

What are the ERNs doing to help patients affected by rare diseases and COVID-19?

The ERNs are facing unprecedented challenge to help patients affected by rare diseases who are also infected with the new coronavirus to receive care and cure adequate to their specific situation. Several ERNs have set up targeted initiatives. This section is updated on a regular basis to better reflect the work of ERNs:

- **ERN-EuroBloodNet** created a COVID-19 dedicated section on the website with informative documents for clinicians and patients regarding [information and management of COVID-19 in patients affected by Rare Hematological Diseases](#). It also launched a [Collaborative platform for Red Blood Cell Defects and COVID-19](#) to share clinical information for supporting daily medical practice while enabling inter-professional consultation of cases through the Clinical Management Support System (CMSS). Furthermore, data will allow the performance of observational studies in the different cohorts of patients including Sickle Cell Disease, Thalassaemia, Enzymopathies and Membranopathies patients in pediatric and or adult stages.”
- **ERN BOND** created a section on their website dedicated to [COVID-19 emergency](#), addressing patients affected by rare bone diseases infected with the new coronavirus and their health professionals. The section includes a specific page with [guidelines and recommendations](#). The ERN BOND Coordination team and Italian BOND healthcare providers, in collaboration with the Italian OI association and the Italian federation of Rare Diseases Patients Associations, set up a 24-hour helpline for rare bone disease patients who need information and clinicians treating COVID-19 patients who are affected by a rare bone disease.
- **ENDO-ERN** developed two webpages on the new coronavirus: a COVID-19 webpage with useful [information for patients and health professionals](#) and a [country tailored information](#) webpage.
- **ERN EpiCARE** issued [recommendations regarding COVID-19 and epilepsy care](#) (accessible in various languages) and organised [COVID-19 themed webinars](#) with topics covering the reorganisation of epilepsy departments in Italy and Spain and the use of antiepileptic drugs
- **ERN eUROGEN** provides advice to their patients, families and colleagues concerning COVID-19, passing information from DG SANTE, [Eurordis](#), the [European Association of Urology](#).
- **ERN-EYE** proposes a [page dedicated to COVID-19](#) on its website with general information, ERN-EYE members' statements and information about activity country by country.
- **ERN GUARD-HEART** published a scientific article on [“SARS-CoV-2, COVID-19 and inherited arrhythmia syndromes”](#).
- **ERNICA** issued a COVID-19 statement addressed to [patients with rare inherited congenital digestive \(and gastrointestinal\) disorders](#) and their families who may have concerns in relation to the Covid19.
- **ERN ITHACA** published on its website a [general advice regarding Coronavirus \(COVID-19\) for patients with rare genetic disorders](#).
- **ERKNet** launched a global [survey on children with COVID-19](#) infections while on immunosuppressive medication, to help assess the need to modify immunosuppressive therapies. This study is supported by the European, Asian and International Pediatric Nephrology Societies (ESPN, AsPNA and IPNA).
- **ERN LUNG** called all its members to share information on their [experience with COVID-19 in patients with a rare lung disease](#).
- **ERN RARE-LIVER** provides [guidance to rare liver patients](#) with reliable and trustworthy information on its website. It also launched a new R-LIVER COVID-19 Registry to collect data of adult and paediatric patients with rare liver disease and patients after liver transplantation with documented COVID-19 infection, to expand knowledge on the clinical features of the virus on rare liver disease patients.
- **ERN ReCONNET** created a section dedicated to Covid19 in the website which is regularly updated with the most relevant sources of information related to [Covid19 and rare and complex connective tissue diseases](#). ERN ReCONNET has also endorsed the Recommendations for patients suffering from Rheumatic Musculoskeletal Diseases published by the French Rare Autoimmune Network and is currently working on the translation of the document thanks to the commitment of the ERN ReCONNET patients' representatives. A webinar will be organised soon to answer specific questions on Covid19 and rare and complex connective tissue diseases.
- **ERN-RND** held a [webinar on "Huntington's disease and COVID-19 - a difficult combination"](#) on Monday 6 April 2020, together with the European Huntington's Disease Association (EHA). A multidisciplinary and multilanguage panel of Huntington's disease (HD) experts from all across Europe answered questions from HD patients and families, addressing specific risks for HD patients, update on consequences for the ongoing HD studies and trials and some advice on how to cope with this new situation. ERN-RND provides also a [list of official websites](#) containing up to date information on the COVID-19 pandemic which is available on ERN-RND's homepage.
- **ERN SKIN** provides advice to patients affected by [rare skin diseases and Covid19](#) on its dedicated webpage.

- **EURO-NMD** has developed two surveys to attempt to assess the impact of the COVID-19 pandemic on the neuromuscular community. The first survey collects basic anonymous information about those neuromuscular diseases patients who suspect they may have contracted COVID-19 in an attempt to identify any specific trends or patterns across the community. The second survey seeks to find out how different hospitals in different member states are adapting to the outbreak. In addition, the Network developed a [dedicated area on Covid19](#) on its website and continues to reach out to the wider community through its established communications channels.
- **MetabERN** published [Recommendations for all rare inherited metabolic diseases patients and caregivers](#) about treatment adherence during the COVID-19 emergency.
- **VASCERN** experts prepared [recommendations for the rare vascular disease community](#).