

Nemzetközi tendenciák és hazánk bekapcsolódási lehetőségei

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Megközelítésem

- Jelen lehetőségei
- A jövő stratégiája
 - Eu-s
 - Hazai szemmel

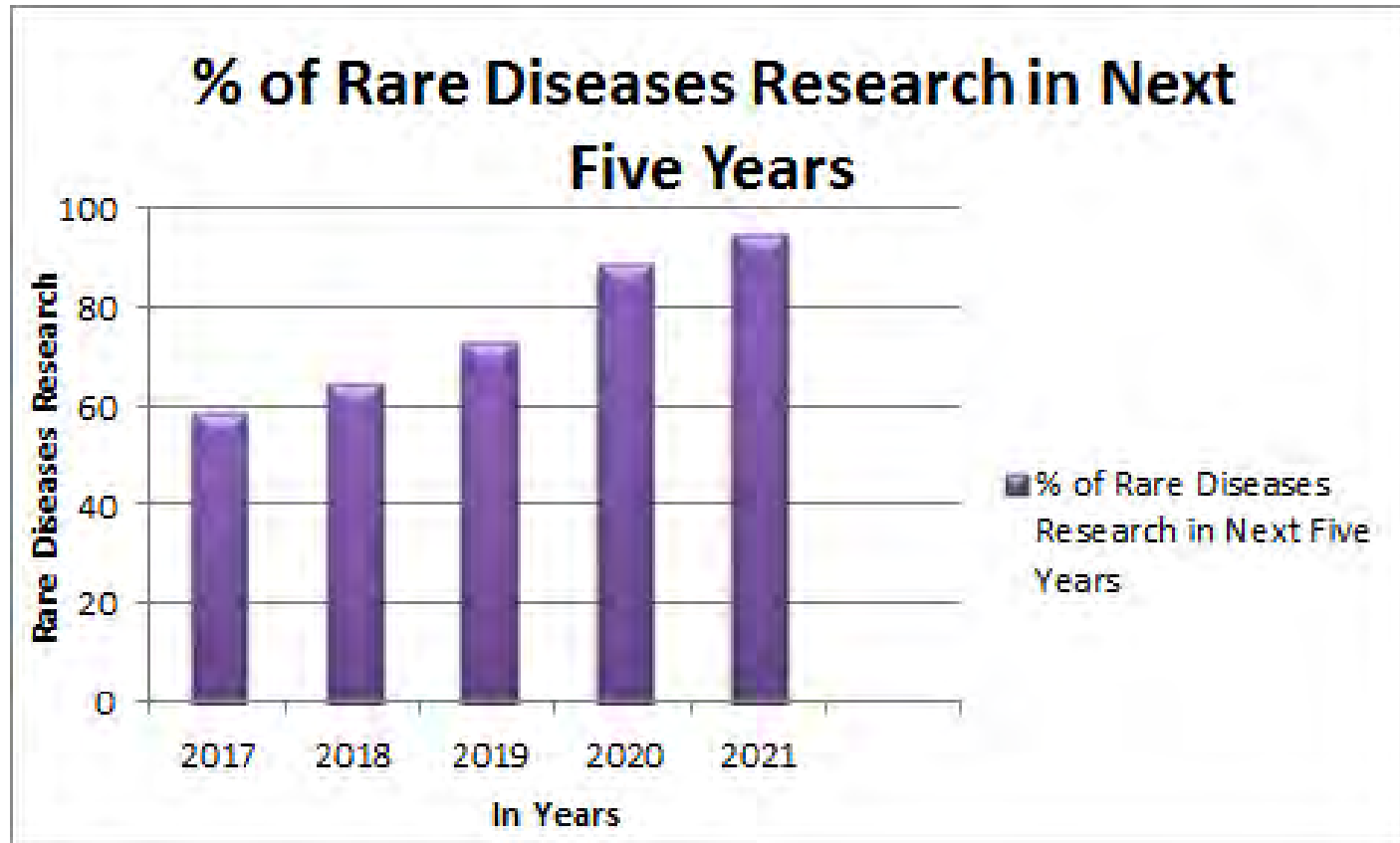
A jelen lehetőségei

EU Supporting Action Rare Diseases 2015

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- **Early Diagnosis**
 - Orphanet Database of 6000 rare diseases
 - European Reference Networks (ERNs), foreseen in the Directive on Patients' Rights in Cross-border Healthcare.
- **European Research**
 - Budget of € 62 million for new therapies for rare diseases
 - Co-funding E-RARE-3: strengthen collaboration EU countries
 - International Rare Disease Research Consortium

A ritka betegségekre irányuló kutatás erősödik



Az EU integrált megközelítése



The Commission Communication and the Council Recommendation on rare diseases

The European Union approach

- **There is probably no other area in public health in which 27 national approaches could be considered to be so inefficient and ineffective as with rare diseases. The reduced number of patients for these diseases and the need to mobilise resources could be only efficient if done in a coordinated European way.**

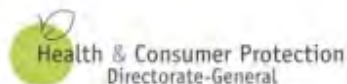
Az EU fő céljai a ritka betegségekkel kapcsolatosan



The Commission Communication and the Council Recommendation on rare diseases - Main objectives

- **Plans and strategies in the field of rare diseases**
- **Adequate definition, codification and inventorying of rare diseases**
- **Research on rare diseases**
- **Centres of expertise and European reference networks for rare diseases**
- **Gathering the expertise on rare diseases at European level**
- **Empowerment of patient organisations**
- **Sustainability**

„The EU tender for newborn screening of rare diseases in EU”



DG SANCO priorities on rare diseases

Web site

Public health actions

http://ec.europa.eu/health/rare_diseases/policy/index_en.htm

Contact point at DG SANCO

antoni.montserrat@ec.europa.eu

Research actions

http://ec.europa.eu/research/health/medical-research/rare-diseases/index_en.html

Contact point at DG RTD

catherine.berens@ec.europa.eu



**European Commission's
Scientific Panel for Health
together for better health and wellbeing for all**

Az SPH gyökerei

Based on a community of stakeholders in biomedical & health research, health care and related organizations, patients and industry

In 2012 a proposal was put forward for a strategic, scientific-led action for health research and to create a *“European Council for Health Research”*



Alliance for Biomedical Research in Europe

<http://www.biomedeuropa.org/>

>> Translated into Horizon 2020 Scientific Panel for Health



Kik vagyunk?

- 27 experts across disciplines and activities - advisors and liaisons to the community - chair
- policy experience and vision
- connected to relevant stakeholders
- complementary to existing bodies
- to consult and connect



SPH mandátuma

- to provide foresight and overall vision, strategy
- identify bottlenecks to innovation and propose solutions



http://ec.europa.eu/research/health/policy-issues-horizon2020_en.html

STRENGTHENING EUROPEAN (BIO) MEDICAL RESEARCH FOR BETTER HEALTH

A vision for health and biomedical research from the Scientific Panel for Health

Biomedical and health research are drivers for better health and patient care through innovation and implementation into practice of novel findings.

**In a changing society new challenges
demand a new research and innovation
framework and strategy.**

Európa erössége

- Excellence of research and forefront developments
- An organised health care system fuels the potential of Digital Health
- Public funding, support and engagement
- Education



Health

- Understanding the determinants of health (including environmental and climate related factors), improving

Horizon 2020 is an ambitious and thriving program fueled by 10% of biomedical research funding

- Developing effective screening programmes and improving the assessment of disease susceptibility
- Improving surveillance and preparedness

Ma **'Better research for better health'**

what works - what doesn't work - a way forward

Cross-border collaboration - around medical needs and beyond Europe

✓ Collaboration and alignment of stakeholders in the innovation cycle

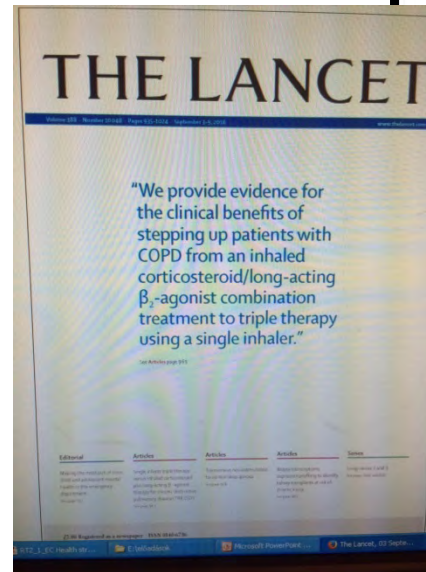
✓ Aligning the regulatory framework with novel health research needs

✓ The research agenda and long-term research policies

Ami jelenleg zajlik



- Vision Paper published
- Widespread consultation with stakeholders and define
 - strategic priorities in research
 - Human resource management
 - Regulatory framework adjustment



BETTER RESEARCH FOR BETTER HEALTH
A vision for health and biomedical research from the Scientific Panel for Health*

Biomedical and health research are drivers for better health and patient care through innovation and implementation into practice of novel findings. In a changing society new challenges demand a new research and innovation framework and strategy.

*The European Commission's Scientific Panel for Health (SPH) is a science-led expert group based on the provisions of the Horizon 2020 Specific Programme that has been tasked with helping to achieve better health and wellbeing for all.
<https://ec.europa.eu/programmes/horizon2020/en/h2020-section/scientific-panel-health-sph>

For more on **Combating Bacterial Resistance** visit <https://www.combacte.com/combacte>

Scientific Panel for Health: better research for better health

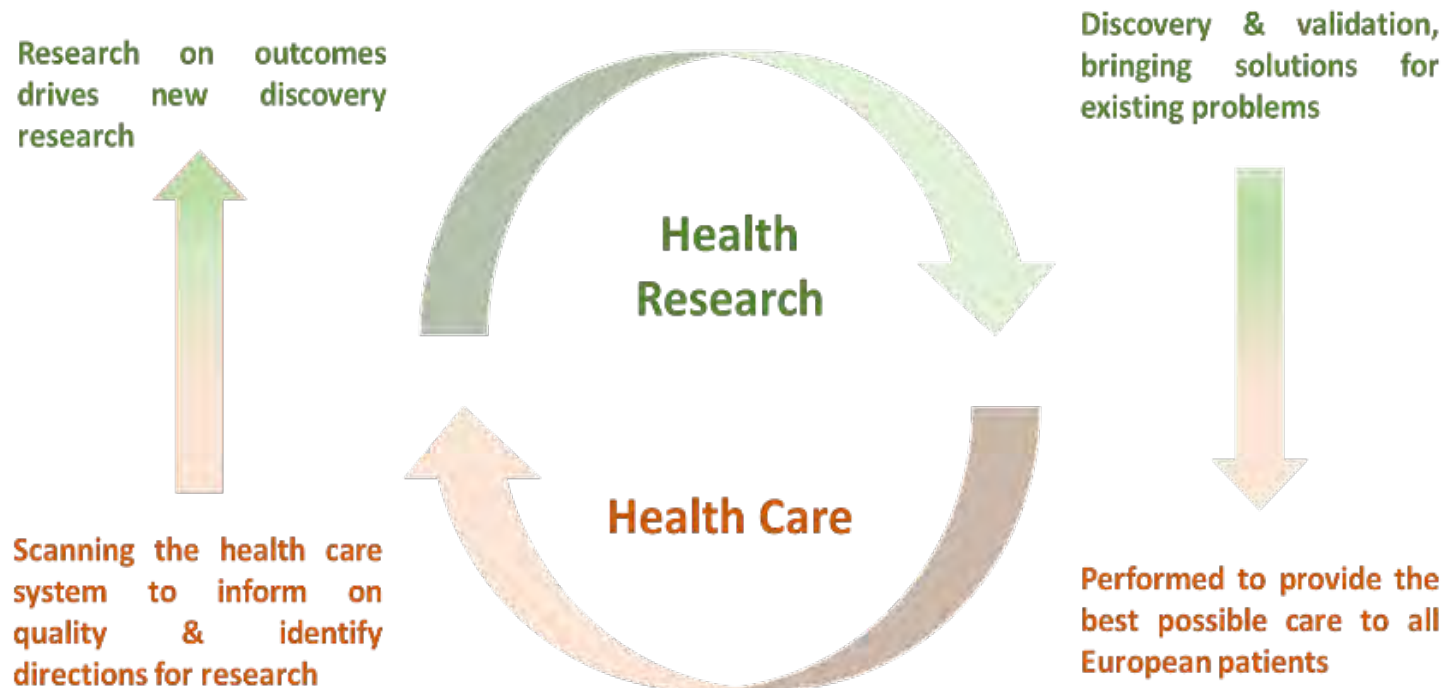
Health is a human right, with research underpinning every advance in health care. Even if political Europe is under siege, health research must remain high on the agenda of all stakeholders. The Scientific Panel for Health,¹ created under the Horizon 2020 Framework Programme for Research and Innovation of the EU, was born out of concerns of the European

Submissions should be made via our electronic submission system at <http://ec.europa.eu/health/scientific-panel/>

momentum now needs ed.
peting interests.

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Az egészségügyi kutatás és ellátás szoros összefüggése



Gyógyszerkutató

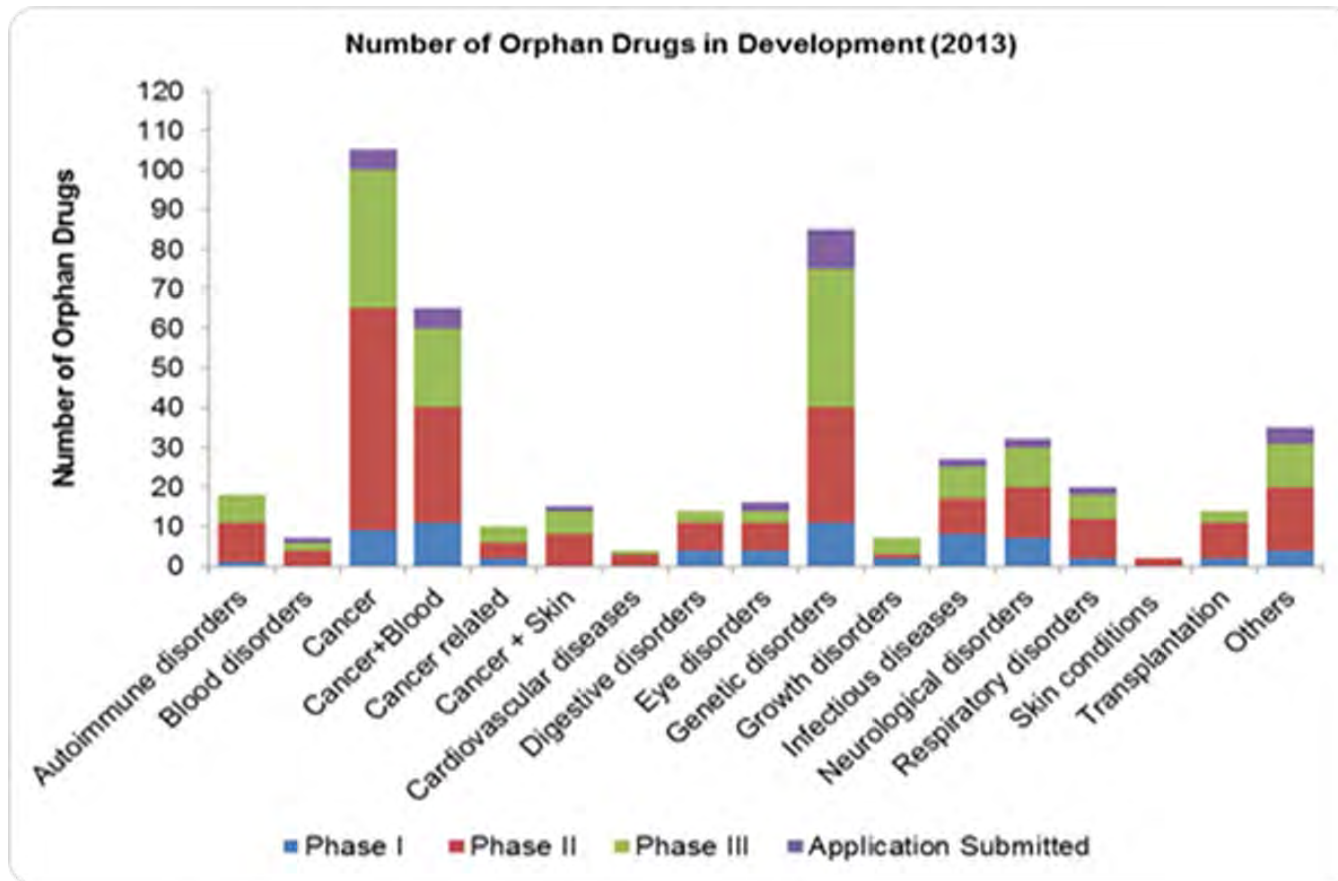
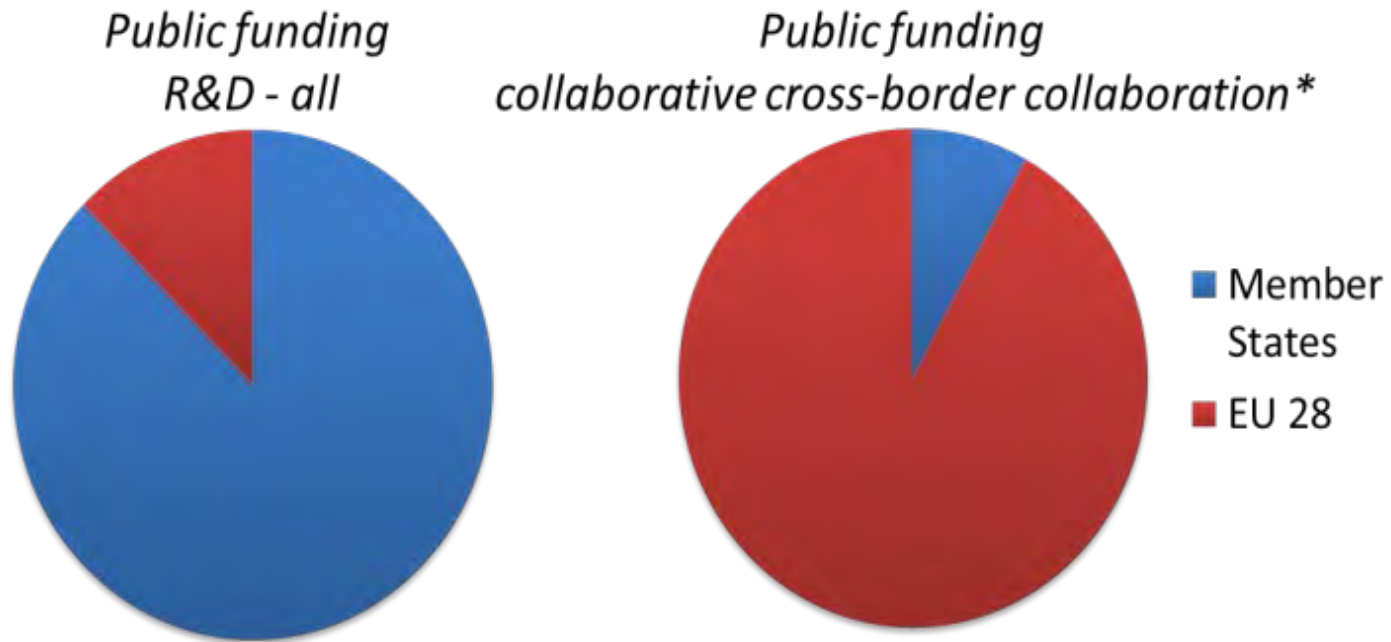


Figure 1; Source: PhRMA Orphan Drug Report 2013

A nemzetközi együttműködések támogatása az EU-ból



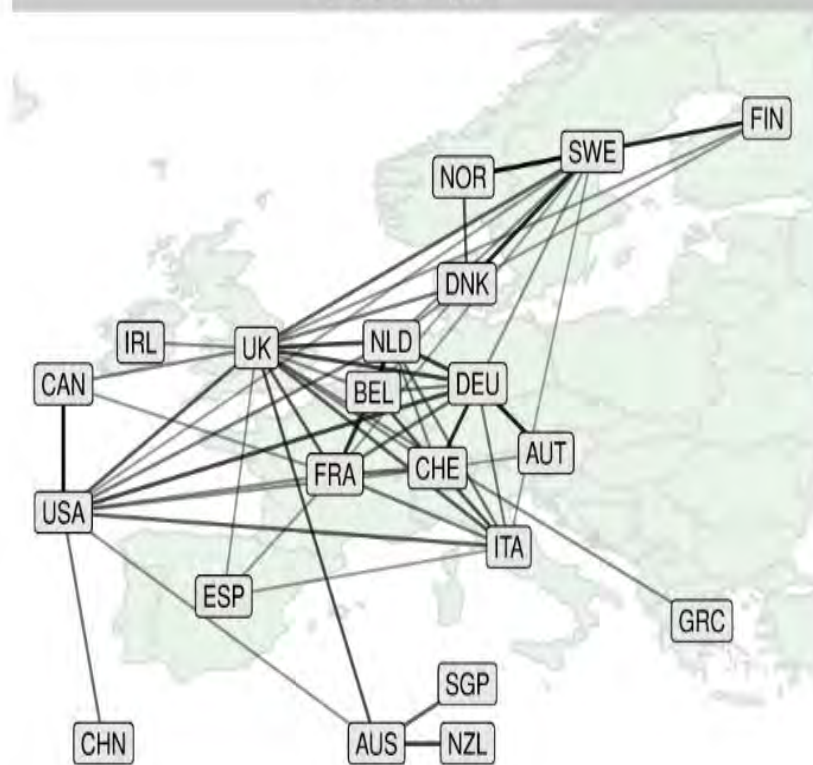
* estimate based on MS funding schemes and EC reporting

Lamy-riport

1992-1998



2006-2012

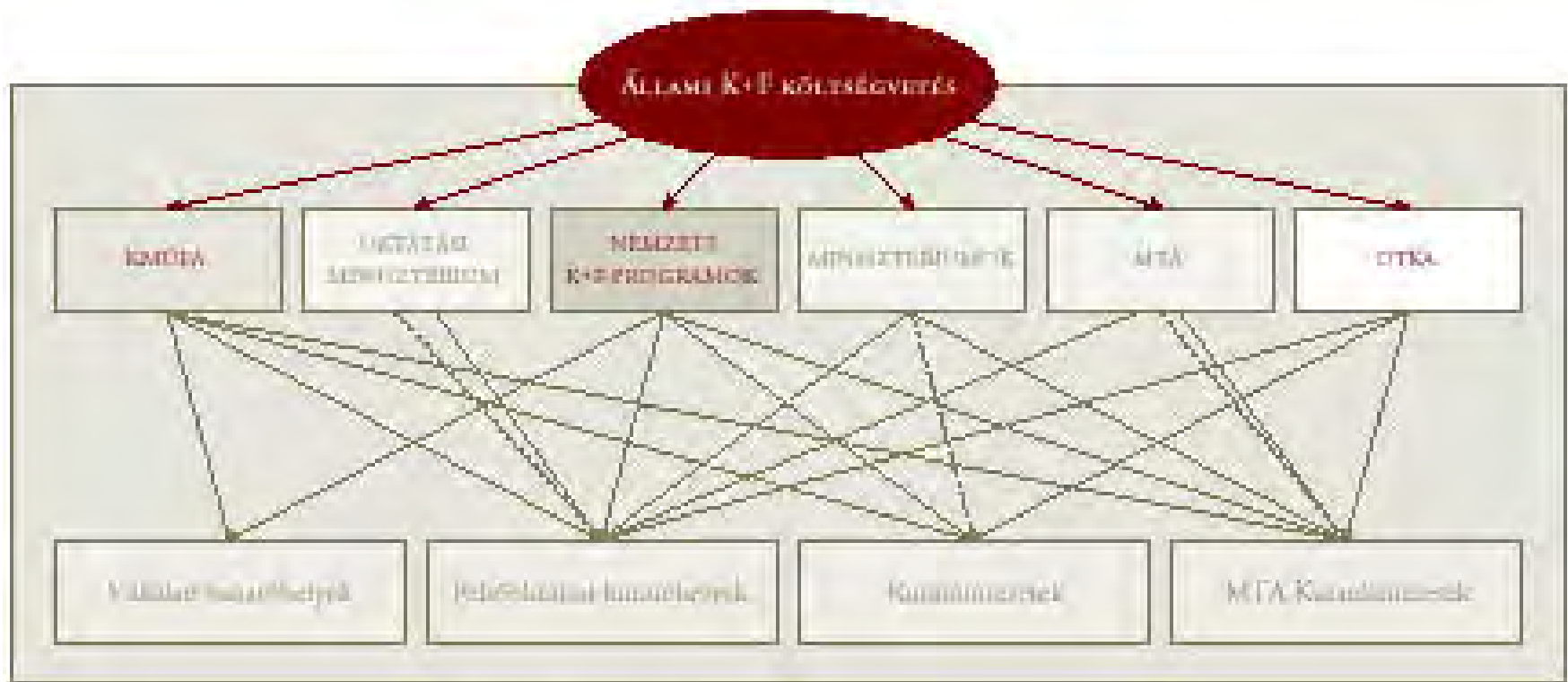


CEE együttműködés



CF: Better together Cisztás fibrózis CEE találkozó 2017. Gárdony

Hazai lehetőségek



—————> pályázat / finanszírozás
- - - - -> igazgatási / intézményi kapcsolatok

Köszönöm a figyelmet

