



Hawai'i Deaf- Blind Project presents:

Resources, Stories, Ideas, Information... Brought to Your Home

Aloha Families,

Hope you have enjoyed reading our latest newsletters that were sent out to you last month. If you have not gotten through it, I have pulled out this following piece just to share with you the fun and the tense moments that I have experienced traveling with my daughter. I believe we all have some kind of sweet "joy and pain" experiences raising our children. Would you share yours with us? Send your thoughts to yhchang@hawaii.edu

Also, be sure to check us out on FaceBook:  Hawai'i & Pacific Deaf-Blind Projects, and if you are not on our listserv send me an email and we will make sure to add you to it.

~ Stella

Traveling With a Medically Fragile Child Stella Chang

Traveling can be fun and exciting and on the other hand stressful especially when you have a child with special needs. My husband and I like to travel and we used to travel about every one to two years to visit our families living abroad. Then our daughter was born. As a family, we started a total different traveling experience.

My daughter was born with CHARGE syndrome, which is a serious genetic disorder that affects multiple parts of the body. She is deaf-blind and requires tube feeding. The first trip my daughter took was flying to California from Hawaii at one year old for her open-heart surgery at the Children's Hospital. It was an unforgettable trip being that it was our first time traveling with a baby, moreover a medically fragile baby. It was also our first trip traveling not for leisure but for a serious medical reason.

That first trip was a difficult one to plan. We did not know if our daughter would be sick on the day of the flight and how the flight would affect her body, especially her heart. It was quite scary for me. Before the trip, there were a lot of things to get ready. Besides what the doctors had arranged, we needed to find lodging near the hospital. The Ronald McDonald House was the best choice because it is close by and they provide many accommodations for families bringing children for medical purposes from out-of-state. I also had to contact the medical supplier for portable equipment - a suction unit and a feeding pump for my daughter. I needed to contact the airline for an oxygen tank just in case my daughter needed it. Another important thing was to get her medicines refilled so that we would have enough for the trip.

For more information about the Hawai'i & Pacific Deaf Blind Project, please contact Stella Chang, yhchang@hawaii.edu or check out our website at www.cds.hawaii.edu/dbprojects/

Then I made a packing list of her things under four categories: routine medication, medication may be needed, supply and clothes/hygiene. There was quite a bit of preparation before the trip. With boxes of formula, a car seat and everything else, it was impossible to travel light

I remember our flight was at night. My daughter had a hard time falling asleep because everything was different. None of us got any rest on the plane. After that experience, we avoided taking night flights. The surgery was successful, but we were worried about her coming back on the airplane. Thankfully, she did pretty well on the airplane with help of the oxygen tank.

The next year we went back to California for another heart procedure for my daughter. Though I was more experienced, I was still stressed out because there were a lot of things to get ready. Over the years, we did more travel for different purposes. There were some incidences where things went wrong. One time we were returning from Seattle. After we arrived at the airport, my husband checked us in and I had to give my daughter her feeding. We thought we still had plenty of time not knowing the situation at the security check. There were so many people that we had a long wait at the line. Finally we passed through and found that we needed to take a shuttle to the gate. By the time we got to the gate, the plane had already left. We could not believe it! We had to wait for the next day to return but our luggage was already checked in. Fortunately, I had most of my daughter's things for the day packed in a carry on bag. Otherwise, it would have been a total disaster. However, we did have to pay for the hotel.

Another time we were on a taxi going to the airport. I just remembered that we left a suitcase in the bedroom. That was the first luggage that we packed because we wanted to start earlier. We put it in the room so it would not be in the way. But we forgot about it. My husband had to go back to get it after the taxi dropped the rest of us off at the airport. While we were waiting, I tried to check if I had everything my daughter needed. Then I could not find the bottle of medicine for my daughter's stomach ulcer. I called home but could not reach my husband. At that time, we did not have cell phones. I was so nervous because we were going to another country. I did not want to miss our flight nor miss the med that my daughter needed. So as soon as my husband came back, I jumped on the taxi to go home. It was about twenty minutes drive. My husband had to check in first. After I got home, I looked and looked but could not find the med. Time was running out so I hurried back to the airport on the taxi. The taxi driver said he had never met any passengers like us. We were panicking. Finally, I checked the luggage again and found it. I did not understand why I could not find it in the first place. Anyway it was a relief!

There were other incidents like forgetting to bring the electric cord for the suction machine and another time forgetting a medicine stored in the refrigerator. As years go by and my daughter's condition got better, we were able to go places that we like to visit. We know better how to deal with situations when things go wrong. The scale of our stress level was able to tipped to a more positive end. We started to enjoy traveling and the opportunity to explore new things as a family. Looking back, we had a lot of memorable travelling experiences to talk about and we were very thankful!

