



#RARENESSAWARENESS

FACTS

- World Rare Disease Day (WRRD) takes place on the last day of February each year and is the official international awareness-raising campaign for rare diseases. 2022 is the 15th official year of this global event.
- The main objective of the campaign is to raise awareness amongst the public and decision-makers about rare diseases and their impact on patients' lives.
- Although individually rare, rare diseases are collectively common. There are more rare disease patients worldwide than AIDS and cancer combined.
- There are over 7,000 rare diseases described to date affecting over 350 million people worldwide.
- In South Africa, there are an estimated 4.1 million people living with a rare disease.
- In South Africa, 1 in 15 people are affected by a rare disease. That is the equivalent to one player in a rugby team.
- While most (70-80%) rare diseases are genetic and inherited in families, some may be acquired.
- 70% of rare diseases are exclusively paediatric in onset (i.e. they only manifest in children).
- For many rare conditions, the cause is still unknown.
- Rare diseases are responsible for 35% of deaths in the first year of life.
- 50% of rare diseases affect children.
- 30% of children with a rare disease won't see their 5th birthday.
- Over 95% of rare diseases do not have one single FDA approved drug
- Rare is many. Rare is strong. Rare is proud.
- Rare isn't scarce, rare isn't infrequent, and rare isn't remote. In fact – rare is not as rare as you think.

Get ready to #ShareYourColours and be part of the #RarenessAwareness on 28 February 2023, International Rare Disease Day



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- Created by EURORDIS and its Council of National Alliances, the very first WRRD took place in 2008 with events in 18 participating countries.
- National Alliances ensure the coordination of WRRD at a national level, working with patient organisations locally and often organising a national event aimed at policy makers.
- The number of participating countries has increased year on year, with thousands of events taking place on all continents on or around the month of February.
- WRRD events have taken place in over 103 countries since 2008.
- South Africa first participated in WRRD in 2010. Since then, patient organisations have launched many successful initiatives.
- The aim of WRRD is to make society aware that millions of people living with a rare disease around the world face inequitable access to diagnosis, treatment, and care.
- WRRD is an opportunity to be part of a global call on policy makers, healthcare professionals, and care services to better coordinate all aspects of care for people living with a rare disease.

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