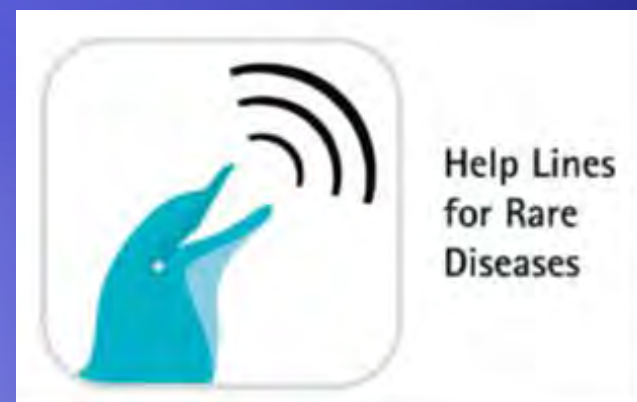


„LIFEBELT” INFORMATION CENTRE FOR THE RARE DISEASE PATIENTS



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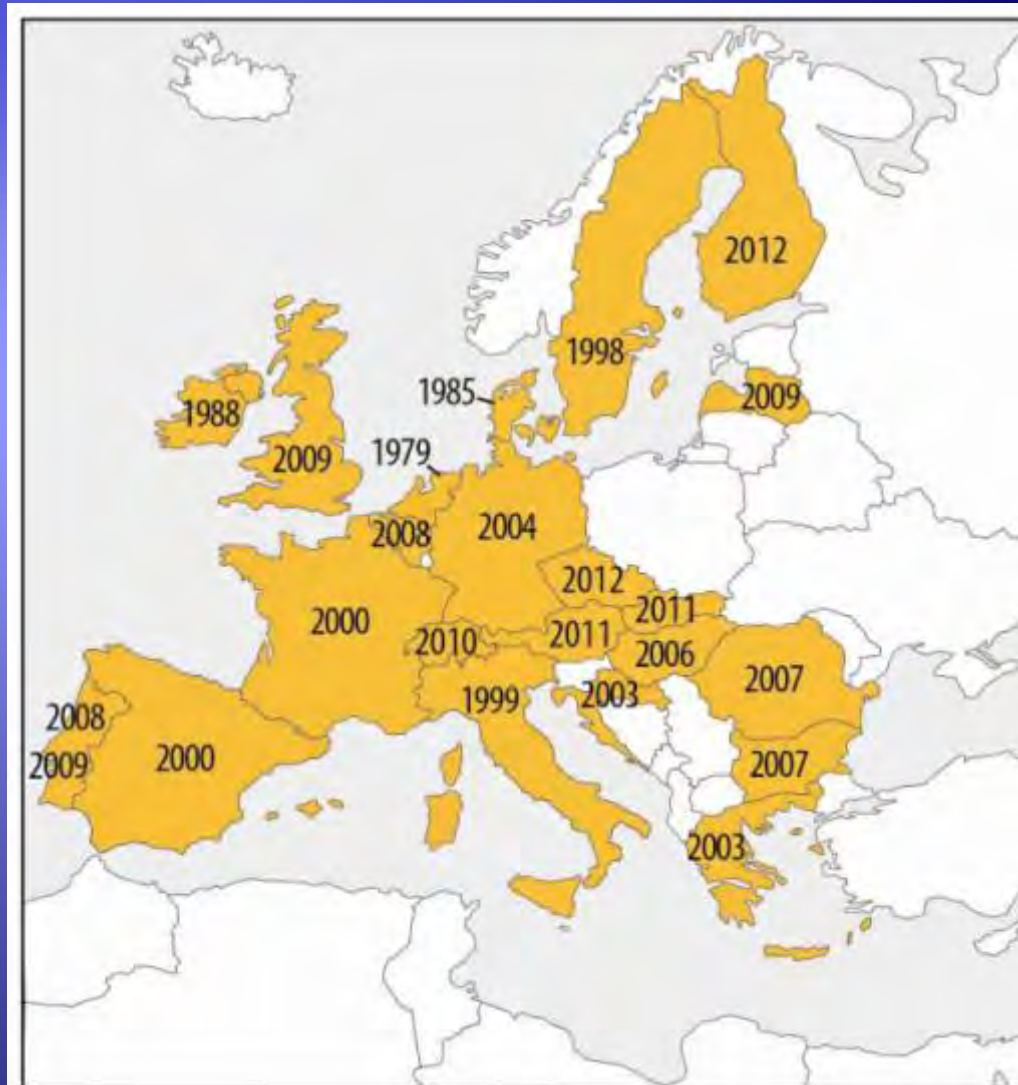
Norway Grants/EEA Grants

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

Hungarian situation at the level of patient organisations:

- Typical is the financial scarcity and uncertainty
- Combined with inappropriate infrastructural background and human resources!
- However, there are lots of unutilized possibility and capacity!
- And huge potential in the national and international collaboration!

National RD Alliances



Therefore HUFERDIS was formed!

- ◆ To reach a critical mass from the point of view of decision makers and the society as well
- ◆ Represent a maximum number of different rare disease patients
- ◆ Cooperation, concentration of resources, better division of labour
- ◆ Unity, moderated competition
- ◆ Increase influence on national policy makers and authorities
- ◆ Share experiences, information and best practices
- ◆ Spread knowledge on rare diseases
- ◆ Represent our country's RD patients on international level

What is HUFERDIS?

- ◆ HUFERDIS was created on 05.05.2006 after several years of preparatory work.
- ◆ It is a network of 45 Hungarian patient organisations and several individuals active in the field of rare diseases.
- ◆ The federation is dedicated to helping people with rare diseases and assisting the organisations that serve them.



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



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



Comprehensive goals



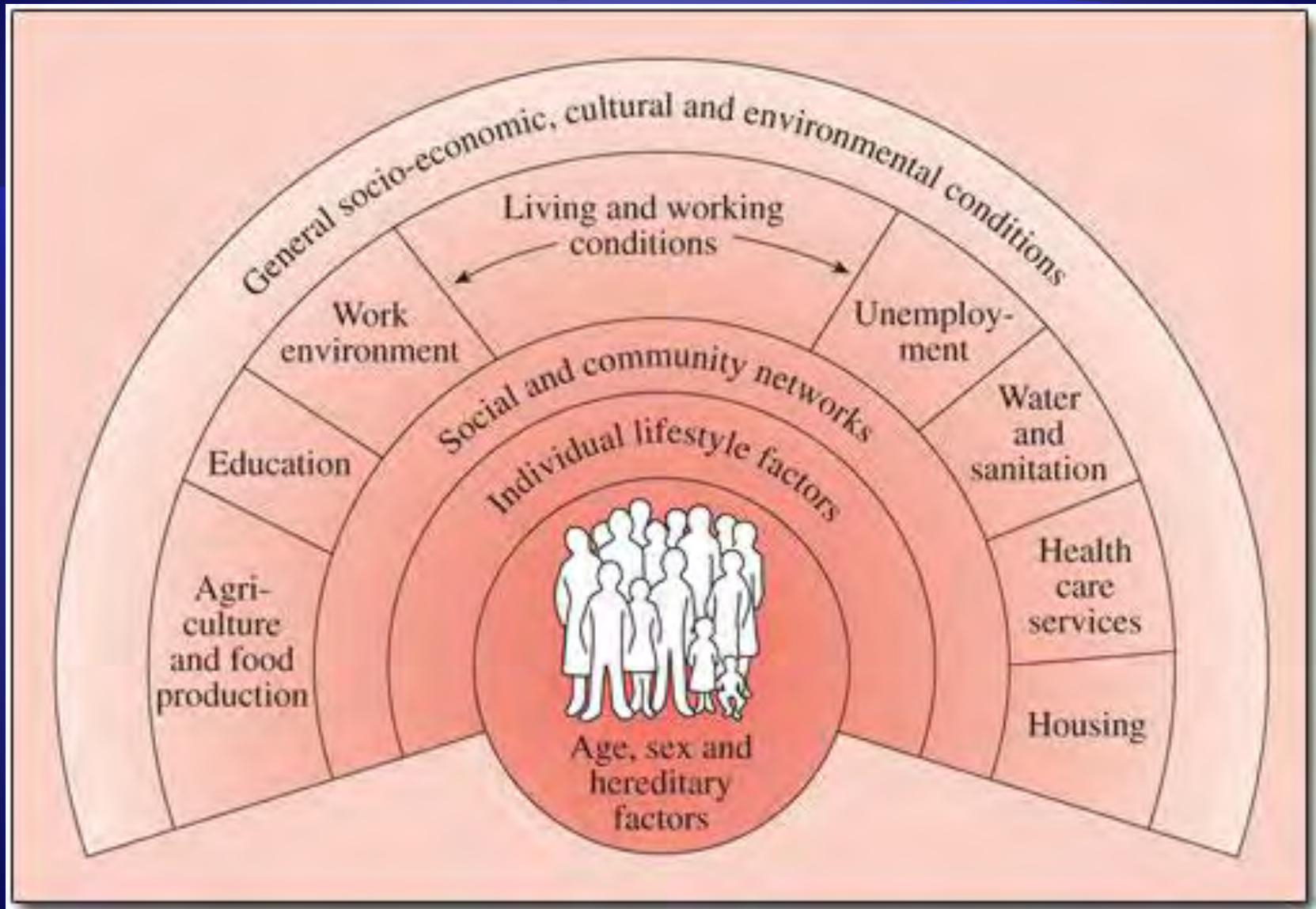
- Necessary to increase the social awareness and the knowledge of professionals for the optimal implementation of RD National Plan
- Moreover, improving patient awareness, and the development of peer communities, besides increasing civil cooperation are also needed.

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



Necessary information



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

Examples of the information needed about drugs

- ◆ Risk of bad life style
- ◆ Benefits of better compliance
- ◆ Effectiveness of original vs. Generic medicine
- ◆ Clinical added value of new innovative drugs
- ◆ Reported side effects (not only with ordinary use but in case of wrong use or abuses)
- ◆ Prevention of taking falsified medicines
- ◆ About ineffective or even harmful „alternative“ drugs
- ◆ About the available clinical trials, and their risks and benefits
- ◆ About possible drug interactions
- ◆ About patient's rights



Currently the Information Centre is formed in a stepwise manner:

- Expansion of existing infrastructure
- Designate the working team members and Advisory Board members
- Development of communication channels: website, FB, Youtube
- Adaptation of call center software
- Cooperating with national and foreign professional institutions
- Building Database



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



By the end of the project

- Creating answering protocol
- Creating Ethic Codex
- Writing reports
- Organizing Final conference
- Create an impact study
- 5 years strategy



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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