

Rare Disease Information Centre and Help Line Created by Patient Organisations.

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Help Lines
for Rare
Diseases



SEGÉLYVONAL
A RITKA BETEGEKÉRT
061 790 45 33

The aim

To give validated understandable and reliable information on time for people with rare disease and for their environment to access adequate medical, social and educational care. It helps through several channels in innovative manner helping also the utilization of received information.



The problem

- Lack of information, diagnosis, medical, social care and support for more than 700000, patients in Hungary
- Needed: medical, social, pedagogic, employment and psychological help

Offered solution

- Validated, understandable and reliable information
- Platform to collect the needs and problems of rare disease patients and their families
- It plays a key role in the development of rare disease network and associations
- Having the proper information is a fundamental right
- This is the most desirable social service
- The better way to utilize the knowledge accumulated by patient organizations

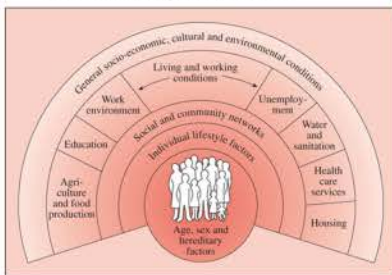


The Information Centre assists

- to get diagnosis or/and care
- to give adequate information for the patients, their families and professionals on the field of health care, legal, educational and social care
- the communication between the civil society and within the patient organizations
- to improve networking and the services of NGOs for their patients
- helping patients to meet each other - peer facilitation - and potential cooperative organizations
- the work of the professionals translating and organizing professional documents



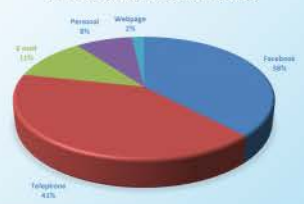
The necessary information



All The main determinants of health
(Dahlgren and Whitehead, 1991)



RATIO OF COMMUNICATION CHANNELS



Multiple communication channels

- User-friendly website (<http://mentoov.rirosz.hu>)
- Facebook groups (close) for searching of fellow sufferers
- Telephone: +361 790 4532
- E-mail: mentoov@rirosz.hu
- Personal consultations
- Active, updated Youtube channel



Perspective

We have created a platform that is beneficial to patients and their families, professionals active in health care, researchers and non-professional people as well. With this help:

- RD patients and their problems become know
- Their social acceptability increase
- The diagnostic process is shorter
- They receive adequate, complex, comprehensive care
- They disadvantage comparing to common diseases decrease

