

## WHY THIS INFORMATION MATTERS

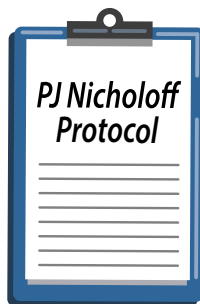
If you or your child is living with Duchenne or Becker muscular dystrophy and taking steroids (such as prednisone, prednisolone, Emlaza (deflazacort), or Agamree (vamorolone)), it is important to understand the risks, symptoms & management of adrenal insufficiency.

While steroids help manage Duchenne and Becker muscular dystrophy, taking for more than 2 weeks can affect the body's ability to make its own stress hormone (cortisol), resulting in adrenal insufficiency. Cortisol is essential during times of physiologic stress like fever, illness, injuries, or surgery. If the body can't produce enough cortisol, it can lead to a dangerous condition called adrenal crisis, which is a medical emergency.



This guide, based on 6 critical concepts outlined in the PJ Nicholoff Steroid Protocol, will help you recognize warning signs and stay safe during:

- Times of increased stress on the body
- Reducing or stopping steroids
- Switching from one medication to another



## KEY TAKEAWAYS

### Steroid Safety is Lifesaving

- Long-term steroids can affect your body's ability to respond to stress.
- You need a clear stress dosing plan and emergency steroid supply.
- Vamorolone (Agamree) cannot be used to stress dose
- Know the signs of adrenal insufficiency and act quickly.
- Never stop steroids suddenly—always taper with your doctor's guidance.

## FOR MORE INFORMATION ON THE PJ NICHOLOFF STEROID PROTOCOL:

VISIT

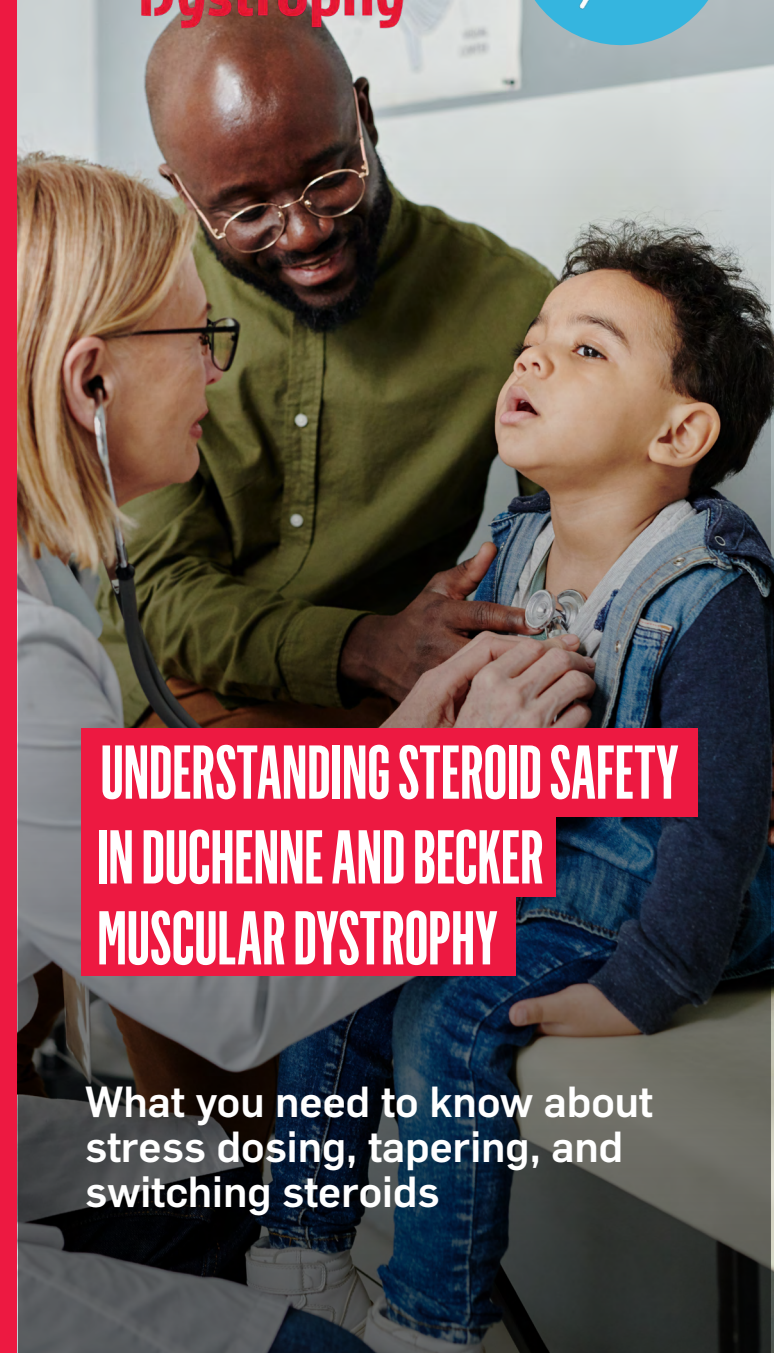
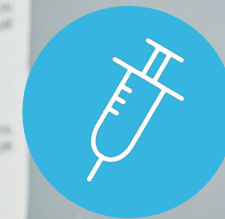
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Project END DUCHENNE.  
Muscular  
Dystrophy

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UNDERSTANDING STEROID SAFETY  
IN DUCHENNE AND BECKER  
MUSCULAR DYSTROPHY

What you need to know about  
stress dosing, tapering, and  
switching steroids

## WARNING SIGNS: HOW TO RECOGNIZE ADRENAL INSUFFICIENCY

Anyone taking steroids—or caring for someone who is—should know the signs of adrenal insufficiency, especially during or after illness or injury

### Symptoms may include:

- Tiredness or weakness
- Low blood sugar
- Nausea or vomiting
- Headache
- Loss of appetite
- Fever
- Abdominal pain
- Fast or slow heart rate
- Muscle aches
- Confusion or disorientation

## IMPORTANT

These symptoms can also happen during steroid “withdrawal” or while adjusting steroid doses. Adrenal withdrawal is different from adrenal insufficiency. The symptoms of adrenal withdrawal may look the same as adrenal insufficiency, but they are not life threatening.

## CHANGING STEROID MEDICATIONS

Switching from one steroid to another must be done carefully with help from your medical team. An endocrinologist may be involved to help guide this safely.



## WHY YOU NEED A STRESS DOSING PLAN

Everyone on long-term steroids must have a stress dosing plan. This plan explains how to give extra steroid medicine when the body is under stress (from illness, injury, or surgery).

### A plan should be in place:

- Before or as soon as steroids are started
- For both home and hospital situations
- For moderate (like a fever) and severe (like surgery) stress

### Make sure to:

- Wear a medical ID bracelet or necklace that says “steroid dependent”
- Carry a wallet card (paper or digital) with stress dosing instructions
- Share the plan with all medical providers, especially in emergencies

When stress dosing is needed, follow your care team’s instructions or refer to the PJ Nicholoff Steroid Protocol.



## HOW TO SAFELY LOWER OR STOP STEROIDS

Steroids must never be stopped suddenly. The dose should be slowly reduced (called a taper) under the guidance of your neuromuscular team to prevent adrenal withdrawal, adrenal insufficiency, or adrenal crisis. Even during a taper, the body might still not make enough cortisol—so stress doses are still needed during illness or injury.



**Until your doctor confirms full recovery of the adrenal system, you will need:**

- A supply of emergency steroid medications (like oral prednisone/prednisolone or oral or injectable hydrocortisone)
- A clear stress dosing plan
- Ongoing follow-up with your neuromuscular and possibly endocrine care team

Recovery of adrenal function can take 6 to 12 months or longer.