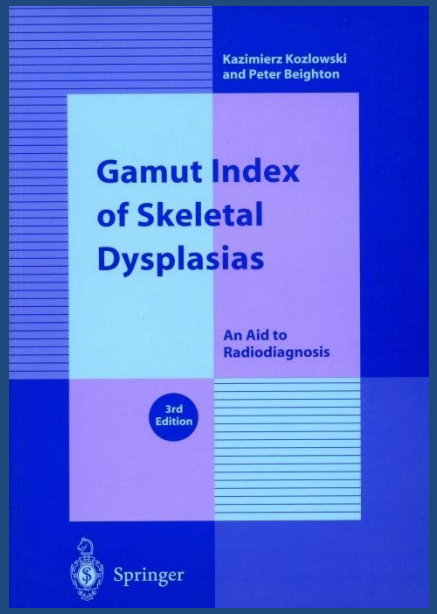
SRD: How Many?



Over 200 disorders

Generalized Skeletal Abnormalities

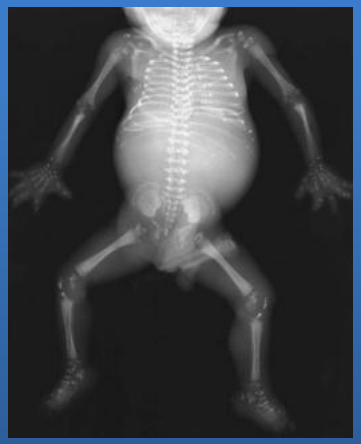
1.1	Osteoporosis
1.2	Multiple Fractures
1.3	Osteosclerosis and Hyperostosis
1.4	Periosteal Thickening and Periostitis
1.5	Exostoses
1.6	Multiple Radiolucent Defects
1.7	Advanced and Retarded Bone Age
1.8	Complex Generalised Abnormalities
1.9	Asymmetry
1.10	Multiple Dislocations
1.11	Soft Tissue Calcification
1.12	Skeletal Dysplasia in the Newborn
1.13	Premature Ageing Syndromes

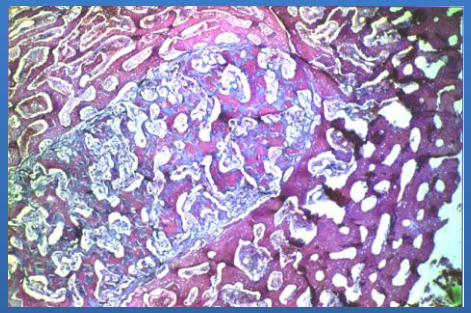
Over 1200 disorders

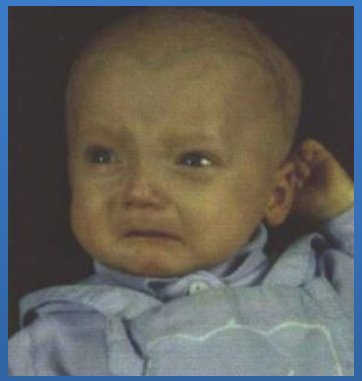
?

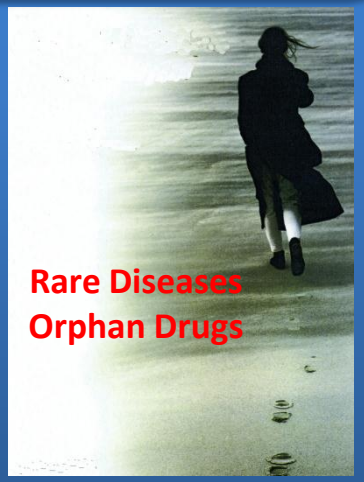
CSA-SRD Working Group

Research Action









CSA-SRD Working Group

OUR OBJECTIVES

- Mentoring and Knowledge-Sharing
- Networking Opportunities
- Develop Bone-Related Projects
- Initiate Advocacy Activities
- Integration of SRD Into Rare Community

CSA-SRD Working Group

PROJECTS 2011

- Website (Specific Databases, Narrative Medicine, Grants Infos)
- Atlas of Investigation and Diagnosis
- Guidelines (using also external collaborators)
- Identification of Centers of Excellence
- Thematic Report
- Rare Bone Diseases Day (Feb.28 for all rare disorders)

Bone health resources at your fingertips
www.bones.nih.gov

ZELFHULP OSTEOGENESIS IMPERFECTA VZW

Associazione Italiana Osteogenesi Imperfetta (Osteogenesis Imperfecta)

Fibrous Dysplasia FOUNDATION

UNIAMO
FEDERAZIONE ITALIANA MALATTIE RARE
ONLUS

AFBOI

BRITTLE BONE SOCIETY

Osteogénesis Imperfecta (OI)
una naturaleza frágil
Asociación de Huesos de Cristal de España

aoi
Association de l'Ostéogenèse Imparfaite
maladie des os de verre

Norsk forening for osteogenesis imperfecta

The Paget Foundation
For Paget's Disease of Bone and Related Disorders

Hypoparathyroidism
ASSOCIATION, INC.

OSTEOGENESIS
IMPERFECTA
OI
FOUNDATION

EGAN
Patients Network for Medical Research and Health

IGA
International Genetic Alliance

GEISER
FUNDACIÓN

OI
NETWORK-OI

N
RARE BONE DISEASE PATIENT NETWORK

madisons
FOUNDATION
MOMS AND DADS IN SEARCH
OF NEEDED SUPPORT

F.I.R.
M.O.
Onlus
FONDAZIONE RAFFAELLA BECAGLI

Bone and Joint
Initiative
USA

LGDA

Lymphangiomatosis & Gorham's Disease Alliance
To give hope and find help

Office of
Rare
Diseases

cure
treatment
care
Melorheostosis
ASSOCIATION

EURORDIS
Rare Diseases Europe

orphanet

REGIONE TOSCANA

Rete nazionale malattie rare

IL REGISTRO REGIONALE MALATTIE RARE DELLA TOSCANA

Centro di Coordinamento Malattie Rare dell'Osso

Direttore: Prof.ssa Maria Luisa Brandi

F.I.R.M.O.
Fondazione Raffaella Becagli

OsteoRare www.osteorare.fondazionefirmo.com

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