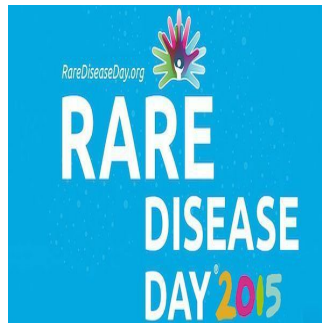


28 February is Rare Disease Day 2015



Rare Disease Day is observed on the final day of February each year. What began as a European event has become a worldwide campaign, with thousands of events taking place in dozens of countries. This year, the theme is “Living with a Rare Disease”, which recognises the millions of family members and friends supporting patients with rare diseases. The slogan is “Day-by-day, hand-in-hand”.

The goal of Rare Disease Day is to raise awareness among the general public about rare diseases and the unique challenges faced by patients and their families. The day also serves advocacy purposes, with national plans and policies being advanced in some countries. By presenting a united voice, patient organisations speak in a collective way for the many individuals affected by rare diseases. The organisers of Rare Disease Day events hope that the last day of February will be officially recognised by the World Health Organization as Rare Disease Day.

What Classifies a Rare Disease?

Rare diseases are usually chronic conditions with debilitating consequences for patients and significant repercussions for their caregivers. Patients and their families face challenges such as finding a diagnosis for their symptoms, locating experts who can provide guidance and recommend appropriate treatments, identifying social services and support systems, and managing the financial burden of living with a rare disease.

In Europe, a disease is defined as rare if it affects less than 1 person in 2,000; in the US, the definition of a rare disease is one which affects less than 200,000 Americans. More than 6,000 rare diseases have been identified, with a wide variety of disorders and symptoms that can differ between patients suffering from the same disease. Approximately 50 percent of rare diseases affect children.

Rare Cancers

Unlike rare diseases with unidentified genetic origins, rare cancers are typically acquired diseases. They affect only 6 out of 100,000 people in Europe each year, but that is not to say that they are uncommon. There are four million new cases of rare cancers in Europe annually, representing 20 percent of all new cases of cancer.

“Challenges that rare cancer patients - and other rare disease patients - face have mainly to do with the difficulties of finding clinical expertise in their community. It is vital for them to get to the right institution,” says Paolo G. Casali, Chairperson of Rare Cancers Europe. “Health systems should identify reference centres, and support them properly, especially by funding and creating appropriate networks between them.”

In addition to meeting with regulatory bodies to speed the development of novel anti-cancer therapies, Rare Cancers Europe is calling for expert centres to be established for each type of rare cancer. Once they are identified, they can be linked to form new networks for information exchange, patient referrals and the conducting of registries.

Ambassador Sean Hepburn Ferrer

The Rare Disease Day 2015 Ambassador is Sean Hepburn Ferrer. He is the son of actress and philanthropist Audrey Hepburn and actor, [© For personal and private use only. Reproduction must be permitted by the copyright holder. Email to copyright@mindbyte.eu.](mailto:copyright@mindbyte.eu)

director and film producer Mel Ferrer. In 1993, Audrey Hepburn died from Pseudomyxoma adenocarcinoma, a rare cancer that affects only one in a million people. He speaks of his family's realisation that the only treatment available for Audrey dated back to the 1960s, and that her rare disease was clearly "not a priority for Big Pharma."

"Rare' is a word most often used to convey the same values as 'precious'...unique...valuable. And if one adds up all of us precious beings that suffer from a 'rare' disease, the number is staggering – 60,000,000 and counting. The way each of us deals with what ails us is always unique and therefore, I feel it is quite easy for any of us to relate to 'rarity'...that rarity that comes in those moments when we must truly face life and adversity by ourselves."

Sources: rarediseaseday.org, European Society for Medical Oncology

Image Credit: rarediseaseday.org

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