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UNIVERSITY OF SANTO TOMAS office of the secretary-general

A.Y. 2024-2025		
ТО	:	THOMASIAN COMMUNITY
FROM	:	OFFICE OF THE SECRETARY-GENERAL
RE	:	NATIONAL RARE DISEASE WEEK (22-28 February 2025) and WORLD RARE DISEASE DAY (28 February 2025)
DATE	:	27 February 2025

The University, in coordination with the Philippine Society for Orphan Disorders, Inc. (PSOD)¹, joins in the observance of the **16th National Rare Disease Week** (February 22-28, 2025), with the theme: "*More Than You Can Imagine*". Established under Presidential Proclamation 1989, this week-long observance aims to raise awareness and garner public support for persons affected by rare diseases in the Philippines.

Throughout the world, over 300 million people are living with a rare disease, which includes approximately 6,000 known rare conditions. On February 28, *Rare Disease Day* will be commemorated globally, uniting communities in their shared purpose to elevate the voices of those affected by rare diseases.²

The Thomasian community is encouraged to support this meaningful campaign and help spread the message that *'Rare is not alone'* by participating in the following:

1. "Light Up for Rare' Campaign

- With the assistance of the Facilities Management Office, the University's landmarks will be lit in violet on 28 February 2025 (Friday), *Rare Disease Day*, 6:00 pm -9:00 pm.
- This will be part of a worldwide effort to create a visual chain of lights, symbolizing solidarity with the rare disease community.
- The Thomasians are encouraged to take photos of the lighted campus landmarks and post them in their respective social media accounts using #CareForRarePH #NRDW2025 #RareDisease.

2. Visit <u>rarediseaseday.org</u> and Share its resources

- RareDiseaseDay.org is the official website for **Rare Disease Day (RDD)**, managed by EURORDIS (Rare Diseases Europe). It serves as a central hub for information, events, and advocacy efforts worldwide.
- Watch <u>RDD Webinar</u>: *Driving Awareness by amplifying Young Voices in the Rare Disease Community* on Youtube.

² **Rare Disease Day**, launched by EURORDIS and its Council of National Alliances in 2008 with 18 countries, has since grown to over 100 countries, 1,000+ events, and widespread media coverage.



¹ PSOD is a non-stock, non-profit organization dedicated to advocating for persons with rare or orphan disorders.



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3. Sharing Thoughts, Raising Awareness

- To share thoughts and stories about rare diseases, whether through formal discussions or casual conversations, in large gatherings or intimate circles, fostering awareness, understanding, and support for those affected.

4. A Prayer for Rare Disease Day

- Let us offer our prayer:

oving and compassionate God,

We lift up to You all those living with rare diseases,

along with their parents and family members who share in their struggles.

Grant them strength in moments of exhaustion, hope in times of uncertainty, and peace in their hearts.

Bless the hands of doctors, caregivers, and researchers, that they may bring healing, wisdom, and compassion. Fill our communities with love and understanding, so that no one may feel alone in their journey.

May we work together to raise awareness, offer support, and be instruments of Your mercy and grace. Amen.

As we observe *World Rare Disease Day*, let us take to heart the words of Our Lord: "Come to me, all you who labor and are burdened, and I will give you rest" (*Mt* 11:28), and continue raising awareness and supporting persons with rare diseases, reminding the world that "Rare is not alone". Thank you.

RONEL, OP

