



Tweet Sheet: Facts on Rare Diseases

During the month of February 2023, get involved and show your support for Rare Disease Day.

Share one fact per day on your social media pages using the Hashtag: [#RDD2023](#), [#ShareYourColours](#), [#1in15](#) and [#RarenessAwareness](#)

Rare Diseases SA will be posting interesting content each day and followers can repost from our social platforms:

Facebook: [@rareawareza](#)

Instagram: [@rare_aware](#)

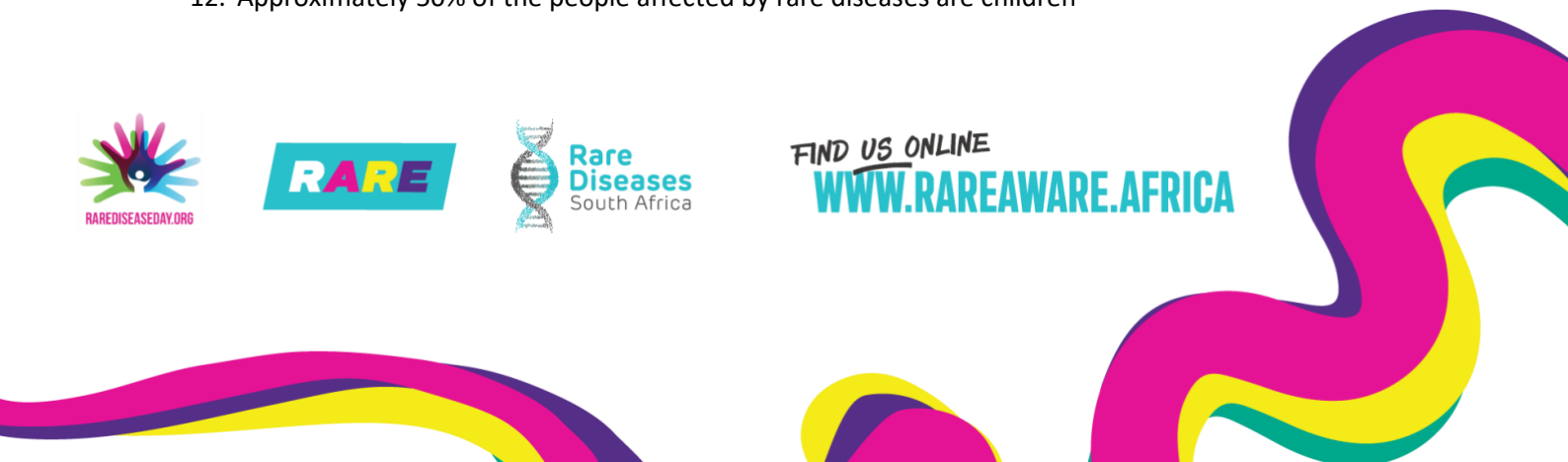
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1. International definitions on rare diseases vary but are commonly defined as affecting fewer than 1 in 2500 persons
2. Rare diseases affect more people than Aids and cancer combined
3. Rare diseases are individually rare but collectively common
4. South Africa has no dedicated Rare Diseases policy in place
5. There are approximately 7,000 different types of rare diseases and disorders, with more being discovered each day
6. In South Africa, an estimated 3.7 million people (1 in 7 individuals) are affected with a rare disease
7. [#1in15](#) South Africans are affected by rare diseases. 30 million people in the United States are living with rare diseases. This equates to 1 in 10 Americans or 10% of the U.S. population.
8. Europe has approximately 30 million people living with rare diseases
9. It is estimated that 350 million people worldwide suffer from rare diseases
10. If all of the people with rare diseases lived in one country, it would be the world's third most populous country
11. 80% of rare diseases are genetic in origin, and thus are present throughout a person's life, even if symptoms do not immediately appear
12. Approximately 50% of the people affected by rare diseases are children



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13. 30% of children with rare disease will not live to see their fifth birthday
 14. Rare diseases are responsible for 35% of deaths in the first year of life
 15. The prevalence distribution of rare diseases is skewed – 80% of all rare disease patients are affected by approximately 350 rare diseases
 16. 95% of rare diseases have not one single FDA approved drug treatment
 17. Approximately 50% of rare diseases do not have a disease specific foundation supporting or researching their rare disease
 18. Genetic testing can help diagnose many rare diseases, but not all genetic testing identifies a genetic cause in an estimated 25 to 30 percent of rare disease cases
 19. Newborn screening for rare diseases is recommended. Screening requirements for newborns vary, but they're increasingly becoming routine, especially for cystic fibrosis, sickle cell disease, and other conditions where early detection and treatment can improve outcomes for the child
 20. Prenatal testing for rare diseases is becoming more advanced. It's now possible to test early in a woman's pregnancy for a handful of rare diseases, including Trisomy 18 syndrome, also known as Edward's syndrome, and Trisomy 13, also known as Patau syndrome
 21. Some cancers are rare diseases. There are cancers that happen so infrequently they fall under the rare-disease threshold
 22. Diagnosis of a rare disease takes an average of 7.2 years
 23. Health care professionals require training to improve access to diagnosis and treatment
 24. Early intervention including accurate diagnosis and appropriate treatment can improve and extend lifespan and quality life
 25. Recognition of a rare disease should be accompanied by comprehensive palliative care, including counselling, pain management etc
 26. Treatment of a rare diseases required a multidisciplinary team of health care professionals and allied health care workers
 27. The rarest disease in the world is Fields disease with only 2 known reported cases ever reported.
 28. Post about Rare Disease Day 2023 using the hashtag: #RDD2023, #ShareYourColours, #1in15 and #RarenessAwareness,



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