



## Rare Disease Day 2014 Theme & Slogan

***Theme: Care***

***Slogan: Join Together for Better Care***

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Caring for people living with a rare disease has many facets. Some patients have access to medicines while others have no treatment available. Some patients are fairly independent while others require intensive physical assistance and equipment. Care can consist of special equipment, expert medical consultation, physical therapy, social services, medicines, respite for family members, and much more. For most children and adults living with a rare disease, primary care is provided by family members.

Rare Disease Day 2014 focuses on care and encourages everyone in the rare disease community to Join Together for Better Care.

Patients and their families who feel isolated by the rarity of their disease should know that there are more than 6000 different rare diseases affecting over 60 million people across Europe and North America alone and millions and millions more throughout the world. Most of these diseases are genetic, serious, chronic and debilitating. Each disease is different, but they affect people in similar ways. Joining together can help patients and their families find common solutions for care and remind them they are not alone.

Healthcare professionals, researchers, pharmaceutical companies, and policy makers also frequently feel isolated in their struggle to find and provide care for rare diseases. Experience shows that bringing together scattered knowledge and resources for people living with rare diseases is the most efficient and effective way to mobilise the care patients and families need and deserve.

In Europe, there are several areas in which access to rare disease care is advancing:

- Shaping policies to improve access to medicinal products for rare diseases
- Identifying and improving access to specialised social services for rare diseases
- Centres of Expertise and European Reference Networks for expert medical care
- National rare disease plans for countries in the European Union ... and beyond

The theme for 2014 highlights that the many different facets of rare disease care represents a universal need for patients and their families around the world. Advocating at the local and national level to improve the lives of people living with a rare disease and their families is necessary.

Considering rare diseases from an international perspective is also essential to send a strong message of hope to the millions of rare disease patients and families throughout the world who can break their isolation through a vast, united international network of solidarity.

This year Rare Disease Day encourages us to continue finding ways to work together to provide the different kinds of care that people living with a rare disease need.

***Let's Join Together for Better Care!***