Rare Disease Day®

# Rare Disease Day 2015 Theme & Slogan

## ***Theme**: Living with a Rare Disease*

## ***Slogan**: Day-by-day, hand-in-hand!*

2015 marks eight consecutive, successful years of Rare Disease Day. Continuing the momentum, Rare Disease Day 2015 puts the focus on the daily lives of **patients, families and caregivers** who are **Living with a Rare Disease**.

Over 6000 different rare diseases have been identified to date, directly affecting the daily life of more than 30 million people in Europe alone. The complex nature of rare diseases, coupled with limited access to treatment and services, means that family members are often the primary source of solidarity, support and care for their loved ones. The Rare Disease Day 2015 theme **Living with a Rare Disease** pays tribute to the millions and millions of parents, siblings, grandparents, spouses, aunts, uncles, cousins, and friends whose daily lives are impacted and who are living **day-by-day, hand-in-hand** with rare disease patients.

Typically chronic and debilitating, rare diseases have enormous repercussions for the whole family. Living with a rare disease becomes a daily learning experience for patients and families. Though they have different names and different symptoms, rare diseases impact the daily lives of patients and families in similar ways.

- How to find a diagnosis?
- How to access treatments?
- How to find appropriate expertise?
- How to work with a team of caregivers, such as doctors or physical therapists, and other healthcare professionals and coordinate care between them?
- How to operate special equipment?
- How to administer treatments?
- How to identify and access social services?
- How to manage the economic burden of living with a rare disease?
- How to ensure the well-being of the entire family and balance priorities?

**Patient organisations** become a crucial source of information, experience and resources. **Day-by-day, hand-in-hand**, together we present a united voice to advocate for the treatments, care, resources and services we all need. Patients, families and organisations are pivotal to the momentum of creating solutions for the daily challenges of living with a rare disease in solidarity with all stakeholders - caregivers, healthcare professionals, specialised social services, researchers, pharmaceutical companies, policy makers, and regulatory bodies.

Internationally, it is essential to send a strong message of solidarity to the countless rare disease patients and families throughout the entire world. Together, we can transform the individual experience of patients and relatives around the world into collective actions, support, advocacy and community building.

In Europe, there are many initiatives designed to improve daily life: Developing and facilitating access to diagnostics and treatments can change the day-to-day reality for someone with a rare disease. Identifying and improving access to specialised social services for rare diseases enables families to improve the quality of daily life. RareConnect, EURORDIS' moderated multi-language online social forum, allows people with rare diseases to break their isolation and to connect and share experiences. Please visit the Living with a rare disease section of the EURORDIS website to learn more about the daily challenges of living **day-by-day, hand-in-hand** with a rare disease and the ways in which patients and families are meeting these challenges.