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April
2020

ERNs and Covid-19

DG SANTE's commitment to tackling Covid-19

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The ERN Board of Member States supports the Commission's Covid-19 Communication Support System

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How are ERNs supporting their patients affected by rare diseases during the COVID-19 pandemic?

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Interviews with key players

Interview with Inês Alves, patient representative in ERN BOND

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**Interview with Inés Hernando, ERN & Healthcare Director,
EURORDIS-Rare Diseases Europe**

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News from the ERN community

**Examination of membership applications for existing
ERNs suspended from 1 April 2020 to 31 August 2020**

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**Call for tender for the provision of an integrated
Assessment, Monitoring, Evaluation and Quality
Improvement System (AMEQUIS) for the European
Reference Networks:**

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**Commission launches “COVID-19 Clinical Management
Support System”**

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Call for tender to promote short term mobility and exchanges of healthcare professionals working in the ERNs

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Capacity building of the European Reference Networks to develop and adapt clinical decision-making tools addressing rare diseases: the ERN-Clinical Guidelines Programme

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Good practices and inspirational stories

Orphanet & ERNs: working together to produce, improve and share knowledge on rare diseases

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The European Joint Programme on Rare Diseases, an opportunity for the ERNs to leverage on research

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Study conducted by the European Brain Council on the value of early coordinated care for patients affected by rare neurological diseases

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ERN eUROGEN: how we use the Clinical Patient Management System (CPMS) to treat a newborn baby with a rare and complex condition requiring multidisciplinary care

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ERN-EYE educational video for healthcare professionals: how to welcome visually impaired people to the hospital?

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ERN-RND educational webinars in collaboration with ERN EURO-NMD and the European Academy of Neurology

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First Italian cross-ERN meeting: an initiative to strengthen coordination and help better integrate the ERNs into the Italian health system

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Citizen Science 2.0: Patient science for research into rare diseases, the experience of ERN-LUNG

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A patient journey for an esophageal atresia patient: the proposal of ERNICA

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ERN RARE-LIVER starts quality of life project

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First clinical guideline on craniofacial microsomia developed by ERN CRANIO

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Rare Disease Day 2020: the experience of ITHACA

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