



## *In Your Own Words*

### **“Elan’s Wide Smile”** *By Meera Oliva*

*Editor’s note: Meera Oliva wrote this account of her experiences in 2010.*

*Elan’s palate repair was completed in July 2011.*

Six months ago, we welcomed our little boy into the world, a perfect little bundle with one major imperfection — a cleft lip and palate. Next week, Elan will undergo the third surgery of his short life, the one where the doctors will cosmetically repair his lip. It has made me think a lot about the last year and what our expectations were for Elan and how different things have turned out to be. Of course, we will still have one more operation to endure to repair his palate, but this one — the lip repair — feels like the big one, the one that we’ve been waiting for since the first day we heard the words “cleft lip,” and now that it’s here, I can’t believe how bittersweet it feels.

My husband, Raul, and I went for our 20-week ultrasound last March. Like most expectant parents we were just excited to see our first baby on the monitor and were not too focused on anything being wrong. At the end of the ultrasound, the radiologist said she never got a good look at the baby’s face and wanted me to come back again.

Since Raul had already missed a lot of work for my appointments, we decided I would go back by myself. That day another

doctor conducted my ultrasound. When he finished, he said he’d be back in a minute to talk about “some things.” I’ll never forget the way my heart dropped out of my chest at that moment.

When he came back, he said, “Your baby has a cleft lip.” And then he continued on about how plastic surgery these days is excellent but that this could be a warning sign of other problems, and he wanted me to have an amniocentesis and meet with a genetic counselor later that day. He was all business, and I was not processing any of it. I held up my hand to stop him and said, “I’m going to cry.” His demeanor instantly changed, and he said, “Well, that’s why we keep a box of tissues right here.”

I called Raul the second I got home, but when he asked me what was wrong, I could barely speak. All that came out was crying. He dropped everything at work and drove the 45 minutes home, while I tried to pull it together enough to just get out the words “cleft lip.” At the time, we knew so little about what that meant. All I had in my head were the pictures of kids in Operation Smile ads, and I felt crushed.

I immediately started Googling more images, which made everything worse.

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I just remember feeling so bad for this baby and thinking about whether he or she would get teased at school and wondering if something else would be wrong. Raul and I went back to the doctor's office that afternoon. The doctor we saw spent a lot of time with us, trying to get a good picture of the baby's face.

After a while, I asked if she thought the baby had a cleft palate, too. I barely knew what that meant but had read enough earlier in the afternoon to know that the two often go hand in hand. She went quiet and finally said that she couldn't get a great image of it, but she was fairly certain there was a cleft palate.

I sat up on the table and started crying again. She put her hands on my outstretched legs and said, "We are going to help you. I know some people who are very, very good at this sort of thing, and I'll talk to them, and we will help you." And then she wiped tears from her eyes. I thought things must be really bad if even the doctor is crying.

They sent us to the waiting room to wait to see the genetic counselor. We felt terrible sitting in that room with all the other parents-to-be. My face was so red from crying, and I felt like people were watching and wondering what happened to us and feeling thankful that whatever it was hadn't happened to them. At some point, the receptionist called me to the desk. I assumed we were ready to be seen, but instead she told me they were going to waive my parking fee since I had been at their office most of the day, and she handed me a validated parking ticket. I laughed a little and thought to myself, "Something's wrong with your baby,



Elan, with Dr. Mulliken and his parents, Raul and Meera Oliva, at the Paces for Faces Walk and Family Picnic in 2010.

but it's not a complete loss, because you do get free parking!"

The next three or four weeks were a real roller coaster. During this time, we learned about a world-class cleft surgeon, Dr. John Mulliken, at Children's Hospital Boston and made an appointment to see him. We had many more ultrasounds and two fetal MRIs in those weeks. We got varying opinions from people about whether other things were wrong with the baby. And we learned a lot about the treatment and special feeding considerations for babies with cleft lips and palates.

At some point, we decided we had done all the preparation and worrying and crying that we could do, and we just wanted to get back to being excited about having a baby. We did a pretty good job of it too, though a fear of all the things we didn't know was always in the back of our minds. How bad would the cleft be? What would it be like to see it for the first time? How hard would it be to feed him and go through the multiple surgeries? What would other people say when they saw him?

I read repeatedly on blogs and message boards that all of these questions and worries would disappear the moment the baby arrived. I didn't believe that for a second, and then it turned out to be completely true. From the moment we saw Elan, we were absolutely in love with him, and with his cleft in particular, and suddenly all of the things to come like surgeries, arm restraints, and special feeding bottles seemed much more manageable.

So here we are ... a little less than a year from that difficult day and just a few days away from having Elan's lip fixed, and everything feels completely different now.

In many ways I think this journey has enriched our lives. Of course we have our struggles, and certainly sending this happy little baby in for surgery every few months has not been easy. But becoming a part of the Children's Hospital and cleft lip-palate communities has been a real blessing. I have spoken to many other mothers of babies with clefts, and they are always so eager to offer support or a bit of advice on how to keep food from coming out your baby's nose. It has helped me see how kind

and helpful and compassionate complete strangers can be.

We participated in a fund-raising walk in October [2009] for the Foundation for Faces of Children, and we felt so loved and supported by all of the people who contributed to our efforts.

We are in awe of Dr. Mulliken every time we see him, knowing how many people's lives he has made immeasurably better, including our little Elan's.

The most shocking thing of all to both of us is how bittersweet it feels to have Elan's lip fixed. To us, his face doesn't need any fixing. His smile is so sweet and part of what makes it so cute is its imperfection. His cleft feels like a part of who he is, and yet if Dr. Mulliken does his job right, Elan will grow up and never feel like his cleft defines him.

But it's hard to imagine. For now, we feel a little sad to be saying goodbye to this wide smile that we have loved so much these last six months. So we will enjoy it as much as we can the next few days, and then we'll get to work on loving his new smile just as much. I'm guessing that won't be too hard.



Photo courtesy of Sarah Santos Photography

Elan and brother Sachin with their parents, Raul and Meera Oliva at the 2013 Paces for Faces Walk and Family Picnic.