

28th February 2019

Bridging health and social care in support of rare disease patients: Show You Care

Today, the Primary Immunodeficiency community worldwide celebrates Rare Disease Day 2019 to raise awareness worldwide of the challenges concerning rare diseases and to advance change in policy and practice to benefit patients.

Rare Disease Day 2019 puts the spotlight on bridging health and social care. People living with a rare disease, such as a Primary Immunodeficiency and their families require a combination of different health, social and local services in daily life. Therefore coordination and communication between those services is of utmost importance to improve patients' quality of life.

Many people with rare diseases and carers find care pathways complex and difficult to manage, while in most countries social services are still not adequately prepared to respond to their needs¹.

A holistic approach to the care of people with rare diseases is inclusive of all actors which play a role in care delivery, from patients and doctors, to allied healthcare professionals, biologists and researchers. But it also goes beyond healthcare, breaking silos with the social sector to deliver services which are truly integrated: this enables patients and their families to combine daily life with the exigences of living with a rare disease, juggling between care and a variety of social and community support services, and to act as active contributors to the society.

Bridging health and social care also underpins a political, societal and healthcare shift towards patient-centricity: re-thinking and re-organising services so they are truly oriented to deliver best value to their end-users, the patients.

Such a person-centred approach to care will be at the heart of the 2019 World Primary Immunodeficiency Week (World PI Week) campaign from 22-29th April, which will focus on "putting primary-immunodeficiency patients at the centre of their care". There are over 320 different types of primary immunodeficiencies² which are estimated to affect over 6 million people worldwide. But those are all different, meaning that each individual requires a customized approach, focused on his/her specific needs. This cannot become a reality for all patients without better coordination of all the aspects of care.

We should not miss the opportunity to improve the care and quality of life of rare disease patients and their families around the world: let's break silos between medical and social care!

World PI Week shows its rare, as we do care! #ShowYourRare

¹ Results from Eurordis survey initiative Rare Barometer

² The 2017 IUIS Phenotypic Classification for Primary Immunodeficiencies