

Facing Forward



A B O U T F A C E

My Security Blanket By Lisa Sooley

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I first got involved with AboutFace shortly after my oldest son Kyle was born with a bilateral cleft lip and palate. After finding out the diagnosis through an ultrasound, they sent me to meet the craniofacial team at the Janeway Children's Hospital in St. Johns, NL. Suzanne Dyke, the head nurse, gave me some information on AboutFace, but being so overwhelmed with everything that was going on, I just put it away when I got home and forgot about it.

After Kyle was born I had so many emotions running through me. I felt fear and anger, but the one that stood out from the rest was the feeling of being alone. Even though I had a huge circle of family and friends there to support me and a great health care team, I didn't feel comfortable talking to anyone about my feelings, thoughts, or concerns. I felt like my family and friends didn't understand because they all had perfectly "normal" babies. I wanted to talk to someone who felt the same as I did. Someone who knew what I was going through. That was when I finally dug out the information on AboutFace and contacted them. From that point on, I swore I would do everything possible to prevent other parents from feeling totally alone like I did.

In the beginning, AboutFace was there to answer questions and concerns over the phone, and via email, however there was no rep in my community, so it was hard to get the one on one support I needed from someone who was going through the same thing I was. I kept thinking - if AboutFace is helping me so much over long distance communication, how much more could they help people if they actually had a representative here?



I then began to volunteer my time with AboutFace, and soon decided to start hosting a playgroup for families that had children with facial differences. After my experience of feeling overwhelmed and alone with no support, I wanted to do everything possible to prevent that in future parents of babies with facial differences. To accomplish this, I knew I had to bring as many programs and services offered by AboutFace to Newfoundland and Labrador.

Our playgroups are held on a monthly basis, and usually take place on the last Saturday of the month from 10:00 -11:30am at a government funded Family Resource Centre. Parents love the peer support they get at the playgroups. Being able to talk to other parents about their experiences and struggles makes them realize they are not alone in what they are experiencing. AboutFace provides informal education sessions during the peer talks, and also provides light

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snacks and beverages. We also ask parents to bring a small healthy snack to share. Right now I have a small group of a few families per session, however numbers are growing each playgroup.

Because I want to help AboutFace any way I can, I also volunteer at Camp Trailblazers Newfoundland every year. I love interacting with the campers and getting to know them. Watching how effective camp is for building their self esteem and watching them grow over the years is amazing. I also host an annual community/family picnic for AboutFace in St. John's. It is another opportunity for families to get together and have fun. We have hot dogs, hamburgers, cake, loop bags, prizes, and many entertainers. It's a full day of fun and we usually have a big turnout.

I love volunteering for AboutFace – I feel it is important for me as a parent of a child with a facial difference, as well as a member of the community to keep as many of their programs and services here in Newfoundland. I also feel that sharing my experiences with new moms and providing them with the information, education and resources that I have acquired since Kyle was born is incredibly helpful to them when they are going through a hard time. I want to make sure that programs like Camp Trailblazers can continue to be offered in my province. Having volunteered there several times, I want to make sure it is something that is available for him when he is old enough to go. If not for AboutFace, the parents in my groups wouldn't have anywhere to get answers to any of their concerns or questions. And it is like a security blanket for me – I know that whatever situations I find myself in with Kyle, support from AboutFace is just a phone call or email away.



Lisa has been a dedicated AboutFace volunteer for years. Thank you for your service Lisa!