

## EMERGENCY CARD

*The emergency card is a personal and nominative card containing the main health information related to the patient's rare disease.*

It is specific to a given rare disease and allows for appropriate management and treatment to be provided during emergency care. Patients should keep their emergency card with them at all times to ensure that anyone providing care for them has all the information and recommendations required for an emergency situation.

This card has been filled in by the doctor responsible for the patient's care and follow-up.

We offer you this English translation of your emergency card to take with you and use when traveling abroad.

## OSTEOPETROSIS

### CLASSIC SYMPTOMS OF THE DISEASE

- Skeletal : dense and diffuse appearance of the skeleton (long bones, skull, spine), deformities of the long bones with medullary canal obliteration, mandibular osteomyelitis, frequent fractures, chronic bone pain, arthropathies (coxa vara)
- Extra-skeletal : rare compression of the cranial nerves (blindness, deafness), growth retardation, anemia, infections

### INFORMATION ABOUT THE DISEASE

#### Type of osteopetrosis :

- Autosomal recessive (severe form)
- Autosomal dominant (adult form)
- Other/ not specified

### COMPLICATIONS

- Atypical bone fractures
- Bone marrow involvement (anemia, thrombopenia)
- Neurological issues (blindness, deafness)
- Bone infections
- Other : .....

### RECOMMENDATIONS IN CASE OF EMERGENCY

#### In case of trauma

- Mobilization must be cautious in all circumstances
- Immobilize the limb concerned (cast, splint)
- Administer appropriate analgesics (morphine derivatives if needed), after the establishment of an IV approach
- Carry out an imaging assessment (standard X-rays, CT) by mobilizing the patient with caution
- Do a preoperative assessment (ionogram, CBC-platelets, blood group, hemostasis)
- Contact patient's referring surgeon or the nearest Reference Center for Constitutional Bone Diseases (MOC) for advice
- A surgery can be performed on site after consultation with the referring surgeon or in a Reference Center after rapid transfer