



## Duchenne Muscular Dystrophy Steroid Management Plan

Name:

Date of birth:

NHI:

Date:

Your child has been placed on a corticosteroid medication (“steroids”). These pharmacological steroids include prednisone, prednisolone and deflazacort.

The body produces a small amount of natural steroid (cortisol) every day, from two small glands called the adrenal glands. In times of physiological stress, such as illness or a serious accident, the adrenal glands produce an increased amount of natural steroid to help the body cope.

When someone is taking pharmacological steroids, this replaces the natural steroid, and the adrenal glands stop their steroid production. For this reason, **it is important your child does not stop taking their prescribed steroid** suddenly, particularly when sick. They could become very unwell – a condition known as an adrenal crisis (low blood sugar, low blood pressure, unwell).

The following guidelines will help you and your doctor know when your child requires additional doses of steroids.

- Boys with Duchenne muscular dystrophy receive high dose steroids long term. The dose is much higher than physiological doses and is adequate as a “stress” dose.
- **Most important to remember, is that your child should not stop taking their steroids, particularly when unwell.**
- If your child is not able to tolerate oral steroids, for example, because of vomiting, you should see a doctor *urgently* for replacement with intravenous or intramuscular steroids.
- If you live or holiday remotely, talk to your doctor about having an emergency supply of intramuscular hydrocortisone, which you could administer if your child is severely unwell and there is likely to be a delay seeking medical review.

### If your child is mildly unwell

*I.e. Respiratory or ear infection, no fever, no vomiting or diarrhoea, and looks well*

- Continue normal maintenance doses of steroids
- For my child: \_\_\_\_\_

### If your child is moderately unwell

*Stable with fever, and reduced activity and able to tolerate oral steroids.*

- Continue regular steroid medication.
- If your child vomits within 30 minutes of taking their steroid, give it to them again.



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- If not able to tolerate oral fluids refer to “Severely Unwell” below.
- Speak to your doctor about having a supply of anti-vomiting medicine.

### If your child is severely unwell

*Unwell with vomiting, diarrhea (greater than 2 watery bowel motions), drowsy) or unable to tolerate oral steroids*

- **You need to take your child to hospital urgently**
- Your doctor can refer to guidelines available on the Starship Website, or speak to a paediatric endocrinologist for further advice if unsure.
  - Bolus IV fluids 10-30ml/kg 0.9% saline, then maintenance 0.9% saline + 5% glucose
  - Start IV steroids
  - Bolus – hydrocortisone: 75-100mg/m<sup>2</sup> IV (or IM) – then
  - Infusion – hydrocortisone 50-100mg/m<sup>2</sup>/day until stable
  - Body surface area  $\sqrt{(\text{height (cm)} \times \text{weight (kg)})/3600}$  or use a BSA calculator. The following table gives rapid estimates of hydrocortisone dose if weight and BSA are not available

| <b>Age</b> | <b>Initial bolus of hydrocortisone succinate (IM or IV)</b> |
|------------|---|
| 5-10 years | 50 mg   |
| >10 years  | 100 mg  |

### Elective surgical procedures

For simple elective procedures:

- Continue your regular oral steroid, prior to the Nil by Mouth period.
- For prolonged procedures, intraoperative intravenous steroid may be required – refer to Starship Clinical Guidelines

### Additional points

- **Do not stop taking steroids**
- You should always seek medical advice early, so that the underlying cause of illness can be established and any necessary treatment started.
- If your child cannot tolerate oral steroid, this needs to be given intravenously or by intramuscular injection.
- Always carry a letter and tell any doctors you visit that your child takes high dose steroids and should have steroids for **severe illnesses** or for **anaesthetics**.
- Remember an extra dose of steroid cannot cause any harm BUT missing the dose in an unwell child can be dangerous.
- Influenza vaccine is recommended to prevent illness