The first World Rare Disease Day was organized and held on February 28, 2008 by European organization, EURORDIS and its Council of National Alliances. 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. 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.

**Rare Disease Types**

7,000+

Identified rare diseases, with more being discovered every day.

**Causes**

80%

of rare diseases are caused by faulty genes.

**Rare Disease Effect**

30 million Americans

RARE DISEASES AFFECT MILLIONS

350 million worldwide

If all of the people with rare diseases lived in one country, it would be the world’s 3rd most populous country.

**The Impact**

Rare diseases impact more people than cancer or AIDS combined.

**No FDA Approved Cures**

Only 5%

of rare diseases have an FDA approved drug treatment.

**What is Considered “Rare”?**

In the United States, a condition is considered “rare” if it affects fewer than 200,000 persons combined in a particular rare disease group.

International definitions on rare diseases vary. For example in the UK, a disease is considered rare if it affects fewer than 50,000 citizens per disease.

**Rare Disease Affects Children**

Approximately 50% of the people affected by rare diseases are children.

30% of children with rare disease will not live to see their 5th birthday.

Rare diseases are responsible for 35% of deaths in the first year of life.

**The Diagnosis**

On average, it takes most rare disease patients 8 years to receive an accurate diagnosis—within this time period, they have seen over 10 specialists and have been misdiagnosed 3 times.

**The Support**

Approximately 50% of rare diseases do not have a disease specific foundation supporting or researching their rare disease.

Support the rare disease community by helping spread awareness, donating to disease-specific foundations or by visiting www.globalgenes.org.