

Management in Primary Care

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Rare Diseases are Rare and also Many. A specific disease by definition is rare and with 7000 Rare Diseases, the prevalence is 6 to 8% in the Community. Also Rare Diseases affect around 30 millions people in Europe. Few data exist to show the role and the effectiveness of Primary Care Practitioners.

Some surveys have showed that Family Primary Care Practitioners (FPCP) played an important role in the care of Rare Diseases (RD).

FPCP see patients with Rare Diseases: 12.7 is the average number of patients with RD seen in Primary Practice. FPCP were the first to identify that « something is wrong » in 89% and established the diagnosis process in 54% of patients. They provided care in 56% of acute, 56% of continuous and 17 % of final care.

The new landscape of health care policy coming from the field of RD show some innovative issues. One of the most positive landmark is the multistakeholders cooperation in developing new tools, methodologies, procedures and frameworks in diagnosis, drug research and development, care, social services, networking and pricing and reimbursements of health technologies. FPCP Involvement is Rare.

FPCP manage common problems in real life and have a great experience of managing of many occurrence of extraordinary situations within the « patient and family centered » model. Their role in the care of patients with Rare Disease is fruitful for the physicians to access to innovative approaches, for the patients in their real life and for a community approach of care. FPCP are involved in the global patient care pathways. A call to action for an empowerment programme for an active role of FPCP will be proposed in the family ecosystem of care. Family Physicians remain the link between disease and patient centered concept of modern personalised medicine.

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