ERN on eye diseases (ERN EYE)

Rare Eye Diseases (RED) are the leading cause of visual impairment and blindness for children and young adults in Europe. More than 900 REDs are listed in the portal for rare diseases and orphan drugs (ORPHANET). These include more prevalent diseases such as retinitis pigmentosa which has an estimated prevalence of 1 in 5 000, as well as some very rare entities described only once or twice in medical literature.

The network's main aim is the development of a virtual clinic — known as EyeClin — to guarantee the best coverage of REDs and facilitate cross-border dissemination of expertise.

ERN EYE addresses these conditions in four thematic groups: rare diseases of the retina, neuro-ophthalmology rare diseases, paediatric ophthalmology rare diseases, and rare anterior segment conditions.

In addition, six transversal working groups are addressing issues common to the four main themes. Additional working groups focus on specific areas, including genetic testing, registries, research, education, communication and patients.

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NETWORK COORDINATOR

Professor Hélène Dollfus
Hôpitaux Universitaires de Strasbourg, France