

# A Parents Guide to Oral Steroids

*Hemangiomas will vary and require different courses of action and management. Your treating physician has prescribed an oral steroid or has recommended this course of treatment; the following information may help you prepare for this type of treatment. Written by Corinne Barinaga: Vascular Birthmark Foundation Administrative Director, Vascular Birthmark Support Group Manager. Edited by Dr. Gregory Levitin of the Vascular Birthmark Institute of New York.*

## **A Systemic glucocorticoid steroid**

Brand name/generic: Orapred, Pediapred, Prelone, Prednisone or Prednesilone

**Why are they being used:** A vascular birthmark specialist has prescribed oral steroids to control the growth of an infantile Hemangioma. Specialists often recommend the use of oral steroids for cases with ocular complications, airway complications, risk to vital organs, or rapid growth causing significant distortion of anatomic structures. Oral steroids are only effective during the proliferative phase of hemangioma growth.

## **Dosage, weaning and rebound growth:**

- Typical dosing varies between 2 to 4 mg/kg/day and should be determined by the treating physician
- Assessment of response should be made within 1 to 2 weeks of starting oral steroids by treating physician, and dosage may need to be increased if continued growth is still noted
- Continued monitoring by treating physician should occur throughout use of steroids
- After an initial sustained dosage level, patients must be weaned slowly off oral steroids; steroids should not be stopped abruptly
- Consult your treating physician before changing dosages.
- Follow dose schedule and advice on administering from your treating physician
- Rebound growth can occur if the steroids are weaned too quickly during the proliferation phase and may require longer periods of treatment
- If rebound growth occurs during the weaning process, the hemangioma may respond to a slightly higher dose strength which should be determined by the treating physician.
- Up to 10% rebound growth is common during the weaning process, and usually doesn't warrant increased dosing.
- Continue use of Zantac (or equivalent GI prohylaxis) throughout the entire weaning process
- Results are typically seen within 2-4 weeks, but can be within days of initial administering of treatment
- Alternate day therapy during weaning process may be an option.

## **What a medical professional should monitor:**

- Changes in the lesion, growth/involution
- Hypertension (elevated blood pressure)
- Eye pressure if on more than 6 weeks (Glaucoma/cataracts)
- Secondary or opportunistic infections
- Immune system response
- Salt and water retention
- Potassium levels
- Hypertrophic cardiomyopathy risk in premature infants
- Bone or muscle weakness
- Abdominal distention/gastro-intestinal complications
- Development/growth
- Wound healing impairment
- Skin abnormalities/discolorations

This information should not be construed as medical advice, but rather a guide in asking your treating physician for more information. Advice on managing the side effects comes from parents that have had children on oral steroids. The parents are all members of the MSN Vascular Birthmark Support Group which serves as a support system for vascular birthmarks. Although many members are very knowledgeable about various treatment options, we are not medical professionals. Please check with your doctor or a medical professional for treatment and diagnosis, etc.

- Other medical concerns

#### What to watch for, contact physician about

- Fever 101F or above needs immediate medical attention for possible stress dose\*\*\*
- Exposure to chicken pox while on oral steroids
- Other inactive vaccines can be given; however, the response to such vaccines can't be predicted.
- Inform your doctor if your child has heart disease, kidney disease, liver disease, lung disease or any other medical concern/drug/food allergies.
- Inform doctor before starting any new drug or nutritional supplement
- Signs of systemic infections (ie respiratory tract infections, ear infections, etc.)
- Signs of local infections (ie ulceration, yellow or foul discharge, surrounding erythema, etc.)
- Shortness of breath,pain
- Lethargy or change in mental status
- Change in heart rate/rhythm
- Extreme/persistent fatigue
- Unexplained bleeding/bruising
- Irregular stool, color texture
- Persistent vomiting
- Seizures
- Change in vision/eye abnormalities
- Rashes or discoloration of skin
- Wounds that will not heal
- Frequent urination, severe thirst, confusion, or abnormal drowsiness

#### Avoid:

- Live vaccines until off steroids for one month
- Exposure to Varicella (chicken pox) \*\*
- Minimize exposure to others with a recent history of viral or bacterial infections
- Laser treatments on large segmental hemangiomas while on initial high doses

#### Common short-term side effects

- Irritability
- Impaired wound healing
- Appetite change. Increase or decrease in appetite
- Weight gain/loss
- Round full face
- Reflux/gastro-intestinal irritation\*\*\*\*
- Sleep pattern changes, insomnia
- Blood pressure elevation at higher doses
- Swelling of ankles and feet

#### Less common short-term side effects:

- Decreased head growth
- Intraocular pressure increase
- Increased excretion of potassium
- Elevated blood sugar levels
- Salt and water retention
- Nausea
- Increased sweating
- Thin fragile skin
- Severe gastro-intestinal irritation/ulcers \*\*\*\*
- Decrease in carbohydrate tolerance
- Negative nitrogen balance due to protein catabolism
- Headaches/dizziness

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- Adrenal suppression \*
- Premature Thelarche- breast growth

#### Possible long term side effects:

- Cataracts, glaucoma with long term use
- Delayed motor milestones (*however, most children quickly “catch up” once treatment is completed*)
- Reduction of bone density with long term use
- Hirsutism- abnormal hair growth

#### Managing side effects: Advice from other parents

- Follow physician’s instructions
- Proper nutrition and rest
- Minimize sun exposure
- Drink plenty of fluids
- Smaller meals more often to help with nausea
- Elevate head/crib to help with reflux
- Add dose to drink/food
- Use prescription of Zantac (or equivalent) prior to administration of steroid
- Use syringe vs. spoon or dropper to bypass taste buds and to help minimize amount spit out.
- Soothing techniques to help with irritability: baths, music, rocking, swings, etc.
- Practice good sanitary health, washing hands frequently
- Minimize exposure to viruses
- Seek permission from treating physician prior to splitting up dosages to minimize vomiting. ++

#### Ask the Doctor:

- Handouts to educate you on the toxicity risks
- Dosing procedures and schedule
- Gastrointestinal protective medication prescription (Zantac)
- Weaning schedule, possible alternate day therapy
- What to watch for and how to contact the physician with concerns
- Appointment schedule for monitoring
- Advice on managing side effects
- With frequent vomiting, options for alternate dosing schedule++
- What to avoid
- Should my child be on any vitamin supplements or have Synagis vaccine?
- Should my child be tested for the effectiveness of the immunizations given while on steroids?
- Should my child be monitored by a Hematologist/oncologist (for high dose/prolonged use cases)?
- Should I avoid giving my child any anti-inflammatory medications (Advil/Motrin) while on steroids?

#### Definitions:

\* Adrenal Suppression: condition in which the HPA axis suppresses the secretion of cortisol by the adrenal glands. Can lead to electrolyte imbalance, suppression of the immune system and Cushing’s syndrome. [www.sdrpharma.com/sj.htm](http://www.sdrpharma.com/sj.htm)

\*\* Exposure to Varicella (chicken pox) should have immediate medical attention. Other adults and children in contact with patient should be immunized or have had the virus.

\*\*\* Stress dose of steroids; Addison’s disease: Addison’s disease is an endocrine or hormonal disorder. Characterized by weight loss, muscle weakness, fatigue, low blood pressure, and sometimes darkening of the skin in both exposed and non-exposed parts of the body. Occurs when the adrenal glands do not produce enough of the cortisol hormone and possibly aldosterone. Also known as adrenal insufficiency, or hypocortisolism.

\*\*\*\* Prescription for Zantac or equivalent GI prohylaxis product to protect stomach from ulcers and reflux/gastro-intestinal irritation

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++Advice from: Hochman, Adams, Williams, Nagy, Brodsky Facial Plastic Surgery Clinics of North America, on ideal dosing schedule: Initial highest dose 4-6 weeks, taper duration to follow at 4-6 weeks. Administer dose as a single dose in the morning, this lessens the alteration of hypothalamic-pituitary -adrenal function that occurs several days after therapy.

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