

**EMERGENCY CONTACTS**

Name: ..... Phone: .....

Name: ..... Phone: .....

**MEDICAL CONTACTS**

Name (GP/pediatrician): ..... Phone: .....

Name (specialist): ..... Phone: .....

Rare disease reference center: ..... Phone: .....



www.ern-skin.eu

**RARE DISEASE  
Emergency card**

Patient

photo

**Inherited epidermolysis bullosa**

Family name: .....

Date of birth: .....



**CAUTION! My skin is extremely FRAGILE**

### **Epidermolysis bullosa (EB)**

EB is a rare genetic skin disease characterized by fragile skin and body linings (mucosae). Minimal trauma (friction or knocks) leads to blistering of the skin and mucosal surfaces leading to erosions and wounds. As a result, there is an increased susceptibility to infections. Pain is constant and exacerbated by procedures. Itch can also be a significant problem. There may be extracutaneous complications which may result in nutritional impairment, swallowing problems, airway narrowing, anemia, poor bone health, renal impairment, dental problems, eye complications and an increased risk of sepsis. Most emergency procedures can be performed but specific precautions must be taken. Analgesic and anxiolytic drugs can be administered.

### **Procedures to AVOID:**

- Never slide me to transfer: use a 'lift and place' approach
- Avoid sticky dressings and tapes wherever possible
- Avoid skin rubbing
- Avoid friction when handling or (un)dressing me

### **Recommended care measures:**

- Listen to me/my care givers; we know about EB
- Remove sticky dressings with a silicone-based spray or, if not available, by soaking them with water
- Dab, don't rub, my skin when cleansing it
- Lubricate all devices (thermometers, catheters, tubes, etc.), and use the smallest effective size for catheters and tubes
- Pad trauma-prone sites (e.g. before applying blood pressure cuff)
- Use lubricated clip sensors for pulse oximetry
- Remove adhesives from electrocardiogram pads and secure with a non-adhesive dressing
- Lance my blisters using a finger prick lancet or a hypodermic needle, and gently drain without removing the blister roof