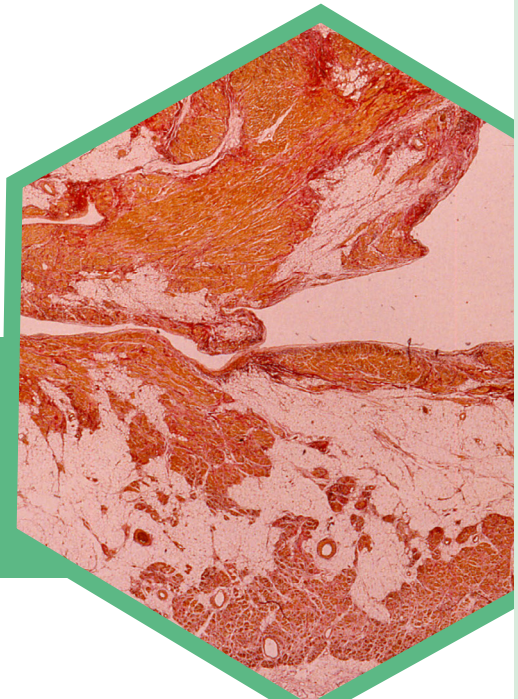
ERN on uncommon and rare diseases of the heart (ERN GUARD-Heart)

Rare cardiac diseases can present throughout a person's life, and most of them are usually either genetic (inheritable) disorders or those which develop during embryogenesis (congenital heart defects). These conditions are characterised by a wide range of symptoms and signs which vary not only from disease to disease, but also from patient to patient. Most of these cardiac diseases carry a unique susceptibility to sudden death at a young age, and may occur in otherwise healthy people.

ERN GUARD-Heart has identified five thematic areas: familial electrical diseases in adults and children; familial cardiomyopathies in adults and children; special electrophysiological conditions in children; congenital heart defects; and other rare cardiac diseases. These themes follow the International Classification of Diseases (ICD10) and Orphanet and are subject to the clinical guidelines of the European Society of Cardiology (ESC).

The network seeks to strengthen the coordination of expertise and resources, in order to facilitate the pooling of multidisciplinary knowledge which is then mapped and disseminated to the public.

Healthcare services are provided through a shared eHealth platform, which ensures patients get wider access to expertise and healthcare professionals around Europe. By fostering closer cooperation between experts, new scientific knowledge is acquired and shared to support the development of new diagnostic and therapeutic procedures, and to identify new rare cardiac diseases.



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