

## VIDEO WHAT IS ERN-EYE ?

The video presents ERN-EYE and is divided into 11 slides that summarize the main actions and goals of the network. The video is made from infographics with blue and white pictograms.

### Slide 1

The video begins with the ERN-EYE official logo and a stylistic eye.

### Slide 2

#### **Rare Diseases in Europe**

In the European Union, a disease is rare when it affects less than 1 in 2,000 people.

80% of rare diseases have a genetic origin. 30 million people from the EU are affected by over 6000 Rare and complex Diseases.

(The slide shows progressively the whole text)

### Slide 3

#### **European reference networks for rare, low-prevalence and complex diseases**

ERNs are European reference networks, bringing together highly specialised expertise from all across the Europe, and make it accessible to the entire medical community.

- 24 ERNs for all Rare Eye Diseases
- Improve Healthcare Pathway
- Env. 7000 Rare Diseases
- Patients groups involved in governance

(The slide shows progressively the whole text)

## Slide 4

ERN-EYE the European Reference Network dedicated to Rare Eye Diseases

- 13 founding countries
- 29 Hospitals
- 900 Rare Eye Diseases
- 24 000 patients in our centers

(The slide shows pictograms for each number)

## Slide 5

### Founding members

(The slide shows the founding members on a map of Europe one by one: Belgium, Czech Republic, Denmark, Estonia, France, Germany, Italy, Latvia, Lithuania, Netherland, Poland, Portugal, and United Kingdom)

## Slide 6

### 4 thematic groups on Rare Eye Diseases:

- Working group 1 : RETINAL RARE EYE DISEASES
- Working group 2 : NEUROOPHTHALMOLOGY
- Working group 3 : PEDIATRIC OPHTHALMOLOGY
- Working group 4 : ANTERIOR SEGMENT

(The slide shows each working group with, in the center, a diagram of the eye to show the different specialties.)

## Slide 7

6 transversal working groups dedicated to:

- Low vision, daily life and patient group
- Genetic diagnostics
- Registries & epidemiology



European  
Reference  
Network

for rare or low prevalence  
complex diseases

Network

Eye Diseases (ERN-EYE)

- Research
- Education, training & guidelines
- Communication, management & quality

(The slide shows each transversal groups with some pictograms to illustrate them)

## Slide 8

### ERN-EYE goals are

- 1) Improve patient trajectory in the EU : Virtual clinic
- 2) Reduce inequalities of patient care in the EU
- 3) Reduce the time to diagnosis and care
- 4) Ensure molecular diagnosis to the largest number of patients in the EU
- 5) Bring diagnosis to the undiagnosed
- 6) Facilitate involvement of patients in clinical trials
- 7) Give access to innovation
- 8) Provide tools for education and communication

(The slide shows the goals one by one)

## Slide 9

### Virtual Clinic

The Networks main aim is the development of a virtual clinic to facilitate **cross-border dissemination of expertise.**

(The slide shows a diagram that begins with the patient, goes to the clinician, then to the healthcare provider and the experts panel (via a computer). These experts give recommendations that come back to the clinician.)

## Slide 10

### To inform you

- Congress presentations
- Website



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**

Eye Diseases (ERN-EYE)

- Social networks
- Communication and media

(The slide shows progressively the whole text with pictograms)

## Slide 11

### Follow us on our network

[www.ern-eye.eu](http://www.ern-eye.eu)

- Facebook
- LinkedIn
- Twitter
- YouTube

(The slide shows progressively the whole text and the logos of ERN-EYE and the European Commission)