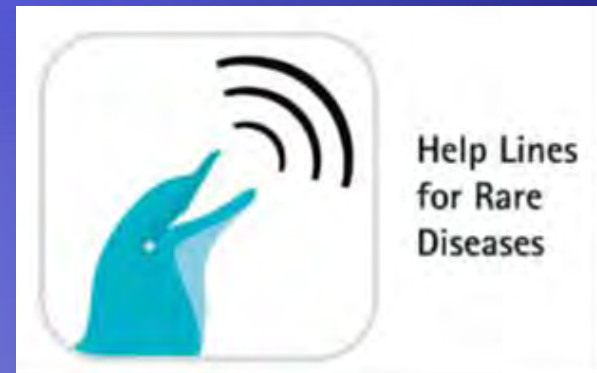


„LIFEBELT” INFORMATION CENTRE FOR THE RARE DISEASE PATIENTS



mentoov.rirosz.hu, www.rirosz.hu

Norway Grants/EEA Grants

Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS)

The relevance of the information service of rare diseases

The current problem:

- Lack of information, diagnosis, medical care and support
- 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

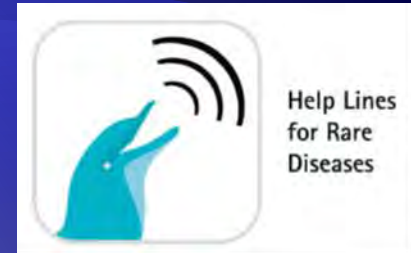
Comprehensive goals



- Necessary to increase the social awareness and the knowledge of professionals for the optimal implementation of RD National Plan
- Moreover, improving patient awareness, and the development of peer communities, besides increasing civil cooperation are also needed.

Steps of establishing an information service

- Define the service goals
- Identification of the target group
- Compile the contents of service (what type of information will be given)
- The definition of necessary human and technical resources
- Devices and time frame needed to answer the questions
- Data protection guarantee
- Identification of information sources



With the help of NCTA-2014-10918-F grant



Information Center assists:

- the communication between the civil society and within the patient organizations
- to give adequate information for the patients and their families on the field of health care, legal, educational and social care
- to improve 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



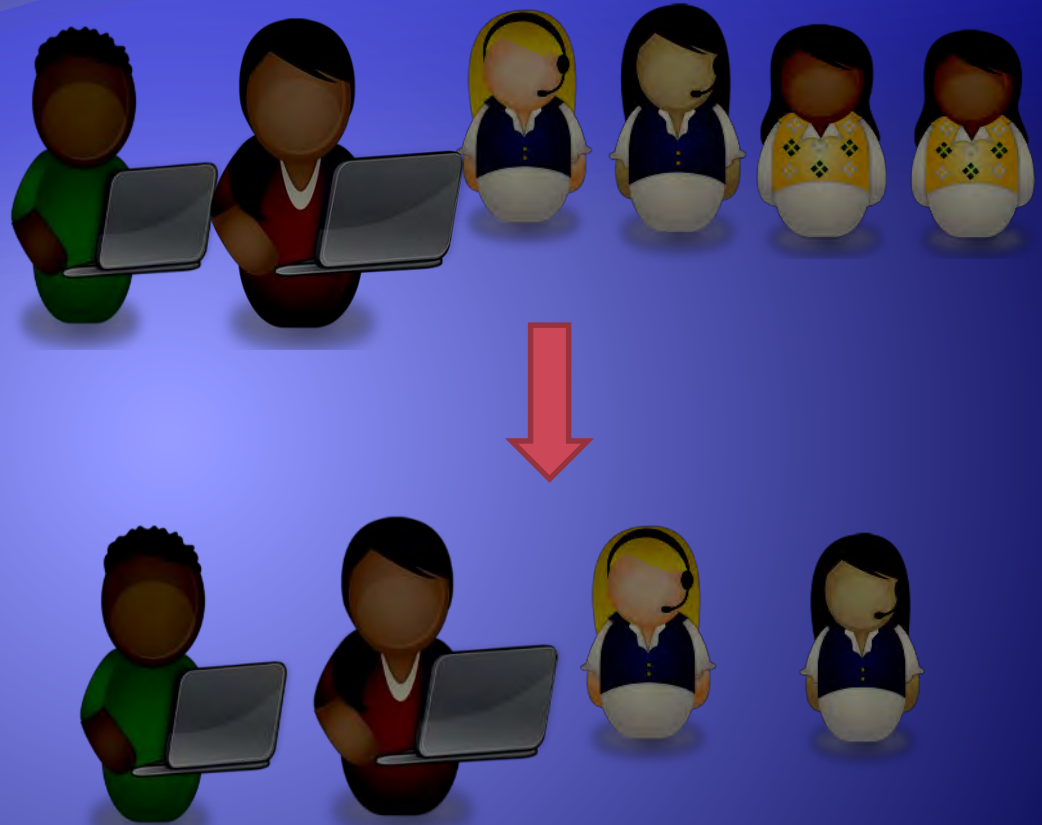
Starts 1.

- ◆ To form the necessary infrastructure
 - ◆ Existing resources, missing needs
 - ◆ Culling, development, purchasing, organisation



Starts 2.

- Form the working group
 - Step by step process



Continuous training

- ♦ European Patients Forum,
- ♦ Blue Line,
- ♦ NoRo Centre
- ♦ Franklin Covey
- ♦ Civil Information Centre
- ♦ FRAMBU Centre



Starts 3.



◆ Establish data bases

- ◆ doctors, service providers etc.

◆ Quality assurance

- ◆ Answering protocol
- ◆ Non-disclosure agreement,
- ◆ Ethic Codex

Communication channels

1. Facebook

- ♦ Fellow sufferer searcher group
 - ♦ Informal
- ♦ HUFERDIS site
 - ♦ Events
 - ♦ Campaignes
 - ♦ Invitations
 - ♦ Grants
 - ♦ Fundraising



Communication channels

2. Website

- ♦ mentoov.rirosz.hu
 - ♦ logo, design
 - ♦ Organized, validated information
 - ♦ Communication area

3. YouTube

- ♦ Videos



The first campaign

- ◆ ARC gigant poster show
 - ◆ Magnetbank, Geometry Global
- ◆ White Raven,
- ◆ Newsletter on the home page,
- ◆ Posters, leaflets,
- ◆ Media releases



Organisation of volunteers



- Translation (from the website of NORD / Orphanet)
- Supporting event organization

Helpline

- ◆ Tel: **06/1/790-45-33**
- ◆ E-mail: mentoov@rirosz.hu
- ◆ Webpage – message box
- ◆ Facebook
- ◆ Personal consultancy



Attributes of the Operation

- Visibility
- Actuation the Rare disease helpline
- Communication campaign
- Expert office hours to assist NGOs to start
- Individualized complex consultations
- Help fellow sufferers
- Provide for sustainability and continuation



Already reached goals

- Creating answering protocol
- Creating Ethic Codex
- Writing reports
- Organizing Final conference

Already reached goals

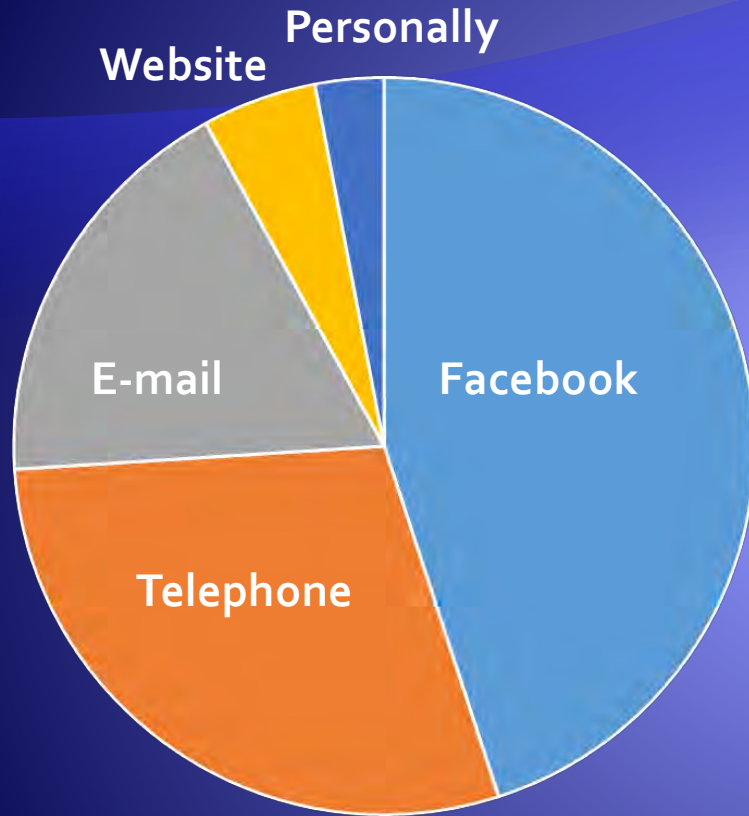
- Expansion of existing infrastructure
- Designate the working team members and Advisory Board members
- Development of communication channels: website, FB, Youtube

In process

- Adaptation of call center software
- Cooperating with national and foreign professional institutions
- Building Database



Type of contact



The purpose of the request



Facebook Telephone e-mail Website Personally

Fellowship Looking for experts, doctors Diagnosis Other

Next steps

- Providing sustainability for the help line
- Call center software and CRM system installation
- Online campaigns to make the help line visible
- Continue building database
- Cooperation with pharmaceutical industries

Perspective

- RD patients and their problems become known
- Their social acceptability increases
- The diagnostic process is shorter
- They receive adequate, complex, comprehensive care
- Their disadvantage compared to common diseases decreases

Thank you for your attention!

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