



# “Spotlight on a NICU Family: Aliyah’s Story”

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Originally published in the Good Beginnings newsletter, “Beginnings Buzz-z-z-z-z”  
Vol. VII – Spring 2004

Aliyah was born September 26, 1998. Her real date of birth was supposed to be sometime around January the 14th of 1999. Needless to say, her early arrival was the most shocking and traumatic experience of our lives. She weighed one pound ten ounces. We had never seen such a tiny person, and we never loved, or prayed so hard. The next seven months were filled with the highest highs and lowest lows.

We found ourselves thrust into a world we never knew existed. A world of heel sticks, breathing tubes, isolettes, and deadly infections to name a few.

These experiences take a toll that can not be explained in words; if you haven't lived it you couldn't possibly understand. Our child wasn't "normal," and as any "parent to be" would, I myself had painted a "rosy" picture of how it all would be. Unfortunately my fantasy had nothing to do with the reality that was our life.

It took literally four to five months before her premature belly would tolerate the smallest amount of milk. She was on more medications than I care to remember, and had I. V.'s at some point in almost every area of her body.

Then came a major setback: Aliyah couldn't shake a deadly bacteria called Klebsiella. It's a blood infection and it was taking a terrible toll on our baby. The antibiotics she was taking weren't effective and so finally she was administered a highly potent medication named Gentamicin, which is a known risk for hearing loss. Thankfully she overcame the infection and after seven months we were going home. It was one of the happiest days of my life. Finally we could try to pull our lives together, to recover from the daily stress.

Upon discharge it was discovered during a routine hearing test that Aliyah was unable to hear. The six week course of Gentamicin had proven to be too much for Aliyah's little ears. We were devastated. We had already been through so much and now this. It seemed so unfair, but in the end we came to realize that we were lucky our baby had even survived, and if she couldn't hear, so be it!! Life would go on.

Our children need our strength, our patience and every ounce of love and affection we have to give. It isn't about how we would like our children to be, or the schedules that we want them to be on as far as development is concerned. To me it is about everything happening in its time. Aliyah is proof of that.

Today Aliyah is 5 years old. Some days we just look at her in sheer amazement. She is everywhere, and into almost everything. We find her deafness to be very challenging but we are doing our best. She is in school and has been for the last two years. At this point she knows about 60 signs. I know about 150-200.

There are no words to describe how grateful we are to have benefited from programs like Westside Regional Center, and Cal. Children's Services. They have helped us in so many ways.

If I could say one more thing it would be: FIGHT for your babies. Do whatever is necessary. They deserve it!!!