



# European Reference Networks

for rare or low prevalence  
complex diseases

 **Network**  
Bone Disorders (ERN BOND)

## ERN BOND

*European Reference Network on rare BONE Diseases*



# Providing high-quality care remotely to patients with Rare Bone Diseases during COVID-19 pandemic

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*European Reference Network on rare BONE Diseases*



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# The Helpline initiative



Why a COVID-19 helpline for patients with rare diseases?

- total COVID-19 cases in Italy 226,000 (to date)
- based on population data, about 6-8% may have a rare disease



# The Helpline initiative



Healthcare professionals workers were at the forefront during this emergency.

Patients felt helpless and abandoned in the face of delays / cancellations of:

- medical visits,
- scheduled surgery,
- renewal of drug prescriptions.



# The Helpline initiative



Over 230 calls and messages asking for information and advice on:

- cardiopulmonary conditions
- orthopaedic problems
- drug interactions

Provided to:

- health workers
- patients





# The Helpline initiative



The experts involved in the helpline were health professionals (doctors, nurses, physiotherapist, etc.) with extensive experience in rare skeletal diseases.



Although social media and chats are most commonly used in offering remote care, a telephone line has allowed all patients to communicate directly, quickly and without any digital barrier (especially for older patients).

# The Helpline initiative



The service is:

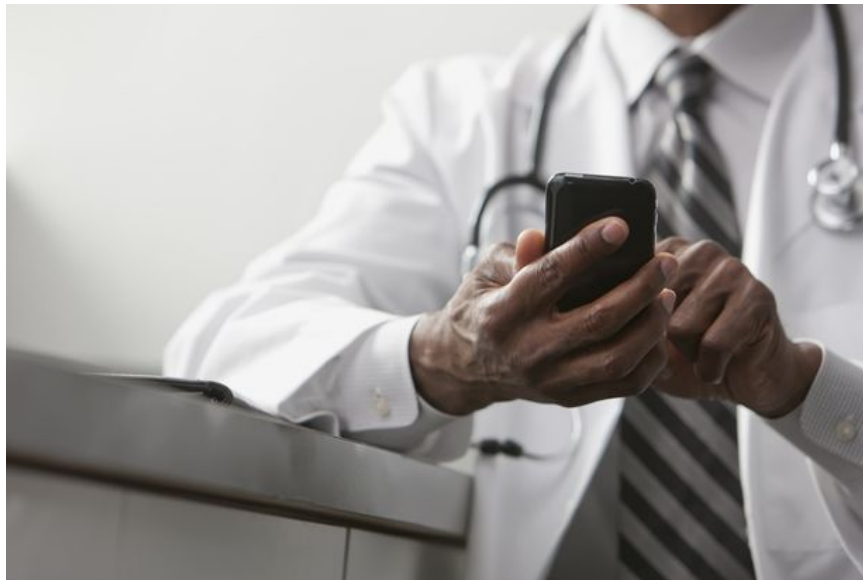
- **free**, with guaranteed access to all individuals of any socio-economic condition
- **provided 24/7** as the emergency cannot be scheduled
- **provided in Italian** in order to avoid any language barrier



# The Helpline initiative



In some cases, patients were followed remotely:



- checking daily developments
- supporting general practitioners in the decision to refer (or not) patients to the COVID-19 departments
- putting patients at home in contact with regional and / or local institutions





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**Thank you**

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