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. 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+ distinct types of rare diseases exist, with more being discovered every day.

THE CAUSE

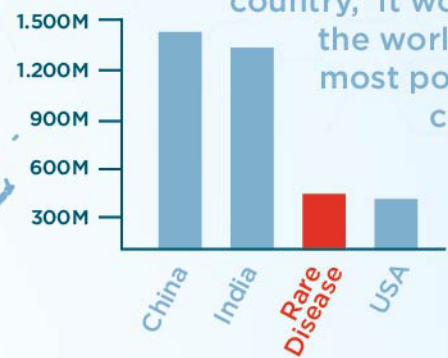**80%** of rare diseases are caused by faulty genes.

RARE DISEASE EFFECT

30 MILLION AMERICANS

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.

Chart axis: 1.500M, 1.200M, 900M, 600M, 300M
Bars: China, India, Rare Disease, USA

THE IMPACT

Rare diseases impact more people than

CANCER AIDS combined.

NO FDA APPROVED TREATMENT

95% of rare diseases **do not** have a single 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

8

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

50%

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.**

Global Genes™
Allies in Rare Disease