

**FortisCare**  
**RARE DISEASE DAY**  
**THURSDAY 28<sup>ST</sup> FEBRUARY 2019**

**What is a rare disease in the UK?**

A rare disease is defined by the European Union as one that affects less than 5 in 10,000 of the general population. There are between 6,000 – 8,000 **KNOWN** rare diseases and around give new rare diseases are described in medical literature every week!

**How rare is a rare disease?**

A disease or disorder is defined as **rare** in Europe when it affects fewer than 1 in 2,000. A disease, or disorder, is defined as rate in the USA when it affects fewer than 200,000 Americans in any given time. In the EU, as many as 30 million people may be affected by one of over 6,0900 existing rare diseases.

**How many rare diseases have treatments?**

7,000 are the number of rare diseases that exist today. While more than 7,000 rare diseases have been identified, only 5% have treatment.

**What are the worst diseases to have?**

DISEASE	TREATMENT	CFR
<p><b><u>NEURODEGENERATIVE DISEASE:</u></b></p> <p><b>Neurodegeneration</b> is the progressive loss of structure or function of neurons, including death of neurons. Many <b>neurodegenerative diseases</b> – including amyotrophic lateral sclerosis, Parkinson's <b>disease</b>, Alzheimer's <b>disease</b>, and Huntington's <b>disease</b> – occur as a result of <b>neurodegenerative</b> processes.</p>	Incurable	100%
<p><b><u>AFRICAN TRYPANOSOMIASIS:</u></b></p> <p>Human <b>African trypanosomiasis</b>, also known as <b>sleeping sickness</b>, is a vector-borne parasitic disease. It is caused by infection with protozoan parasites belonging to the genus <b>Trypanosoma</b>. ... Within an infected area, the intensity of the disease <b>can</b> vary from one village to the next.</p>	If Untreated	100%
<p><b><u>CRYPTOCOCCAL MENINGITIS:</u></b></p> <p><b>Cryptococcal meningitis</b> is a serious infection of the brain and spinal column that can occur in people living with HIV. It is caused by a fungus called <b>Cryptococcus</b> neoformans. This fungus is very common in the environment and can be found in soil and in bird droppings.</p>	If Untreated & Co-Infection with HIV	100%

DISEASE	TREATMENT	CFR
<p><b><u>PLAGUE – SPECIFICALLY THE SEPTICEMIC OR PNEUMONIC TYPE</u></b></p> <p><b>Bubonic plague.</b> The most common form of plague is bubonic plague. ...</p> <p><b>Septicemic plague.</b> When the bacteria enter the bloodstream directly and multiply there, it's known as septicemic plague. ...</p> <p><b>Pneumonic plague.</b></p> <p>The <b>difference between</b> the forms of <b>plague</b> is the location of infection; in <b>pneumonic plague</b> the infection is in the lungs, in <b>bubonic plague</b> the lymph nodes, and in <b>septicemic plague</b> within the blood.</p> <p><b>Pneumonic plague</b> is more serious and less common than <b>bubonic plague</b>.</p>	<p>Untreated</p>	<p>100%</p>

## WHO IS RARE DISEASE UK?

Rare Disease UK is the national campaign for people with rare diseases and all who support them. They provide a united voice for the rare disease community by capturing the experiences of patients and families.

They work with their supporters to raise the profile of rare diseases across the UK. They seek to bring about lasting change offering better health and quality of life for individuals and families affected by rare diseases.

Rare Disease UK is working with health departments across the UK to implement the [UK Strategy for Rare Diseases](#) to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support.

Rare Disease UK is a campaign run by [Genetic Alliance UK](#), the national charity of over 190 patient organisations, supporting all those affected by genetic conditions.

If you would like to find out more regarding Rare Disease Day UK, please click on the link below:

<https://www.raredisease.org.uk/news-events/>