



INTEGRATIVE APPROACH FOR PEOPLE WITH RARE DISEASES AND THEIR FAMILIES

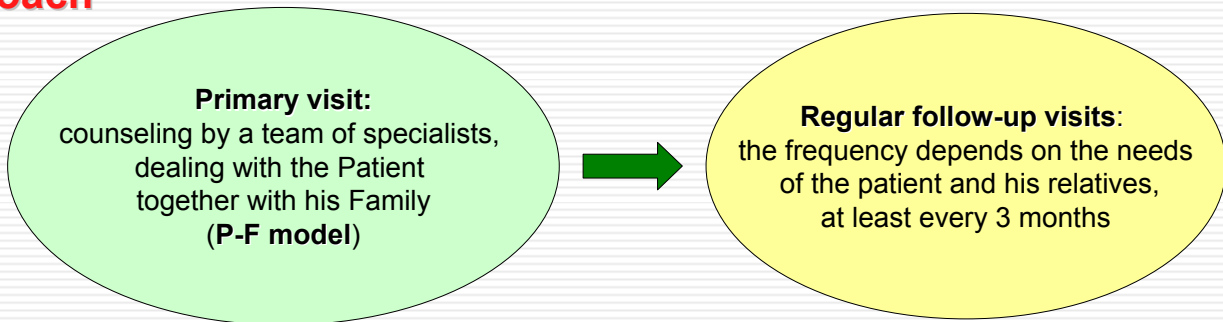
Simeonova R, Stefanov R
Medical Centre "RareDis", Plovdiv, Bulgaria

Idea

In May 2009, the **Bulgarian Association for Promotion of Education and Science** started a new initiative – a highly specialized medical centre for rehabilitation and education of people with rare diseases "RareDis".

The main idea is to upgrade the services of the **Information Centre for Rare Diseases and Orphan Drugs**, starting a tertiary-level rehabilitation centre, aimed at improving quality of life of people with rare diseases.

Approach



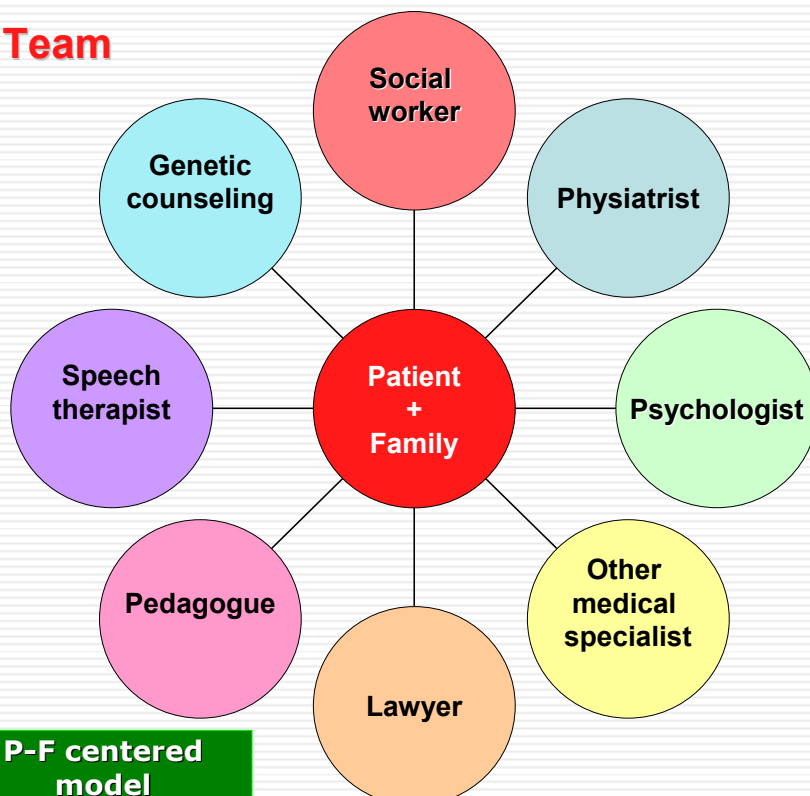
Mission

- Target the patients and their families
- Provide three levels of rehabilitation
- Raise quality of life
- Make living better
- Help people with rare diseases gaining independence in motion, occupation and finances

Principles

- Increase the ability of the person to function optimally within the limitations by a disease process for which there is no known cure (e.g. most rare diseases).
- The emphasis is the optimization of the quality of life.
- A team approach to chronic conditions, using interdisciplinary team meetings to coordinate care.
- Educate parents in providing quality daily healthcare

Team



Rehabilitation protocol

- Unique for each rare disease
- A multidisciplinary approach providing all three levels of rehabilitation for the patients.
- It comprises of several sections with information about the disease.
- Separate points for etiology, genetics, clinical symptoms, diagnostics, therapy and rehabilitation and the stress is on the last one which is separated on stages according to the chronologic progressing of the rare disease.
- Establishment of a high-quality standardized approach for each of these rare diseases, supported by evidence-based studies and the latest achievements of medicine.