

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.

HYPOPHOSPHATASIA

MANIFESTATIONS OF THE DISEASE

- **Perinatal presentation** : impaired skeletal mineralization, respiratory insufficiency, large anterior fontanelle, hypotonia, seizures
- **Infants** : hypotonia, feeding difficulties, bone deformities, bronchopulmonary infections
- **Children** : bone hypomineralization, metaphyseal and diaphyseal fractures
- **Adults (including pediatric forms that have progressed into adulthood)** : osteomalacia with fractures, chondrocalcinosis, ectopic calcification/ossification
- **All ages** : dental anomalies, muscle fatigue/weakness, pain, hypercalcemia (more rare in adults) +/- renal lithiasis, +/- nephrocalcinosis

ACUTE COMPLICATIONS

- Fractures, including atypical fractures, delayed healing pseudarthrosis (regardless of age)
- Malaise, seizures (infants)
- Symptomatic hypercalcemia
- Acute respiratory distress
- Craniosynostosis with intracranial hypertension
- Kidney stones

EMERGENCY SITUATIONS

- Seizures
- Malaise
- Respiratory distress (early onset forms)
- Fractures
- Hypercalcemia

EMERGENCY RECOMMENDATIONS

Infantile forms

- **Malaise/feeling unwell** : Look for hypercalcemia and/or B6-dependent seizures
- **Seizures** : Standard treatment plus the addition of 100 mg of vitamin B6 (pyridoxine chlorhydrate) administered intravenously over 20 minutes, then 50 to 100 mg administered intravenously over a period of 20 minutes once daily.
- **Respiratory insufficiency** : respiratory assistance, possible ventilation difficulties
- **Hypercalcemia** : IV infusion for hydration without calcium; **AVOID bisphosphonates**

Infantile forms

- **Fractures**: Analgesics and light immobilization; orthopedic consultation in collaboration with the center where the patient is being followed. No contraindications to analgesics
- **Kidney stone**: analgesics and antispasmodics