

EMERGENCY CARD

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

Consult the PNDS :
(French Diagnostic and Care Guidelines)



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.

FIBROUS DYSPLASIA OF BONE

CLASSIC ELEMENTS OF THE DISORDER

Fibrous dysplasia of bone is characterized by a single lesion (monostotic form) or multiple lesions (polyostotic form) which generally manifest as:

- Bone pain
- Deformities
- Fractures

Sometimes associated with: McCune-Albright syndrome, characterized by the triad of:

- Café au lait skin stains
- Fibrous dysplasia of bone
- Endocrinopathies (most often precocious puberty)

HIGH-RISK LOCATIONS

(tick the corresponding boxes if the complication is known)

- Cervical spine (caution to be taken during general anesthesia)
- Base of the skull

EMERGENCY SITUATIONS

Acute pain

- Radiographic imaging of the painful area, to be supplemented with a CT scan in order to eliminate a fissure/fracture; analgesics tailored to the visual analog scale; immobilization; intravenous anti-inflammatory drugs, if necessary and in the absence of contraindication.
- No bisphosphonates in an emergency situation, to be discussed with the reference center.

Fractures

- Radiographic imaging of the painful area, to be supplemented by a CT scan in order to evaluate the condition of the bone around the fracture; preoperative assessment; analgesics tailored to the visual analog scale; immobilize with splint; orthopedic advice in conjunction with the reference center

Visual disturbances :

seek emergency ophthalmological opinion

(Search for optic neuropathy)

- Emergency brain MRI with slices of the optic nerves; analgesics tailored to the visual analog scale
- If optic neuropathy is confirmed: corticosteroid therapy (1mg/kg)
- No indication for emergency surgery: any decision to operate on the optic canals must be discussed with specialists of the disease due to the risk of post-operative blindness.