

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.

ISOLATED KLIPPEL-FEIL SYNDROME

Complete neurological examination (Cranial nerves, muscle tone, pyramidal tracts, sensory and motor pathways)
Risk of difficult intubation

POSSIBLE MANIFESTATIONS OF THE DISEASE

(Tick the corresponding boxes which apply to the patient)

- Congenital fusion(s) of vertebrae (predominantly cervical)
- Torticollis, limited neck movement
- Scoliosis
- Chronic headaches
- Cervical and cranial neuralgias (occipital neuralgia, trigeminal neuralgia ...)
- Spinal cord or nerve root compression, cervicobrachial neuralgia...
- Cranial nerve anomalies (extraocular movements)
- Muscular pain, cervical contracture, amyotrophy
- Rarely: Abnormal movements

SOMETIMES ASSOCIATED

- Cleft palate
- Ophthalmologic anomalies
- Hearing impairment
- Cardiac malformations
- Lung malformations
- Renal malformations

EMERGENCY SITUATIONS

If anesthesia is required

- Airway assessment (possible intubation difficulties)
- Intubation under vigilant fiber-optic control is preferred
- Very cautious general anesthesia in emergency situations, or after specific assessment for a scheduled intervention

In case of trauma

- Complete neurological examination in case of trauma
- Eliminate spinal cord compression (using imaging techniques)

AVOID

- Neck manipulation/forced cervical mobilization

RECOMMENDED

- Cervical collar in case of neuralgia or migraines
- Muscle pain can be alleviated by heat.