



Parley

Parents And Relatives
Listening and Empathising
with You

Niamh's Story

Hi all my daughter Niamh was born 21 weeks ago with congenital bilateral cataracts when we were first told we were very unaware of what we were about to face and thought it would be a simple laser job in and out end of story as it is with adults. We couldn't have been more wrong, because of the light being unable to hit the eye the cataracts have to be removed before 6 weeks for the best results. So at 3 and 4 weeks old my daughter had surgery to remove her cataracts a week apart each, The fear I felt that I may lose my little girl was immense and I was a wreck but trying to be strong and optimistic for my other family members who were also struggling especially my mam.

She responded well to her surgery and after weeks of 4 sets of 2hrly drops was supposed to have contact types lenses fitted asap after 16 weeks of making complaints and asking where were they we finally had an appointment. In the mean while Niamh developed glaucoma in her right eye due to a drain being blocked and had to have further surgery to relieve the water that had built up and stretched her eye (it looked twice the size of the other eye and we had to bring it to the attention of the consultant as he left her 6 weeks with no appointment) we have since changed hospitals and consultant and she under went another general to check her glaucoma pressure just last week which were fine, her new consultant then fitted her lenses straight away and she is responding great to them. We have been told that she will always have very poor vision even with lenses/glasses. We have to try and think ahead about her educational needs, also our living accommodation etc as I want her to have the best life possible.

If I could give any parent advice it would be to find what ever help and support you can in what ever form it comes as my friends haven't been there for me but through my family, husband and help group am coping with it all, and trust your instinct their your child and you know when something isn't right so keep pushing only the best will do!

