

RESPIRATORY CARE:

- **Risk: Respiratory failure.** Do not give oxygen without checking end-tidal or blood CO₂ level. A low hemoglobin saturation may indicate CO₂ retention and a need for positive pressure ventilation. **IF** supplemental oxygen is given, please monitor CO₂. Non-invasive ventilation may be required.
- Assisted coughing helps to clear sputum & mucus plugs. Use the Cough Assist machine (Respironics) if available. If not available, an AMBU bag may be used.

CHILD'S MAIN DOCTOR / PHONE NUMBER

Emergency Information Card
For Parents of Boys with Duchenne

Parent Project
Muscular Dystrophy

LEG FRACTURE TREATMENT:

- If your son was able to walk well before his leg fracture, ask the doctor: "Can my son have surgery (internal fixation) rather than casting (external fixation)?" Surgery should help preserve muscle and allow your son to walk sooner than casting.
- If your son is breathing rapidly and/or if he has neurologic deterioration (like confusion) after a fracture or body trauma, doctors should consider fat embolism syndrome.

RECOMENDATIONS AND PRECAUTIONS:

- Keep all of your son's immunizations up to date.
- Do not use live vaccines if your son is taking corticosteroids.
- Always wear seat belts!

ANAESTHETIC PRECAUTIONS:

- All general anaesthetics should be given by intravenous route (IV) only. Do not use inhaled anesthetics on your son.
- Local anaesthetics and Nitrous Oxide are safe for minor dental procedures for your son.

IF YOUR SON IS VOMITING AND/OR UNABLE TO TAKE CORTICOSTEROIDS FOR 24 HOURS:

- Take him to a hospital emergency department.
- Tell staff that he needs a substitute corticosteroid by IV until he can take his pills by mouth again. Show hospital staff this conversion: **6 mg of deflazacort equals 5 mg of prednisone.**
- Remind hospital staff: "If my son has blood tests, his AST/ALT (liver enzymes) will be high. That is **normal** for boys with Duchenne."