

So here is the truth. I was born with a bilateral complete cleft lip and palate; the second child born into my family with the same condition. My brother, who is four years older, also has a bilateral complete cleft. I have been told, although have not confirmed, that for all sorts of genetic reasons it was extremely unlikely that I would be born with a cleft. It does not matter how likely it was; what matters is that it is, and I am okay with that. The way I look at it, I was meant to be born this way. It makes me different, it makes me special, and most importantly, it makes me who I am. **Being different is divine.**

Both my brother and I were born with birth defects and never spoke about it. Never. I don't even know when I realized that something was different with us. My parents never spoke about it. Even though we each went through multiple surgeries – the clefts were never mentioned. It was as if the situation did not exist; as if the surgeries, the doctor visits and the speech therapy were normal. I am not an advocate of “pulling an ostrich” approach to life, but it is how my family dealt with our clefts and for better or worse – how I dealt with it too. I don't blame my parents for anything and think this approach was the only way they knew how to deal with our facial differences. They did the best with what they had; the access to knowledge and support we have today did not exist back then.

Sometimes I wonder - is ignorance really bliss? Did the fact that we never spoke of my birth defect make me think of it less often; make it less of a big deal? I don't know, but I do know that I did not think about it at all; especially as a small child. When I was about six years old I do remember looking in the mirror on my mother's dresser and staring at the scars on my lip. That was really the only thing I saw. I did not see my flat nose, or even how uneven my top lip was; all I saw were the scars. I wasn't upset – I just noticed them.



Gina Butchin

As I grew into my teenage years, I thought about my cleft a bit more, but never let it define who I was. I was not the girl with the cleft lip or even the girl with the funny nose. I was just Gina. The cleft was just one part of me. I was made fun of for having scars on my face and for talking funny, but I was not teased anymore than the fat kid or the kid with the glasses. The teasing did impact me profoundly – but it also made me the person I am today. For that I have to be grateful. I am sure the feelings of self doubt and pity that sometimes bubble to the surface are somewhat related to being born with a cleft, but I know they're also connected to a multitude of other things that shape and determine who we are. Having scars on my face has been a big deal to me, but it is not as life altering and devastating as people without facial differences might think. Did it stop me from becoming a super model; sure it did – but no more than did the fact that I am only 5'3"!

When I was in my late twenties I remember telling my mother that if God came to me with a magic wand and told me that he would change one thing about my body – I would pick my hips! It's important to know that when I made that statement, I still had over four surgeries to go to completely repair the defect. That is the other interesting part of my story. My brother and I stopped having corrective procedures around the time I was ten. All the "medically necessary" stuff was complete, but the more aesthetic repairs were not. My hard palate still had a hairline opening, my scars went horizontal on my lip, I was still missing tissue on my upper lip, and my nose was still pretty flat. I could not drink out of a straw or even a water fountain because of the hard palate opening, yet I still wanted the magic wand to fix my child bearing hips. My parents claim they stopped the repairs because I said I was tired of the surgeries and did not want anymore. I am not sure how true that is, but it is true to them. At ten I don't think I really knew what I wanted. I do know that I did not miss the visits to the children's hospital where I would have to go to speech therapy and say silly things like "puppy paws" and "spaghetti sauce" so they could listen to the nasality in my voice. And I did not miss having to see all of the other children who were in worse situations than me. I remember this little girl who had a hole in her spinal cord. She was so sweet and so happy and her life was never going to be "normal." I used to think that if you had to have a birth defect, mine was the best to have, because I could still have a normal life! I lived out my childhood with an obvious birth defect, right smack dab in the middle of my face. My nose was flat, my scars were bad, my voice was difficult to understand at times and yet I can honestly say I had a pretty normal childhood.



"Being different is divine."

I recently had the opportunity to talk with a counselor that works primarily with children born with facial differences. She was telling me that it was extremely common that children with clefts have a hard time making eye contact, whisper when they speak, and often times cover their

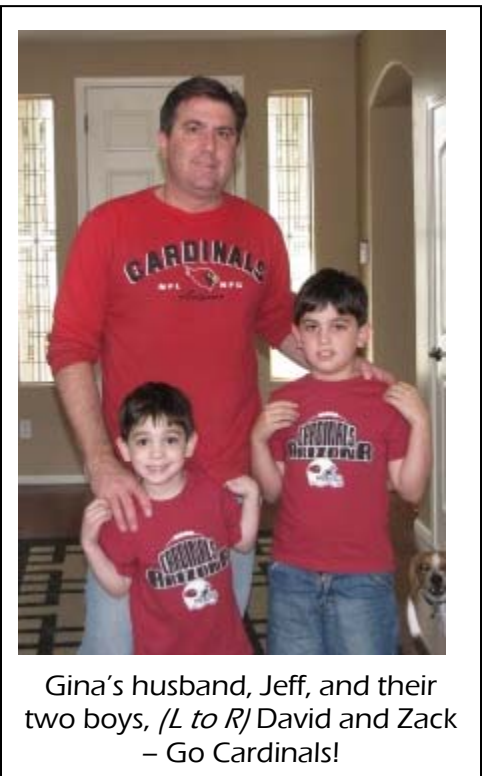
mouths when they talk. As she was telling me this, I could see myself as a small child doing all of those things; I could even hear my grandmother telling me to "speak up" because she couldn't hear me when I whispered. What an epiphany! All this time, I just thought that I was shy as a child; I did not know that my behaviors were common among people born with clefts. Good thing I did not know that while I was growing up; because it allowed me to be me and not define myself by my birth defect.

I should mention that my brother and I did not share the same experience. As I mentioned, we have never really spoken about the cleft or the repercussions, but I can tell from his behavior and his life choices that we do not share the same outlook or experience. He made bad choices and blames his life on how he was born. I guess that is what he needs to do for himself. Looking at life through my brother's eyes, I realize that a facial abnormality can be devastating. Just because it wasn't for me it doesn't mean it is that way for everyone. Even someone who grew up in the same house can have a completely different experience. I grew up thinking there wasn't anything different about me; Tom grew up thinking there was something wrong with the world.

My grandmother had, and still has a huge influence on my life. I adore her. Growing up, she was my best friend. She used to tell me all the time “Oh, Gina, **but** you are beautiful on the inside and that is all that matters.” I know she meant only good by saying that, but what I heard was, “Gina, you better be beautiful on the inside because you are not on the outside”. Later on in life I realized that she actually did me a huge favor by saying that to me. Not only did I learn to understand the importance of being beautiful on the inside and loving myself, but it also stirred something in me. It helped to wake up that fire inside of me that I am so well known for in my adult life. It helped release my fierce independence and made me think on some unconscious level that I was not going to let anyone tell me that I couldn't be beautiful inside **and** out.

I did not start really thinking about more repairs until sometime in my late twenties. It took me a long, long time to decide to have additional surgery. I have no idea why. Nothing happened in my life, no event caused me to start looking for a surgeon; I just did. When I started telling my friends that I was going to begin my search for a plastic surgeon, many of them looked at me in awe. For all the years they had known me, I never even mentioned that I had a cleft, let alone talked about getting it repaired. That was when I first started to realize that people may have thought that my birth defect was a burden or a curse; but I did not. They didn't talk to me about it out of fear or not wanting to make me uncomfortable, I didn't talk about it, because there was nothing to say. Now, there was something to say. Now was the right time for me to get the repairs done because I was doing it for me and not for society or any other reason.

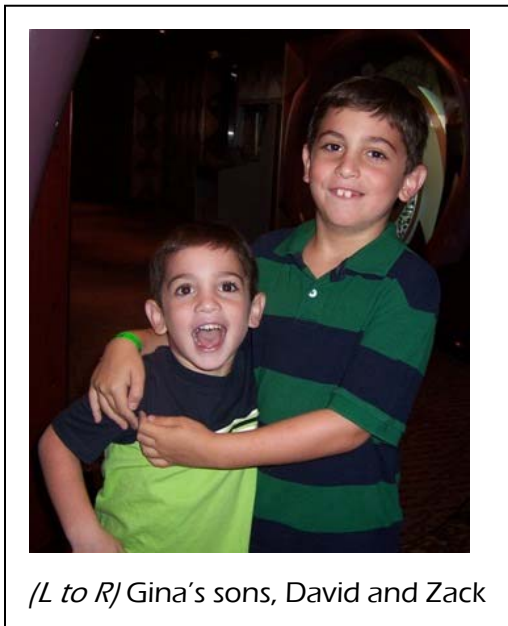
The surgeon I had when I was a child was long retired, and I needed to find another doctor that I felt comfortable with. I honestly thought that fixing the scars on my top lip was the **ONLY** thing that needed to be done. I called my insurance company and began the process that I affectionately call “the dance”. Before the dance could begin, I needed to find a partner. I interviewed several surgeons and none of them were a good fit. The first one was a hand specialist – yes my insurance company sent me to a hand specialist to repair a facial abnormality. The next surgeon I interviewed was obnoxious. Almost immediately he made me feel deformed and like there was something wrong with me. He talked about how he could fix me, and then told me he would give me “pouty lips.” He obviously did not have a lot of experience with clefts and his personality left a lot to be desired. I left his office in tears. For the first time in my life, I felt like I was deformed. He actually used the word “deformed” when speaking with me. Having had experience with plastic surgeons before, I knew they were not known for their bedside manner, but this was too much for me. I liked who I was and I did not feel deformed, I just wanted to have my scars look a little better. He made me feel like I was misshapen freak. I was about to give up, but I decided to interview one more doctor. I don't remember his name; but I owe him my life! He took one look at me and said that while he could help me, he would strongly recommend that I go speak with a facial cranial specialist in Phoenix, Dr. Stephen Beals. That conversation would change my life forever.



Gina's husband, Jeff, and their two boys, (L to R) David and Zack
– Go Cardinals!

From the moment I walked into Dr. Beals' office, I knew it was the right choice for me. At our first meeting he began to evaluate the situation and diagnose issues that I never even knew I had. I asked him to fix my scars, but little did I know at the time, he was going to do so much more. I found the surgeon I wanted and the dance began. Fighting with the insurance company was quite possibly the most frustrating part of the entire process. Dr. Beals' staff was great at helping me make my case, but it was both challenging and heart wrenching. The dance went a little something like this: I requested surgery and all of the tests that led up to it, they denied me, saying the surgery was cosmetic in nature, and I gathered up all of the proof (doctor reports, etc.) to show that while the words may have said something that looked like I was getting a nose job, the surgery was anything but cosmetic. Finally, I won.

The dance over and my partner set – we could start the music and let the fun begin. One of the first things Dr. Beals did was send me to a speech pathologist. He wanted to confirm his suspicions that I had what he called a malfunctioning soft palate. In layman's terms that means that my soft palate would let too much air through when I was speaking; giving me a very nasal sounding, very airy voice. I didn't even realize anything was wrong with my voice. Sure people had trouble understanding me; especially over the phone, but I thought my voice was my voice and nothing could be done about it.



(L to R) Gina's sons, David and Zack

The speech pathologist conducted some basic tests and determined that Dr. Beals was correct. A procedure called a pharyngeal flap which moves the skin flap from the pharynx to the soft palate could be performed to correct the problem and change my voice. For as long as I could remember people would have a difficult time understanding me when I spoke. I never realized it was something that could be fixed and now for the first time, there was a solution.

I met with Dr. Beals again to discuss the operation and all that it would entail. In my mind, he had one shot to get it all done. I was not thrilled with the idea of being put under anesthesia, and I was only planning on doing it one time. I told him he could do anything he wanted, my goal was for my scars to look better, and anything more than that, was just gravy to me. We talked about closing the hard palate, the pharyngeal flap and rearranging the tissue on my lip to help make the scars less noticeable. He also mentioned doing a rhinoplasty, but I felt that would be too much to recover from and it was

not that important to me anyway. We agreed on the treatment and the date was set.

I did not really think about the operation anymore until a few weeks prior. Then I started to panic. I was petrified. I did not realize how frightened I was of being "put under" until I had to come face to face with that reality. I could not get myself to a place where I was comfortable with being that trusting. I kept thinking they are going to put me to sleep; that was what they called it when they put my dog down. Not to mention, being asleep and allowing someone to take a knife to my face, why was I doing this? I almost talked myself out of it a million times. I really was okay with the way that I looked and my voice never really bothered me all that much – was this all worth it? I worried and I stressed, but I never backed out.

The night before my surgery I was all alone in my house, wide awake and crying my eyes out. My nerves were getting the best of me. I knew I had to face my fear and go for it. My mother and grandmother picked me up in the early morning to take me to the hospital. I was a nervous wreck. We got to the facility in the pitch dark where they took my information and walked me to the back to get me prepped. It was there, sitting on the bed with my legs under warm blankets, dressed in a hospital gown, shaking like a leaf that I met the next person that would help alter the course of my life. Her name is Dr. Drewson and she is an anesthesiologist.

Dr. Drewson came and sat down by the hospital bed and before she could even speak, I began to weep. This was the person I was more afraid of than anything. At the very worst the surgeon could disfigure me; but she could kill me.

I was asking my mother through the tears if it was too late to back out. My mom said no – it was my decision to make. But Dr. Drewson was an angel. She understood what I was so afraid of without me saying anything. She talked me through the entire process, explaining the real and the misunderstood dangers of anesthesia in a way that helped me to feel more comfortable. Just as I was starting to feel more at ease, Dr. Beals walked into the room and seemed shocked to see me so upset. He was expecting to see an excited young woman ready to get a new voice and improved face; I was excited, but I was more frightened. Both doctors spent a few moments talking with me and explaining the medicine behind it all and eventually I was ready. The talk helped, but the “cocktail” from Dr. Drewson really did the trick!

While I was in the recovery room, Dr. Beals went to speak with my mother and grandmother. He told them that I did great. My grandmother fired back, “That is good, but how did you do?” He smiled and said that the procedure was a huge success, that I would be surprised at how different and clear my voice would be, and that the appearance of my scars would be greatly reduced. He went on to say that I was a beautiful girl and that he could make me perfect, to which my grandmother retorted, “She already is.”



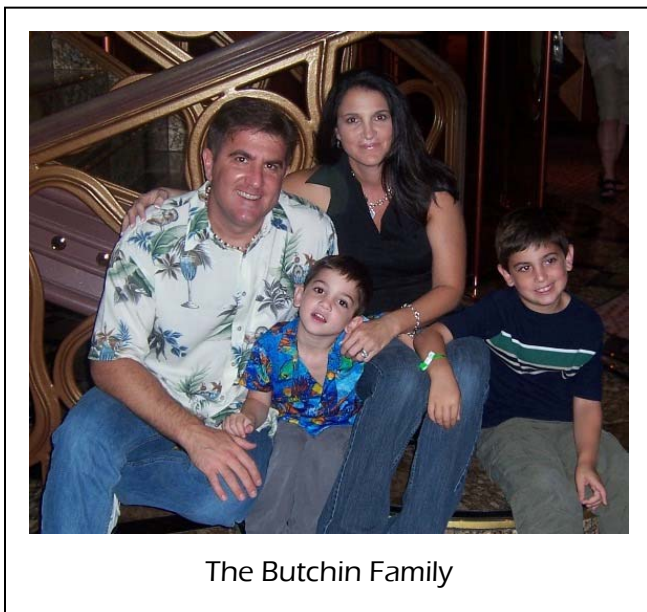
Gina was a Blessings-in-Disguise panelist at CPF's 2009 Connections Conference.

The recovery was hard, but not as bad as I would have imagined. I could not swallow because of the soft palate flap, and the roof of my mouth was covered in stitches from closing the hard palate. At some point I got so dehydrated they threatened to send me back to the hospital, but eventually I got up the nerve to swallow and began drinking water. I was on a liquid diet for ten days and while it was difficult, the weight loss was a nice bonus! The pain in the front of my throat was the hardest part. After a few days it was manageable, and once I could talk, the pain was all but forgotten.

The scar revision was secondary compared to the transformation my voice went through. Once I could speak, I was amazed at how different I sounded. I am so thankful that I have the video tape the speech pathologist did so that I can always have a reminder of what my voice used to sound like. I still sound like me, only better – clearer and more confident. After the surgery, my voice was so different, my nephew cried when I answered the phone and he did not recognize my voice. While I was worried about him, I was so thankful that my once nasal, hard to understand voice was a thing of the past. Since then I've had several old friends contact me who I have not spoken to in years, and they all

comment on my voice. It was truly life changing for me. Over the years I have become more and more comfortable speaking in groups, and now some even say that you can't shut me up.

The small hole in my hard palate was finally closed, and the scars on my lip looked fantastic too. The scars on my lip used to look terrible and now they are almost unnoticeable. In addition to my new voice and my new look, I was so excited to be able to drink out of a straw and a water fountain. It sounds funny, but believe me when you have gone your whole life not being able to do that – it really is a big deal. All the times as a child in gym class when people would run to the water fountain to get a drink and stand there for minutes at a time drinking...I would feel awkward. The only way I could do that would be to take the water in my mouth, stand up straight and swallow, then bend down again to the fountain and repeat. So believe me when I say, it was a phenomenal feeling to be able to drink out of a fountain. All in all, I was ecstatic. That was December of 1998, and I would not see Dr. Beals again for several years.



The Butchin Family

As I said, one surgery was it. I was done, I was happy. A year later I met the man who would become my husband. Jeff and I married in January of 2000. Jeff never seemed to notice or care about the cleft and we did not talk about it much. I told him my story and how much I owed to Dr. Beals but left it at that. In 2002 we had our first son and welcomed his little brother to the world in 2004.

One day, when our youngest was just a few months old, I had this strong urge to call for another visit with Dr. Beals. I always knew there was more he could do and finally felt like I was ready to find out what. Dr. Beals wanted to rebuild my nose; inside and out. I was so comfortable with

him, basically I let him do whatever he thought best and I did not ask questions. We talked about the missing tissue in my top lip and decided to go with implanting AlloDerm – which I later found out was cadaver tissue and really wished that I had not found that out. He also did a rhinoplasty and septoplasty. My only request was for Dr. Drewson to be my anesthesiologist and as luck would have it, she was willing and able.

This surgery was a long one and I looked rough when it was over. But once the swelling went down and the bruises faded – a new person was revealed. I tell everyone that Dr. Beals created the face that I have today, but in reality he has helped to create so much more than that. My appearance improved, but the personal growth I experienced was truly transformational. Because of him- I found my *voice* and it changed my life. His compassion helped give me the courage, his skill helped give me the confidence and his passion helped give me will to complete surgeries that were not done when I was a child. I recently had my last visit with Dr. Beals. At 40 years old I can finally say that my surgeries are complete. I could not be happier with the way that I look and the way that I feel.

I know I was born the way that I was to help people. I hope that people can learn from my experience and know that everything that is different about them is a blessing!