

We first started using cysteamine eye drops when our eldest son was 3yrs, 5mths old. He was quite photophobic by then and would sometimes even look to wear sunglasses indoors when the room was very bright. We very diligently administered eye drops in his eyes every waking hour 10 to 12 times a day. Our schedule was:

Regime: One drop in each eye administered once every hour for a total of ten times daily.
Times: *[Due to school attendance]* 9am - 6pm (inclusive) [Thurs - Sun]
9am - 12pm & 2:30pm - 7:30pm [Mon - Wed]
Total time span: Seven months

Seven months later at the Ophthalmic Surgeon's clinic, the level reading was the same! We discovered the eye drops that were being supplied were in fact a weaker strength than those recommended. Cysteamine 0.55% strength had been the recommended since at least 1990 but we had been given 0.11%. Our Paediatrician contacted the hospital in question and initiated a change-over to the correct strength. Within two months the change-over process was complete and he began on the 0.55% eye drops. Our schedule now was:

Regime: One drop in each eye administered once every hour for a total of ten to thirteen times daily {never less than ten}.
Times: *[Due to school attendance]* 8am to 8pm (inclusive) on the hour [Sat - Mon]
8am ; 8:30am [Tues - Fri]
1pm to 4:00pm (every half hour) [Tues - Fri]
5pm to 8pm (every hour) [Tues - Fri]
Total time span: Four months

At an appointment with the Paediatrician two months after beginning 0.55% cysteamine eye drops we asked if he would consider letting us begin our second son on the eye drops. Our logic being:

- He was now showing signs of some crystals building in his eyes and although they were minimal, they were there and would continue to build. {He was at this time 23 months old}.
- He would eventually have to start the eye drops anyway.
- Since we were already administering eye drops 10 to 13 times a day with our other son, we may as well 'chase' him around too. Hopefully their crystals would clear out around the same time and then we could go on to a maintenance dose. Then at least the quality of family life would improve sooner rather than later.

Our Paediatrician agreed. We began our second son on the eye drops too, using the schedule above. By now our first son was 4 yrs & 4 mths old.

At the Ophthalmic Surgeon's clinic two months later (four months after first beginning the correct strength drops), both boys eyes' were crystal free. Our new regime was now 5 times a day for four months. Our schedule being:

Regime: One drop in each eye five times daily.
Times: 2am ; 8am ; 2pm ; 5pm ; 8pm
Total time span: Four months

Another four months later and they were still clear of crystals. Our present schedule is:

Regime: One drop in each eye four times daily.
Times: 2am ; 8am ; 2pm ; 8pm {This ties in with giving Cystagon}.
Total time span: Trial to next appointments

The next Ophthalmic appointment is for 2 months and 2 months again, as by now the Ophthalmic Surgeon is determined that if crystals are to start re-building at 4X daily administration, this regime can be adjusted sooner rather than later, with minimal crystal build-up.

~~A & S Ó Cathasaigh, Ireland~~