



Facts & Stats about Rare Disease

- ✓ There are over 7,000 distinct types of rare diseases
- ✓ In the United States, a disease is defined as Rare when it affects less than 200,000 at any given time
- ✓ Rare Diseases affect 30 million Americans, or 1 in 10 people, and 350 million people worldwide
- ✓ If all of the people with Rare Diseases lived in one country, it would be the world's 3rd most populous country
- ✓ Approximately 50% of the people affected by Rare Disease are children
- ✓ 30% of children with Rare Diseases will not live to see their 5th birthday
- ✓ Rare Diseases affect more people than AIDS and Cancer COMBINED
- ✓ 95% of Rare Diseases do not have a single FDA approved drug treatment and there are no cures
- ✓ Approximately 50% of rare diseases do not have a disease specific foundation supporting or researching their rare disease

About World Rare Disease Day

- ✓ The first World Rare Disease Day was organized and held on February 28, 2008 by European organization, EURORDIS and its Council of National Alliances
- ✓ According to EURORDIS, World Rare Disease Day was created because treatment for many rare diseases is insufficient, as are the social networks to support individuals with rare diseases and their families
- ✓ Even though World Rare Disease Day started as a European event, it has progressively become a world phenomenon, with the USA joining in 2009, and participation in a record-breaking 84 countries around the world in 2014
- ✓ On World Rare Disease Day and leading up to this day, people around the world come together to raise awareness of rare diseases and the impact on those affected
- ✓ World Rare Disease Day is now held on the last day of February each year
- ✓ Global Genes will be using World Rare Disease Day as the first day of World Rare Disease Month, which will be celebrated throughout the month of March—because we feel that Rare Disease deserves MUCH more than just a day!



Sources:

www.rarediseaseday.org; www.eurordis.org; www.globalgenes.org; everylifefoundation.org; blog.sermo.com; www.sireninteractive.com/sirensong