

Madelynn was diagnosed with congenital glaucoma when she was 1 week old. We had a referral to a pediatric ophthalmologist who didn't have the tools that we now know are necessary to measure pressure in children with glaucoma. He pried her eyes open with a speculum and pressed a metal medieval-looking tonometer device into her eyes while she squirmed and screamed! It was a terrible end to a terrifying day.

Madelynn is now three years old. She has had 6 surgeries to open her original drains and to install various valves. We have had more eye-doctor visits than we care to count to check her eye pressure. We hold our breath at each visit as we wait to hear the pressure reading.



Between surgeries, we go the eye-doctor to check her eye pressures at least every three months. Several times, her eye pressures have sky-rocketed between visits, leaving us scrambling around to plan her next surgery, worried about damage to her optic nerve, and her vision worsening as the pressure elongates her eyeball. It has been a long, difficult journey of so many unknowns, so much that is out of our control. This has been the story of our lives over the last three years.

We received an iCare from the Duke lending library in September, after Madelynn's last surgery. This has made a huge difference for our family. We check her pressures every day. It has been such a relief to know what her pressures are, especially while we wait for her drains to open. You see, after the drains are implanted, it takes 5 to 8 weeks for the stitches to dissolve and the drain to open. Whenever the drain opens, we are supposed to stop her eye pressure drops immediately, so that the pressures don't go too low, and begin an entirely different eye drop regime, which lends to the success of these valves working in the long run. This has historically been a time of waiting, not knowing, lots of eye doctor appointments, and even more stress. But now, instead of waiting for a visit with the eye doctor, we check her pressures ourselves, at home. One day during week 6 after this last surgery, her eye pressure was 32 in the morning, 17 at lunch, and by evening it was 6. We stopped her pressure drops that evening and started her on the new drop regimen. It was simply wonderful! We are so grateful to the Duke lending library for letting us use the iCare—it's a huge stress reliever in our family and has made such a difference in Madelynn's eye care.