"My Story" – Nina Owczarek (mother of Bailey Owczarek)

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I am the mother of a beautiful 16 month old boy Bailey, who was born in August 2010 and diagnosed with Congenital Glaucoma when he was 3 months old.

My husband and I had been going through the usual challenges that all first time parents face in the initial 3 months of their child's life (sleep routine, feeding challenges to mention just a few), when we noticed that our son's left eye was looking slightly cloudy and a bit "bulgy". We initially thought Bailey may have scratched his eye, but being nervous first time parents we booked him in to see a GP at our family clinic. Our GP was not certain that there was a difference between our son's left eye in comparison to his right, but advised that "eye's made her nervous" and sent us straight to our local Children's Hospital emergency department (Royal Children's Hospital Melbourne). Bailey was seen by an Ophthalmologist that afternoon, and booked in for an EUA with a possible goniotomy 4 days later. After the EUA Bailey was diagnosed with Congenital Glaucoma (unilateral at that stage), with the initial goniotomy performed. We have both our GP and the team at the Royal Children's Hospital to thank for the early diagnosis of Bailey's CG, and feel very lucky that the glaucoma presented in one eye first so that we could have early diagnosis and treatment.

Over the next 3 months Bailey had a further 2 goniotomies on his left eye, which has maintained a stable pressure for his left eye in the low teens. His right eye then presented with high pressure when he was approximately 6 months old. Our surgeon performed 2 goniotomies on Bailey's right eye over following next six months, however, unfortunately these procedures were not successful and Bailey was scheduled for a trebeculectomy in October 2011. To date, the trebeculectomy has been successful, with the last EUA in December 2011 recording pressure in the low teens for both Bailey's right and left eyes. At this stage Bailey's vision prognosis is fairly good (short sighted), with glasses not required until he starts primary school and needs to see the black board (if there will be black boards by then – it may be iPads or tablets for each child in the next 4 years!).

I have found that there were times when I felt that myself and my husband were dealing with Bailey's CG well, and other times when we have both felt overwhelmed. We have been very lucky to have a great surgeon and close group of friends and family who helped us get through the surgeries and recovery. Our son has also been an absolute trooper, and has continued to amaze us with his strength and ability to recover and continue smiling through a difficult start in life. The CGN site has also been of great benefit, providing comfort that we are not the only family dealing with congenital glaucoma. Although our son's pressures are doing well currently, we are acutely aware that CG is a condition that will need to be monitored and potentially treated for the rest of Bailey's life. We try to provide Bailey will as "normal" a life as possible (if normal is a term that can be used when dealing with toddlers), and look forward to days out in the sunshine with sun glasses and a hat for all ☺