

EMERGENCY CARD

Contact information



World Duchenne Organization

For families and HCPs

In an emergency situation take with you:

- » emergency card
- » medicines
- » ventilation machine and Cough Assist
- » instantly inform your Neuromuscular Team

Remember Stress Dose if:

- » unable to take steroids in orally (vomiting, diarrhea)
- » any stress situation (fracture, severe inflammation, surgery)
- » offer your doctor PJ Nicholoff protocol (also after admission)

Watch out for oxygenotherapy – emphasize the need to use an ambubag.

In case of a fall/fracture: watch out for signs of Fat Embolism Syndrome:

- » difficulty breathing
- » pain in your chest or head
- » a change in your behavior, like confusion, dizziness or not acting like yourself

This is an emergency, contact your doctor.

For health care professionals

Duchenne Muscular Dystrophy

Elevated risk for:

- » Fat Embolism Syndrome (also with small fractures)
- » hypercapnia (avoid oxygen alone, provide ventilation support f.e. ambubag)
- » ventilation (BiPap) may be needed
- » adrenal crisis (when using corticosteroids, stress dose is required)
- » rhabdomyolysis (avoid suxamethonium, avoid inhaled anaesthetics and neuro-muscular blocking drugs)
- » ketoacidose (fasting is a serious risk)
- » aspiration (avoid laying patient flat if breathing is compromised)
- » changing cardiac medication is a risk (hypotension is common)

For more medical information:

