



EuRR-Bone

European Registry for Rare
Bone and Mineral conditions



European
Reference
Network

for rare or low prevalence
complex diseases

Network
Bone Disorders (ERN BOND)

EuRR-Bone

is the first registry for all
**Rare Bone and Mineral
Conditions** in collaboration
with **ERN**

BOND and **Endo-ERN**.

Together with EuRRECa,
EuRR-Bone aims to capture
clinical data from healthcare
professionals as well as the
needs and reported
outcomes of patients and
carers



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EuRR-Bone Structure

EuRR-Bone is composed of 5 Work
Packages and 5 Working Groups that in
synergy act to realize and implement the
Registry

WP1 - Management &
Coordination

WP2 - Access & Dissemination

WP3 - Evaluation & Quality
assessment

WP4 - Clinical Outcomes

WP5 - Patient Outcomes

VT1 - Core and e-REC

VT2 - Fibrous Dysplasia/McCune
Albright Syndrome

VT3 - Osteogenesis Imperfecta

VT4 - Rare Hypophosphatemia

VT5 - Achondroplasia

 @EuRRBone

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Endo-ERN

European Reference Network
on Rare Endocrine Conditions



EuRRECa
European Registries For
Rare Endocrine Conditions

