

Caregiver/Nanny Tip Sheet (Shared by the Mom of 1 year old boy with CG)

The below is a set of useful tips that we have provided to our son caregiver for the treatment and management of his congenital glaucoma, including a daily check for medications and changes to watch for in his eyes.

- Eye Colour – as this was the first thing that we noticed when our son was diagnosed with congenital glaucoma, so we have asked our nanny to look out for variations in our son's eye colour.
- Eye cloudiness – the easiest way we can describe this is a change in the definition or "less bits" in the iris.
- Bulging of the eye – look out for any increase in the eye size (this is obviously easier if the pressure varies between the two eyes, or the glaucoma is more pronounced or only occurring in one eye).
- Irritability or moodiness – although hard to use as the only indicator in a baby or toddler, until our son can tell us when his eyes are giving him a headache, his mood is another indicator that the pressure is up in one or both of his eyes. We have often realised that our son's pressure has been up for a number of days by taking note of the three indicators above, and then note that he has been quite irritable and cranky until he has received an oral dose of dimox or pressure reduction eye drops such as Cosopt.
- Weeping eye(s) in direct sunlight

Daily Medications Checklist - we provide our nanny with a daily eye drop checklist & any additional medications (dimox if he is on an oral dose). This checklist ensures that it is clear with handover what medications and eye drops have been given, & prevents a double dose or missing a dose.

Other handy tips:

- If in doubt, call or take your child to the ophthalmologist. We have been very lucky to have an excellent ophthalmologist who has given us his mobile to call at any time, however, if you do not have a direct number and it is outside of hours I would recommend taking your child to your local emergency children's hospital. A parent knows their child better than any health care professional, and if you think the pressure is up in your baby or child's eyes then the sooner you can receive medical advice and pressure reduction treatment the better both you and your child will be.
- Photo's over time help – we received advice from a maternal health nurse early on in our son's treatment, to take a photo of our son's eyes every day to watch for changes in their size. Although we have not taken a photo every day, we take regular close up shots of his face to see variations in his eye size every week. Although this is not a formal or accurate measure (the only accurate measure we know of is by the surgeon measuring his eye ball size whilst under anaesthetic, or ultrasound), it helps us track whether his eyes are looking bulgy or one is looking bigger than the other.
- Trust your assessment of your child's eyes. When we initially sought medical advice for our son's eye at our local GP clinic (prior to his diagnosis with CG) the Doctor could not see the difference between his two eyes, however, my husband and I could see that they were different and that one looked a little cloudy and bulgy, and as we were adamant that there was something wrong the GP referred us to the emergency department at our local Childrens Hospital. As a parent, you look at your child's face every day and notice small changes that someone else would not notice, and this helps as you continue to manage your child's glaucoma.
- See help from family and friends – looking after a child through surgeries and medical treatment can be emotionally and physically draining (I type this as I prepare for my son's post trabeculectomy EUA tomorrow, and his 9th general anaesthetic), so ask for help from your friends and family if you can.