

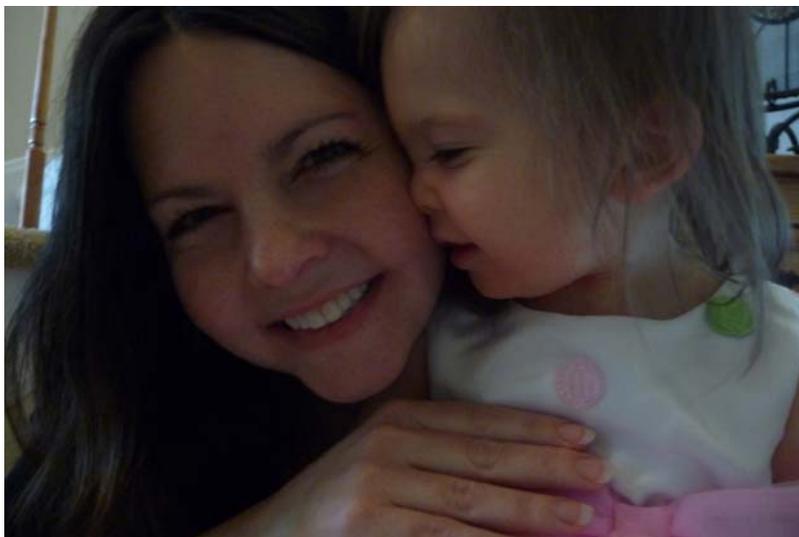


## A Little Love Can Go A Long Way

by Melissa Tumblin, Founder of Ear Community and the Microtia and Atresia Support Group

...continued from newsletter

I remember the day when my youngest daughter Alyssa (Ally) was born. It was one of the happiest moments in my life. My husband, Brent, and I were so thrilled to finally meet her and welcome Ally into our world. I remember her little smile and how beautiful she was, but I also remember Brent coming over to me with tears welled up in his eyes when he said “Something is wrong with her ear.” Ally's right ear was only partially formed. Immediately, I began blaming myself wondering what I had done wrong during my pregnancy and trying to remember if I had ate or drank something that could have caused this. When we asked the OR staff why Ally's ear was missing, no one said anything...they didn't know what to say. At this point, Brent and I became concerned and wanted answers. That night, Brent went home and researched on his own about missing ears. When he returned to the hospital, he told me that Ally may have what is called Microtia. Our pediatrician verified this the next morning in the hospital.



Soon after meeting with an audiologist, hearing tests confirmed that Ally had hearing in her right ear, but at a severely reduced level due to an absent ear canal. After meeting with an ENT we learned that Ally also had Atresia (the absence of an ear canal). We were reassured that Ally would be just fine and it was suggested that we bring her back in one year for a follow-up visit. We did inquire about hearing aids and were informed that Ally was not a candidate for a Cochlear implant. We also inquired about surgery and we were told that there was an option for

surgery called Rib Graft, but not until Ally was nine years of age. After having left the ENT's office, we began to feel better about Ally's Microtia and Atresia.

As the months passed, my feelings of sadness and remorse about Ally's ear began to slowly subside. I realized how lucky Ally was because she was only missing her ear when things could have been so much worse. However, I still felt very alone. I worried about Ally and I often wondered if her missing ear would affect her in life. I was curious if we were the only Microtia family in our state. So, I decided to do some more research on Microtia and Atresia. During my research, I began reading about children wearing BAHAs (Bone Anchored Hearing Aids) and having speech therapists for helping correct speech and communication delays that have resulted from unilateral hearing loss. I learned about cholesteatomas (benign skin growths inside the ear) and to keep an eye out for ear infections. I read more about prosthetic ears and I also learned about another surgical option for ear reconstruction called Medpor. I discovered that helpful resources, such as the AboutFace Organization



and the Hands & Voices Organization, could help put me in touch with other families in the same situation. I learned about early intervention services and how they could help Ally with additional resources if she needed them.

I discovered that many families either received calls about these resources, or were informed about them while in the hospital. This is when I realized we had fallen through the cracks. Eventually, when Ally was almost 11 months old, I was able to connect with a few families. I was so relieved to speak with someone else who had a child with Microtia and Atresia and to hear about their experiences. I soon realized that I was not alone, and neither was Ally. The conversations I had with these families were priceless and will never be forgotten. Since then, I have learned how to become a better advocate for myself and for Ally. I now realize how important it is to do my own research and to find out what options are available that can help me make the best decisions for Ally now and along with her in the future. Sometimes, we may need to seek a second or even a third opinion when trying to find a doctor who is the best fit for both us and our children. I've discovered that in some situations, medical professionals may not have the latest information related to Microtia and Atresia and that by passing along new information can be beneficial in helping update them.

I will never forget the feeling of being lost, and alone, and not having anyone to talk to. Finding a support group or community can be invaluable in learning to accept and embrace Microtia and Atresia. We can learn from other parent's experiences on how to help raise our children with plenty of self confidence or how to comfort our children if they get their feelings hurt because of a comment that was made about their ear(s). We can learn from the experiences of individuals who are living with Microtia and Atresia and see how they are doing in life and what decisions they have made. The most important thing to realize is that someone with Microtia and Atresia can live a happy and healthy, normal life and that as parents, it is perfectly fine to consider helpful options if believing our children can benefit from them.



In hopes of making things easier for the next family who has a child born with Microtia and Atresia (including Goldenhar Syndrome, Treacher Collins, and Hemifacial Microsomia families), I have founded an on-line support group called EarCommunity.com that launched on February 1<sup>st</sup> of 2012. Ear Community helps promote educational awareness about Microtia and Atresia including hearing loss. Ear Community also helps promote advocacy, and helps members learn what options are available to them. Ear Community is currently being utilized as a helpful resource by medical professionals and medical facilities around the world. One of Ear Community's main goals is to help



bring families together so everyone can share experiences and realize that they are not alone. This summer, Ear Community will be hosting a series of family picnics across the United States and in Canada. I am deeply touched by the medical professionals and hearing aid organizations (Oticon Medical, Cochlear Americas, and Sophono) who have come together to help Ear Community bring these families together. Every time I receive an e-mail from an individual who says they have never met anyone else with “little ears,” I hope they will be able to attend one of our picnics so they can be able to finally meet someone in the same situation. I just don't want anyone else to be alone like I thought I was with Ally. This is my way of giving back to the community. I hope that individuals and families with Microtia and Atresia realize they are not alone when they have all of us at Ear Community.

For more information about Ear Community, please visit [www.EarCommunity.com](http://www.EarCommunity.com) or visit the Microtia and Atresia Support Group on Facebook at <https://www.facebook.com/pages/Microtia-and-Atresia-Support-Group/118851728152174>

**Melissa volunteered with AboutFace by hosting our Parent Workshop Conference Call in March. Please check the “Upcoming Events” page of the newsletter for information on Ear Community’s picnics.**