Zmazek,Vlasta 2020 INTEGRATED CARE FOR RARE DISEASES: DEBRA CROATIA
International Journal of Integrated Care, 21(S1) : A341, pp. 1-8, DOI:
doi.org/10.5334/ijic.ICIC20549

CONFERENCE ABSTRACT

INTEGRATED CARE FOR RARE DISEASES: DEBRA CROATIA

ICIC20 Virtual Conference – September 2020

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A rare disease is a disease that occurs infrequently or rarely in the general population. In Europe, for example, a rare disease is defined as affecting less than 1 in 2.000 citizens. The rare disease patient is the orphan of health systems, often denied diagnosis, treatment and the benefits of research. For patients, families and individuals affected by rare diseases, gaining access to services is often extremely difficult. Finding expert help is too frequently a matter of luck rather than a consequence of systematic planning by national health systems.

Rare diseases are often life-threatening. They are chronic, progressive, degenerative and disabling. People living with rare diseases face many common challenges, such as delayed or inaccurate diagnosis, difficulty accessing care and lack of knowledge or access to expertise. Rare diseases not only affect the person diagnosed-they also impact families, friends, care takers and society as a whole.

Integrated health and social care is essential to enable people living with a rare disease.

The aim of the presentation is to present the problems faces by the patients, parents and families. The presentation will present research of the first European- wide survey on the everyday impact of the rare diseases- “Juggling care and daily life: the balancing act of the rare disease community, conducted by EURORDIS survey initiative, Rare Barometer Voices and involving 3000 patients and carers. The research findings show the importance of community collaboration and an integrated and multidisciplinary approach to people with rare disease.

Promote integrated care and bridge the gaps between health and social care for rare diseases is not only necessary but crucial to increase the life expectancy, quality of life and autonomy of people.