

Is he shy? Il est timide?

Suddenly it is August 30th, 2014, 10 days before the due date but Enzo is born! Right away we learn a new French word: *pied bot* or clubfoot. Enzo's left foot is not positioned correctly and thus he starts a treatment from day 1 consisting of physiotherapy, 12 weeks of casts and a small surgery. That all sounds overwhelming but somehow we were not worried or scared. The doctors were professionals and we had read in the scientific literature that it should all be fine. We were convinced that his doctors would apply the Ponsetti method for straightening his foot very well. And yes! 'His foot.... that will work out well! But, he will need physio!'

Three months later his physiotherapist starts to worry. "Enzo does not look at the toys that I give him: '*Il ne suit pas les objets*'. Subsequently the orthopedic surgeon is saying the same at the last visit we have with her. We still think that he is just late in his visual development but to be sure we make an appointment with the pediatrician. From one diagnosis, clubfoot, we roll into the next one, a vision problem. Now we are worried! Would he really have a visual impairment?

Luckily we can see the pediatric ophthalmologist and the pediatric neurologist right away. Enzo seems develop as a typical kid except for his eyes. His eyes move in all directions and do not seem to focus, this is called *nystagmus* or dancing eyes. In addition, it is clear that his pupils adapt really slowly to changing light conditions. The child neurologist wants to see the results from a MRI for a check-up of his brain development. Luckily the MRI shows that this is all fine. Enzo starts occupational therapy at home for his nystagmus; one hour per week. Unfortunately, his eyes continue to dance. After a lot of phone calls from our side the doctors finally schedule an ERG and VEP at the eye hospital in Lausanne. Directly after the analysis the assistant tells us that the data have to be analyzed in more detail but that they do not seem very abnormal and that Enzo needs corrective glasses, +6. Directly we head to an optician and order glasses for Enzo. What a bright guy!



Enzo continues his weekly vision and physiotherapy sessions thinking nothing ventured, nothing gained. However, 3 months later Enzo starts poking his eyes a lot. People often ask us whether he is tired or shy. No he is not, that is just what he does. Would we have to change his glasses or is something else going on?

Months later the neuro-ophthalmologist had finally finished the ERG and VEP analysis. And yes, Enzo does not just have nystagmus, he is diagnosed with Leber's Congenital Amaurosis (LCA). We had already read the literature and this was one of the things that we were not hoping for. His retina is not functioning well and it can deteriorate.

While walking home from this last doctor's appointment we are in shock but after a while we realize that Enzo has not changed. He is still our cheerful son that likes to sing and cuddle. We wonder how we can raise Enzo as normal as possible and how we can help him discover the world. The solution turns out to be simple: we will not despair and come up with creative solutions so he can participate in everything that this world has to offer.