and families endure.
- Lack of scientific knowledge and information on these diseases can result in a delayed diagnosis and inappropriate health care or treatment.

A few rare diseases known are:

Fields disease is named after Wales twins, Catherine and Kirstie Fields. This neuromuscular disease is a progressive muscle disorder, which causes painful muscle spasms, slow muscle deterioration and movement restrictions.

Microcephaly is a very rare birth defect affecting one in 7 000 newborns. It occurs when a baby suffers from diminished brain development, which makes their head appear smaller than normal.

Hutchinson-Gilford Progeria Syndrome - a congenial disease affecting one in every eight million births - causes a striking appearance that resembles premature aging in young children. This fatal, genetic condition also causes hair loss, hearing loss and osteoarthritis.

Show your support:

Support the rare disease community by joining this month's face paint social media campaigns.

Paint your face and share a selfie on social media using the hashtags *#ShowYourRare* and *#RareDiseaseDay.*

Ensure to partake in advocacy activities for Rare Disease Day within your community.