

# „LIFEBELT” INFORMATION CENTRE FOR THE RARE DISEASE PATIENTS



[mentoov.rirosz.hu](http://mentoov.rirosz.hu), [www.rirosz.hu](http://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



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# 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



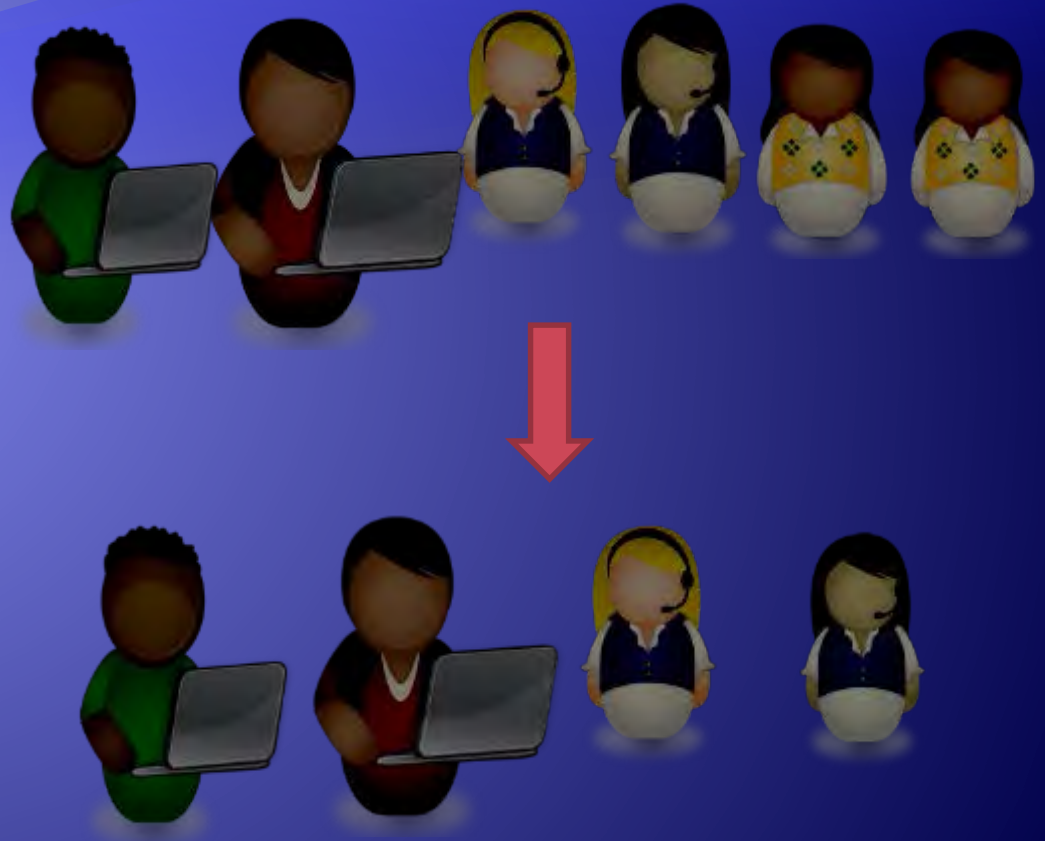
# Starts 1.

- ◆ 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](http://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](mailto: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

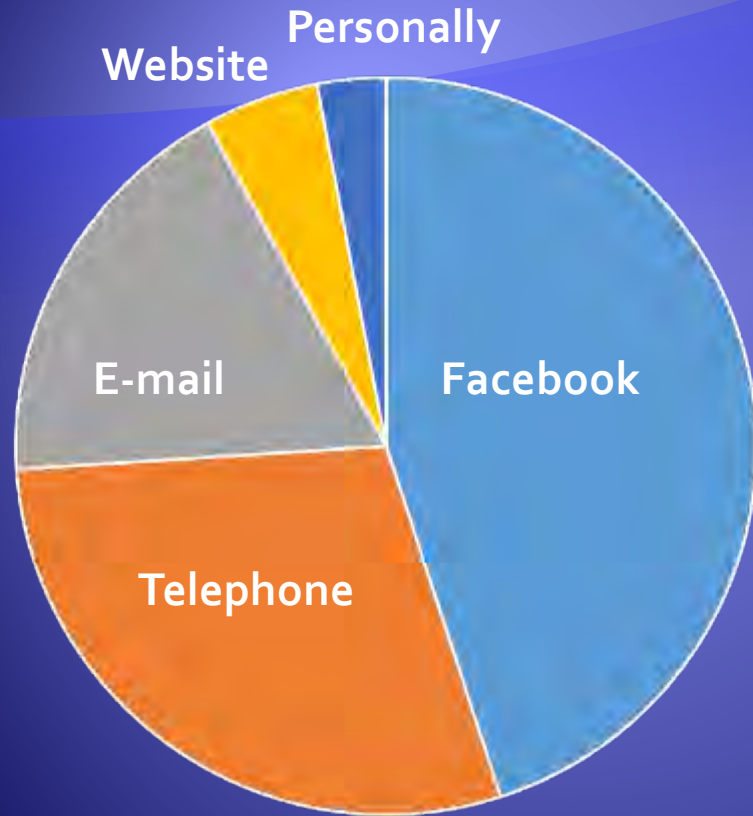


# In process

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

# Thank you for your attention!

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