



UMC Utrecht



Endo-ERN

# ERN 'rare endocrine conditions'

Nationale coördinatie van ERN activiteiten

Gerlof Valk

Internist-endocrinoloog



European  
Reference  
Networks



# Scoop en context

## European Reference Networks

2011: Article 12 *Directive of patients' rights in cross-border healthcare*

### Networks of healthcare providers aiming at

- Improving quality and safety and access to highly specialised healthcare across the EU
- Patients affected by rare or low prevalence and complex diseases



Imagine if the **best specialists** from across Europe could join their efforts to tackle **medical conditions** that require **highly specialised healthcare** and a concentration of knowledge and resources.

That's the purpose of the **European Reference Networks** and it's becoming a reality.

Share and enhance your expertise. Talk with your colleagues. Join a **Network proposal** in early 2015.

More information at [ec.europa.eu/join-ern](http://ec.europa.eu/join-ern)

**Share. Care. Cure.**

Supported by the



### Added value ( EU level )

#### Need for Cooperation:

- ✓ Scarcity of knowledge
- ✓ Need for education
- ✓ Complexity / high costs
- ✓ Effective use of resources

# Key issues addressed in EU directive

## Directive 2011/24/EU of patients' rights in cross-border healthcare

Right to **choose** and be reimbursed for healthcare provided by public or private providers located in the EU

More **transparency** about their rights, treatment options or, the quality and safety levels of healthcare providers

**Thus:** maximum focus of ERNs on **transparency and dissemination of expertise** is key to make an individualized choice for best care

***PATIENT IN THE LEAD***



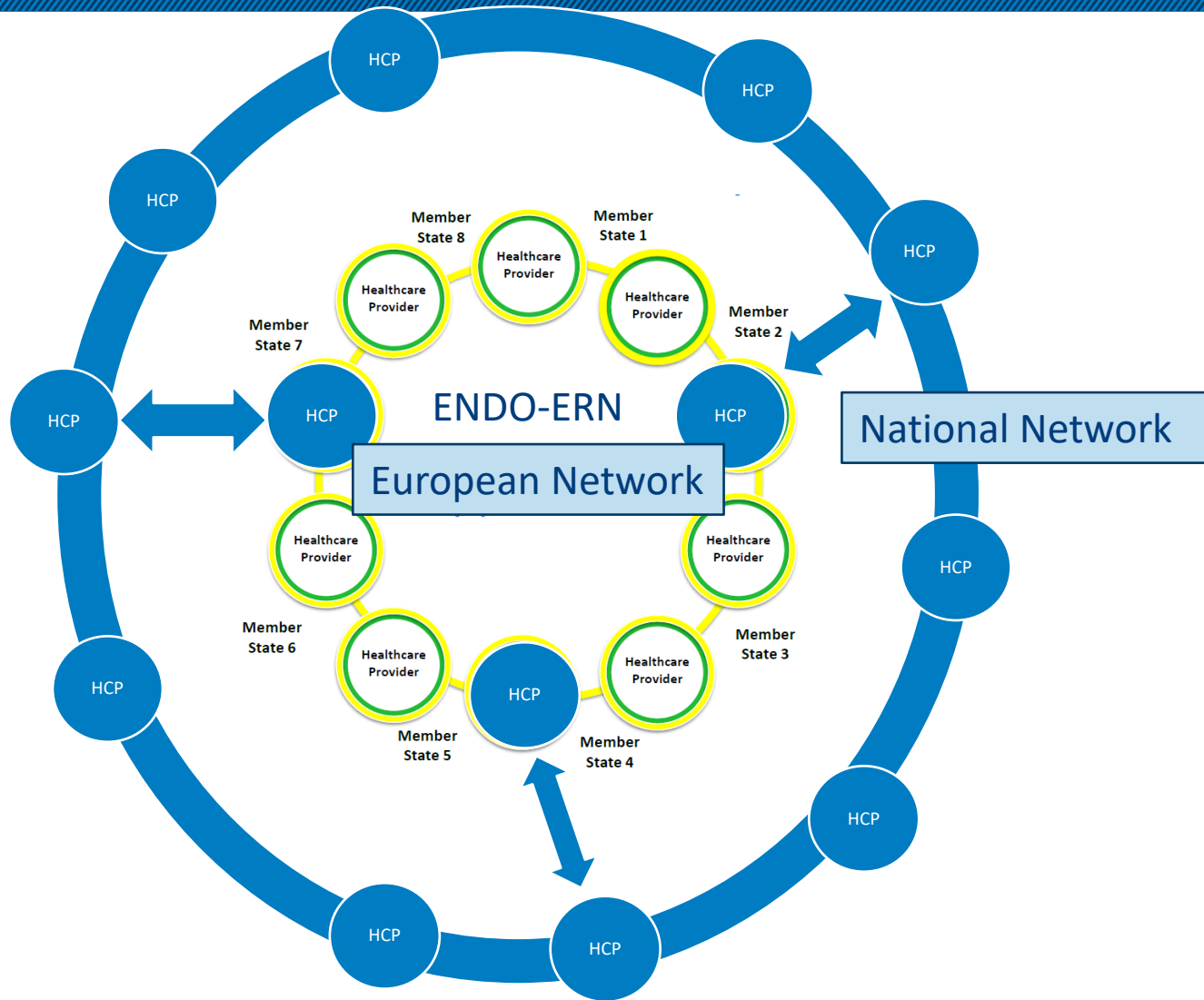
### Did you know?

You have the right to receive medical treatment in another EU Member State and the right to have your home country cover some or all of the costs.

You have the right to be informed about the treatment options open to you, how other EU countries ensure quality and safety in healthcare, and whether a particular provider is legally entitled to offer services.

Look inside to find out more...

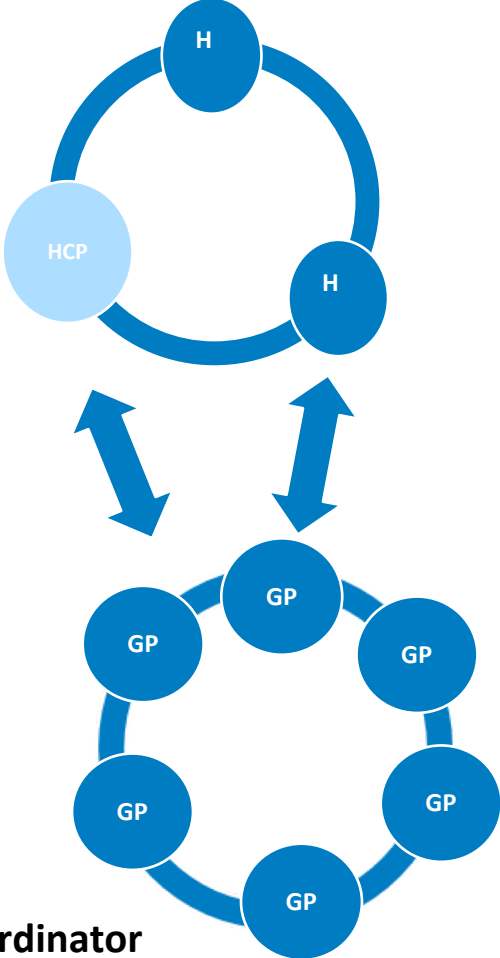
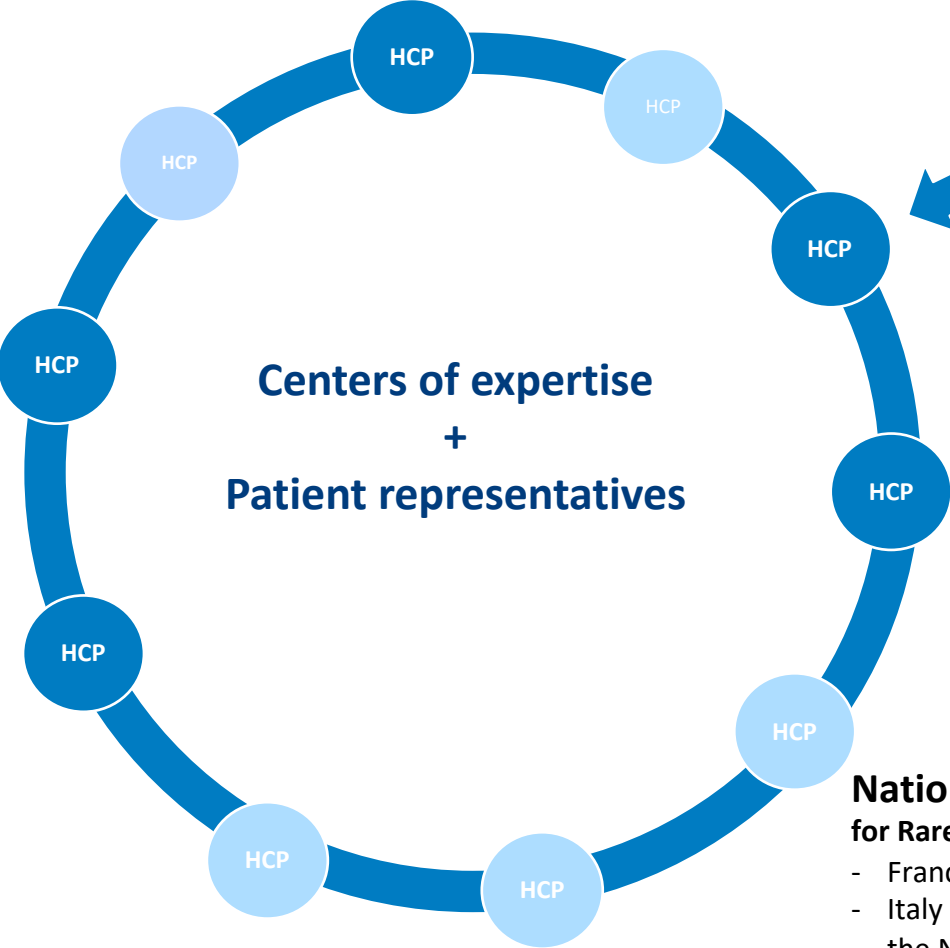
# ERNs should inter-connect with national and regional networks for optimal dissemination of expertise



# Organization in NL example adrenal centers of expertise

Regional Network

National Network



### National Coordinator for Rare Endocrine Conditions

- France (since 2005: prof J. Bertherat)
- Italy (2016: prof A. Colao)
- the Netherlands (2017: prof G. Valk)

# 2013: BijnierNET



# Endo-ERN: Added value for patients



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions

Increase awareness amongst general public  
and health care professionals by:

- Dissemination of information on endocrine conditions
  - Collaboration of Network with patients associations
  - Conferences
- Network website
- Actions towards health authorities



Patient Pathway



Shorten delay in diagnosis by:

- Multidisciplinary diagnostic expert consultation
- Use of telemedicine
- Patient pathway monitoring (tracer patient method)
- Access to specific diagnostic tools: genetics / lab-hormonal measurements



Education of patients

- Instructions to GP's following the patient
- Transition from childhood to adulthood
- QoL surveys
- Training of delegates
- Prevention of complications and co-morbidities

# Endo-ERN in The Netherlands: leading role BijnierNET



Endo-ERN  
European Reference Network  
on Rare Endocrine Conditions

## Thema's



Kwaliteitsstandaard /  
Goede zorg



Stressinstructies



Medicatie



Nood en spoed

## Producten



Hitteprotocol



Animaties



Infographics



Ervaringsverhaal

## Informatie



Nieuwsbrief



Dossier



Onderzoek,  
publicaties



Snelzoeker

## Zorg & behandeling



bijnier app



Kindzorg



Diagnostische  
vertraging

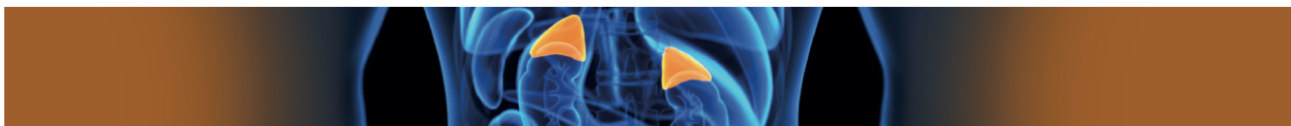


Mantelzorg

[Home](#) [Bijnieraandoeningen](#) [Producten](#) [Educatie](#) [Blijf op de hoogte](#) [Over BijnierNET](#)

[Home](#) » [Educatie](#)

## Scholing over bijnierschorsinsufficiëntie voor verpleegkundigen





# Endo-ERN: Added value for patients



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions

Increase awareness amongst general public  
and health care professionals by:

- Dissemination of information on endocrine conditions
  - Collaboration of Network with patients associations
  - Conferences
  - Network website
  - Actions towards health authorities

- Guidelines
- Individual care plan defined by the Network
- Facilitation of clinical trials / research



Patient Pathway



Shorten delay in diagnosis by:

- Multidisciplinary diagnostic expert consultation
- Use of telemedicine
- Patient pathway monitoring (tracer patient method)
- Access to specific diagnostic tools: genetics / lab-hormonal measurements

allowing the patient  
good to adulthood

ations and co-morbidities





# Endo-ERN: Added value for patients



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions

- Guidelines
- Individual care plan defined by the Network
- Facilitation of clinical trials / research

Increase awareness amongst general public and health care professionals by:

- Dissemination of information on endocrine condition
  - Collaboration of Network with patients association
  - Conferences
  - Network website
  - Actions towards health authorities

1<sup>st</sup> contact with  
health care professional

Referral

Diagnosis

Treatment

Follow-up

Patient Pathway

Patient Pathway

Shorten delay in diagnosis by:

- Multidisciplinary diagnostic expert consultation
- Use of telemedicine
- Patient pathway monitoring (tracer patient method)
- Access to specific diagnostic tools: genetics / lab-hormonal measurements

Education of patients

- Instructions to GP's following the patient
- Transition from childhood to adulthood
- QoL surveys
- Training of delegates
- Prevention of complications and co-morbidities

# Kwaliteitsstandaard Bijnieraandoeningen

Bijnierschorsinsufficiëntie  
Adrenogenitaal syndroom  
Syndroom van Cushing  
Primair hyperaldosteronisme  
Feochromocytoom



# Endo-ERN: Added value for patients



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions

Increase awareness amongst general public  
and health care professionals by:

- Dissemination of information on endocrine conditions
  - Collaboration of Network with patients associations
  - Conferences
  - Network website
  - Actions towards health authorities

- Guidelines
- Individual care plan defined by the Network
- Facilitation of clinical trials / research



Patient Pathway

- Education of patients
- Instructions to GP's following the patient
- Transition from childhood to adulthood
- QoL surveys
- Training of delegates
- Prevention of complications and co-morbidities

# Endo-ERN in The Netherlands: leading role BijnierNET



Endo-ERN  
European Reference Network  
on Rare Endocrine Conditions

## Thema's



Kwaliteitsstandaard /  
Goede zorg



Stressinstructies



Medicatie



Nood en spoed

## Producten



Hitteprotocol



Animaties

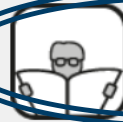


Infographics



Ervaringsverhaal

## Informatie



Nieuwsbrief



Dossier



Onderzoek,  
publicaties



Snelzoeker

## Zorg & behandeling



bijnier app



Kindzorg



Diagnostische  
vertraging



Mantelzorg

[Home](#) [Bijnieraandoeningen](#) [Producten](#) [Educatie](#) [Blijf op de hoogte](#) [Over BijnierNET](#)

[Home](#) » [Educatie](#)

## Scholing over bijnierschorsinsufficiëntie voor verpleegkundigen



## Inform through dissemination of expertise:

### ERN =

- samenwerken en soms verwijzen
- juiste zorg op de juiste plaats 'dichtbij als het kan en verder weg als het moet'
- juiste informatie op het juiste moment voor patiënten en dokters
- transparantie over wat we bieden en doen

*'PATIENT IN THE LEAD'*

**WAAROM  
MOEILIK DOEN  
ALS  
HET SAMEN KAN**

*Loesje*



European  
Reference  
Networks



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions

**BijnierNET**

