

**Working together for a voice in research & health policies and  
benefiting from genetics, genomics & biotechnology**



**The contribution of the  
Central & Eastern European Genetic Network (CEEGN)  
towards prevention and treatment  
of genetic diseases**

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On behalf of CEEGN Board  
Budapest, Aug 2008



# CEE GN

- Founded in October 2003 in Cavtat, Croatia, by patient representatives from 8 Central and Eastern European countries
- Registered in Hague in 2008



Founding meeting in Cavtat



# CEE GN

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- Patient-driven network
- Currently **the only network organization from CEE Region** with focus on the common needs of CEE patients with **genetic disease** and their families, related to the backward position of CEE countries.
- Members: patients, parents, individuals, doctors and scientists (Medico Scientific Committee) from Central and Eastern European countries (CEE).
- CEEGN functions in line with the European Genetic Alliances' Network (EGAN) and the International Genetic Alliance (IGA).



# Unique focus

	<b>EGAN/ CEEGN</b>	<b>Eurordis / Rare disease org.</b>
<b>Format</b>	Network / Umbrella	Organization
<b>Target group:</b>	Common and rare genetic disease	Rare disease
<b>Limited to:</b>	Genetic and congenital conditions	Rare disease
<b>Membership:</b>	National alliances & umbrella organizations	Rare Disease organizations
	Medico scientific societies can be affiliated members	100% patient driven
<b>Focus on:</b>	Disease prevention, early detection, accurate diagnosis, genetic counseling and medicines development.	Disease care, access to treatment and policy
<b>Strong in:</b>	Research & development collaborations with science(ESHG, ESGCT, BioVision &) and industry (EuroBio, Roche, DSM, Genzyme, &)	Advocacy & policy making



## Aims

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- Focus on the **common needs** of patients and their families from CEE countries, related to the backward position of CEE countries and strives to **facilitate their integration** in the EU as a top priority (implement EU standards in CEE countries).
- **Promote research and development** of medicines in genetic field in the countries of CEE
- Encourage CEE patients **involvement and active participation in research**, towards early detection and accurate diagnosis, genetic counseling, and ultimately disease prevention.
- Build up up **awareness and knowledge** on genetic, common and rare conditions among public and science, and increase political influence.
- **Voice** the situation in genetic field in CEE on the EU level, and **support the local genetic patient organizations** in the countries of CEE.

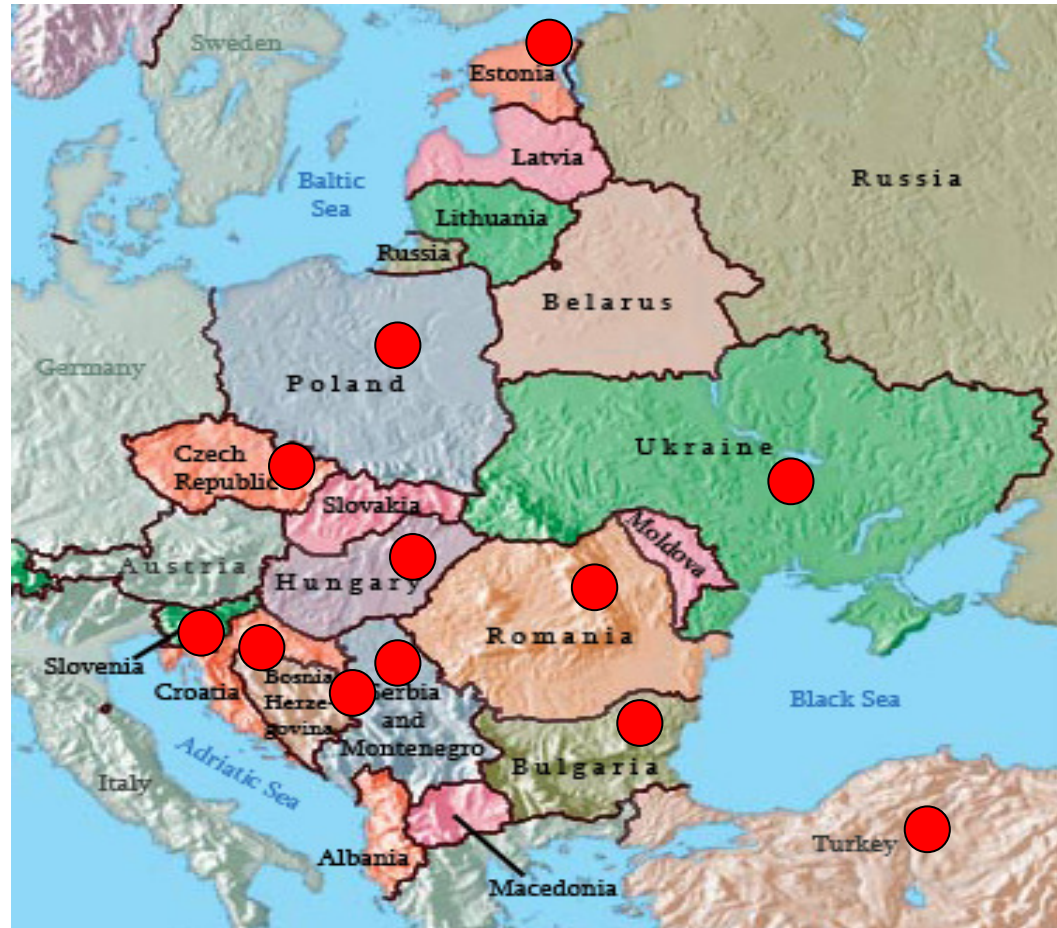


## Aims (cont.)

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- CEE GN welcomes **collaboration** with other networks of patient organisations, scientific and industrial groups, as far as this serves the interest of patients in CEE countries and has a focus on research & development in the field of genetics, genomics and biotechnology.
- CEEGN refrains from working fields where other organizations are already active
- CEEGN advises and promotes membership with other patient organizations.

# Current Member Countries



# Projects

## Participation and Partnering

Project	Website	Description
<b>EUROGENGUIDE</b>	<a href="http://www.eurogenguide.eu">www.eurogenguide.eu</a> <a href="http://www.eurogenguide.org.uk">www.eurogenguide.org.uk</a>	A Patient Led Guide for Genetics Research Participants. A three year project funded by the European Commission which aims to improve and provide information about genetic testing and research in Europe.
<b>EUROGENTEST</b>	<a href="http://www.eurogentest.org">www.eurogentest.org</a>	Genetic Testing in Europe - FP6 Network of Excellence: Network for test development harmonization, validation and standardization of services. UNIT 6.EDUCATION
<b>ROADMAP TO TREATMENT</b>	<a href="http://www.efgcp.be">www.efgcp.be</a>	Medical Genetics Roadshow (working title). A proposal is in the process of submission for education and training of patients and patient organisations for partnering in research and drug development in the context of EU/DG research FP7.
<b>PATIENT PARTNER: Patient participation in clinical trials</b>	<a href="http://www.efgcp.be">www.efgcp.be</a>	Identifying the needs for Patients partnering in Clinical Research. Organized by the European Genetic Alliances' Network and the European Forum of Good Clinical Practice. This project will lead to communication platform and guidelines to enable the mutual beneficial interactions between patients and clinical trials professionals.
<b>IMD (Integrated Medicines Development) - work package 10: Training Programmes for Patient Organisations</b>	<a href="http://www.imi-europe.org">www.imi-europe.org</a>	Aim to increase the knowledge of patients and members of patient organizations in Europe of the medicines development process - including ethics, scientific methodology, regulatory requirements and assessment of risk and benefits – to enable them to make a more strategic and considered input to medicines development.





# Partnerships

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## **CEEGN partners or intends to become a partner with:**

- European Genetic Alliances Network
  - European Platform for Patients' Organizations, Science and Industry
  - International Genetic Alliance of Parent and Patient Organizations
  - European Patient Forum
  - European Organization for Rare Disorders
  - European Society of Human Genetics
  - European Federation Pharmaceutical Industries and Associations
  - European Association for Bio industries
  - European Federation Biotechnology
  - Orphanet
- EGAN**  
**EPPOSI**  
**IGA**  
**EPF**  
**EURORDIS**  
**ESHG**  
**EFPIA**  
**EuropaBio**  
**EFB**  
**Orphanet**



# Contribution towards prevention and treatment of genetic diseases

- CEEGN actively **promotes understanding of genetic diseases** through
  - Building awareness on EU projects focusing genetics, genomics and biotechnology among the patients, scientists and politicians in Central and East European countries, such as Eurogenguide and Eurogentest, Roadmap to treatment, Patient Partner
  - Participation in genetic disease conferences and other events organized in CEE countries
  - Distribution of newsletter and leaflets, website
  - Supporting prevention and diagnostic programs
  
- **CEE GN stimulates interaction** between government, physicians, regulators, industry and patient groups in CEE countries through
  - Organization and support of different events and meetings with aim to increase collaboration between all stake holders (for example CEE meeting in Cavtat 2003, EPPOSI in Munich 2005)



## Contribution towards prevention and treatment of genetic diseases

- CEEGN will **lobby for more investments in research for development** of new drugs, for better services, facilitating legislation and equitable healthcare budgets in CEE countries through
  - Working closely with research (scientists and industry) to improve their understanding on patients needs and encourage patients involvement from CEE
- Through **supporting the local genetic patient organizations** in the countries of CEE, CEEGN will ensure that the **information from EU** has reached various people from those countries who are interested and active in the genetic field



# WebSite

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**[www.ceegn.org](http://www.ceegn.org)**