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NEWS

THU 11 OCTOBER, 2018

THEME 2019

RARE DISEASE DAY 2019 THEME ANNOUNCED: BRIDGING HEALTH AND SOCIAL CARE

The theme for Rare Disease Day 2019 is **'Bridging health and social care'**.

For most people living with a rare disease, as well as their family members or carers, the reality of daily life can include any combination of the following: collecting and taking medicines, attending appointments, participating in physical therapy, using specialist equipment and accessing various social and community support services and respite care. Managing these care-related tasks alongside their usual daily activities such as work, school and leisure time can be challenging.



There are over 6,000 rare diseases that affect over 300 million people worldwide. Each

disease has an impact on everyday life, including the need for a daily care routine. According to the first ever Europe-wide [survey on juggling care and daily life](#) with a rare disease carried out by [Rare Barometer](#), 8 in 10 patients have difficulties completing basic daily tasks. As a result, the majority of care is usually coordinated by people living with a rare disease and their family members who spend a significant amount of time organising care. According to [the survey](#) 70% of patients and carers describe it as time consuming.

Organising care can involve researching local services, making phone calls, accessing treatments and rehabilitation, handling administrative procedures and adapting the home or work space. As a consequence, people living with a rare disease are often off work or school. It becomes a complex and frustrating process, especially when a lack of coordination across services means having to repeat the same information over and over again. Communication between different services needs to improve so that services are delivered efficiently to meet patients' best interests.

RARE DISEASE DAY 2019

The 12th edition of Rare Disease Day will focus on bridging the gaps in the coordination between medical, social and support services in order to tackle the challenges that people living with a rare disease and their families around the world face every day.

Rare Disease Day 2019 is an opportunity to be part of a global call on policy makers, healthcare professionals, and care services to better coordinate all aspects of care for people living with a rare disease.

SHOW YOUR RARE

The theme, 'Bridging health and social care' guides patient organisations and all Rare Disease Day participants around the world in their advocacy activities for Rare Disease Day 2019.

In addition, and due to its success in 2018, the [#ShowYourRare](#) social media campaign continues for 2019. People around the world will paint their faces and show their rare for Rare Disease Day. [Get involved!](#)

TRANSLATION OF THIS YEAR'S THEME

The theme 'Bridging health and social care' has been translated as:

French : Vivre avec une maladie rare !

Spanish : Creando puentes en la asistencia social y sanitaria

German: Gesundheitsversorgung und soziale Betreuung gehören zusammen

Italian: Integriamo l'assistenza sanitaria con l'assistenza sociale

Portuguese: Fazer a ponte entre a saúde e a assistência social

TRANSLATION OF THIS YEAR'S SLOGAN

The slogan 'Show Your Rare. Show You Care.' has been translated as:

French: Rare fier, soyons solidaires !

Spanish : Rare muestro a el mundo la maravillosa que eres

German : Setzt ein Zeichen für die Seltenen!

Italien : Mostra che sei con i malati rari !

Portuguese: Apoie as doenças raras. Mostre-o

Russian: Расскажите о своей болезни

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RARE DISEASE DAY 2019 OFFICIAL POSTER IS OUT NOW!

Download the official Rare Disease Day 2019 poster to display at your events, workplace or home and raise awareness of the impact of rare diseases in your community. The Rare Disease Day poster is
15 Jan 2019



MEET FILIP

Filip, aged 8, is the youngest person to feature in the Rare Disease Day 2019 testimonial videos (coming soon!). He is from Bucharest, Romania and lives with the rare disease achondroplasia, which affe...
14 Jan 2019

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