

Vietnamese Organization for Rare Diseases

Vietnam



VORD

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for Rare Diseases

rarediseases.vn

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1. About

We are non-profit social enterprise established in 2021. We want becoming represent for who are living with Rare Diseases in Vietnam. Until now we support Spinal Muscular Atrophy, Duchenne Muscular Dystrophy and Brittle Bone communities.

“Disease is rare but love is not rare”

2. Mission

Our goal:

- Raise awareness about rare diseases and what PLWRD facing with everyday.
- Promote diagnosis and treatment for PLWRD.
- Help PLWRD build their own community.
- Connect Local communities with global.
- Sharping Policies for PLWRD.

What drives me:

- I'm patient with Photosensitive reflex epilepsy. I used to be facing with unbelieve, with isolation, with no hope and cannot understand what is waiting me in the future.
- As a medical doctor I find that a lot of patients without hope after they have symptoms or die with doubting themself.
- Pain of the parents (as my parents)

What are my priorities:

- Help the patients have a better quality of life not only better quality of healthcare.

3. Focus.

Our organisation's main initiatives, projects and/or accomplishments:

- VORDAcademy: a place where patient, family and also medical staff can find information about rare diseases and knowledge about diagnosis or treatment for Rare Diseases,
- SoRareSoCare: A Project helping PLWRD access essential medical equipment or learning new skill and gain their suitable job for better quality of life (at least they can improve their daily meals),
- Helping Vietnamese SMA patient can approach treatment in China, dealing with supplier for reduce pricing for SMA newborn screening.
- Connect with Japan government for access orphan drug, reduce gap between Vietnam and International.

4. Coming up

What we will do in next year is trying to help other disease's communities for treatment, diagnosis and dealing with daily difficulty, especially in financial.

What we are facing now is misinformation and it's push our patients to the wrong way.