

QUESTIONS TO ASK YOUR DOCTOR

At the Jack McGovern Coats' Disease Foundation, we are often contacted by anxious parents or patients who are seeking information after receiving a diagnosis of Coats' Disease. The questions below are provided as a resource to assist you as you and your doctor decide the best approach for treatment. These questions do not constitute any form of medical advice or diagnosis. Each patient is unique. An experienced retinal specialist who has examined the patient is the best source of information for diagnosis and treatment. We always recommend getting a second opinion. To identify an Ophthalmologist with experience in treating Coats' Disease, visit our web page at www.coatsdiseasefoundation.org/coats-disease/find-a-doctor/.

BEFORE YOU BEGIN

Ahead of any treatments or procedures, it is important to ask yourself and the doctor the following questions:

- How do you know that this is Coats' Disease?
- Has your doctor treated other patients with Coats' Disease?
- Have you sought a second opinion? If not, please consult our Doctor Directory for knowledgeable doctors in your area. (see link above)

COATS' DISEASE QUESTIONS TO ASK YOUR DOCTOR

1. What Stage of Coats' Disease is he/she in?

- Will his/her vision get worse over time?
- Will the eye have pain?
- Will his/her eye start to turn out? Is muscle corrective surgery an option?
- Are cataracts likely?
- How likely is glaucoma? (due to retinal detachment)
- Is there calcification?
- What is the anticipated disease progression?

2. Is there a thorough vision exam available?

- Where is the vision affected? (central /peripheral/ distance)
- Does he /she have depth perception? (3D visibility)
- What about the non-Coats' eye?
- To what extent is his / her vision affected?
- Will we be able to use this as a baseline to measure progress/decline?

3. If there is a retinal detachment:

- What percent is the retina detached?
- Will it continue to detach?
- How quickly can it detach?
- Can you treat with laser or freezing treatments (also known as cryotherapy)?
- Is reattachment surgery advised?
- What are the risks associated with reattachment surgery? (i.e. further vision loss/re-detachment/success rate?)
- Will you be doing retinal mapping to compare progress with laser/cryotherapy?

4. Is laser/cryotherapy always successful?

- What are the risks with scarring?
- What about alternatives such as Avastin / Lucentis, which can help prevent new blood vessel growth?
- Is there a risk when using these anti-VEGF's to the rest of the body?

5. Is shrinking of the eye something to watch?

- What about pain in the eye – is that something to be anticipated? If so, would that indicate a need for removal of the eye (enucleation)?
- What is the difference between eye pain and an eye ache?

6. In his/her Non-Coats' eye, what will you be looking for?

If this isn't Coats' now, can we be confident it won't be in the future?

7. What are the cutting edge treatments on the horizon?

- Scleral shell to cover cataract or turning eye? Retinal Chip? Orbital eye implants? Stem cells to regenerate retinal tissue?

8. What is his / her IOP (Intraocular Pressure)?

- 12-18=normal, under 9 and over 20 a concern?
- What can affect his IOP?
- How can I tell if his IOP is changing?
- What drops are recommended at that point? (Cosopt/Atropine/Iopidine/Generic)?

9. Do you recommend glasses or protective eyewear to prevent injury to his/her non-Coats' eye?

- Polycarbonate Lens glasses? Tinted glasses?
- How often should he/she wear them?
- Should we restrict any sports or activities? Swimming after an EUA (exam under anesthesia)?

10. School recommendations?

- Educate staff and other kids/PE & recess?
- Where is the best place to sit in the classroom?

11. Are there vitamins specifically for the eye?

- What are the benefits of patching therapy and what the intent of patching? Vision therapy?

12. Should both eyes be dilated at each visit? Why?

- Dilating the pupils – how long does it last?
- Will the yellow glow in pictures go away with treatment?

13. What other doctors / specialists do you work with?

- Could his / her Coats' Disease be a symptom of another disorder? (FSHD, FEVR, Retinoblastoma)
- What resources do you have available for newly diagnosed patients/parents?

14. At what age do you stop doing EUA (exam under anesthesia)?

- What is the purpose of an EUA and what can be done during that time?