

PLANE TRAVEL –by Jeanna Huette

Hi Brad,

I can offer a ton of suggestions for flying as Ally has been on 8 planes already for her clinical trials from Chicago to CA monthly. She is only 10 months old now. I learned a lot of what I know from Jeanna and another family in IL, but things have gotten smoother and smoother each time.

Here's a few to start with, but feel free to call too:

1) You must call the airlines ahead of time and talk with the special needs department or medical desk. It is good to call up to 2 weeks in advance if possible. Here are some things that you can tell them.

- Tell them a little about SMA and the child's needs.
- Most machines are listed on a pre-approval sheet with airlines, but you will very likely need to give the make, model, manufacturer and even telephone # for each machines you want to use. If it is listed, you don't have to look up all of them. They will get back to you to be sure to tell you if all the items are approved. It can vary by airline and the actual type of plane. Some may be for continuous use and some may be over a certain feet. Our pulse ox and suction are suppose to be over a certain height on some planes, but the airline didn't say anything when we used them during take off.
- You also have to tell them if you are bringing a sealed battery and inverter to run the machines.
- Ally did much better when she flew with her bi-pap on since everyone's oxygen level goes down at higher altitudes. If you are worried, test yours and the child's to see if it is really a problem. You know how to read your child and know if the numbers are sorta off.
- We lay her across our laps, flat as a lap child. We didn't buy an extra seat, but often receive one. Depends on age and size of the child. I bring a big pillow to make her and me more comfortable.
- Tell them that you must pre-board to set up your machines and get the child settled.
- It's sometimes nice to be near the front or back of the plane because the flight attendants cater to you and treat you like royalty (most of the time).

2) I use a big rolling duffle bag for all of Allyson's machines. A foldable luggage cart will also work. This way we roll them through the airport. We have to take a few out and then it kinda flattens to go in the overhead. Be sure to bring all your machines on the plane so that nothing happens to them.

3) It's best to have a doctor's note of all the things your child needs to fly with and may need to use in flight. Include that water is needed for her feedings and bi-pap. Also list her special foods and possibly breastmilk or medications. I had to show the letter the first few times but not anymore.

4) ***I went to the National TSA website and looked at the special needs section. Then I called the 1-800 number and told them I needed to make going through security easier with my daughter. The first two trips, we found that every agent had different rules.

They had both airports main customer service TSA person call me. I told them all of Ally's needs and mostly that she needs to have all her liquids approved, that it is best if she stays in her stroller/wheelchair with some of her machines. Then they have us call a special number so that we can meet a manager at the gate. They tell them to let all liquids (including open waters) through and just do a gentle pat down of myself and Ally. My husband puts most of her machines through the scanner and they swab the other ones that stay with Ally (suction and pulse- ox). You can put all the machines through and just take her through the scanner, but I like not having to flatten everything and Ally to be able to stay comfortable in her stroller. Sometimes it can take forever to get everything through and she may need to be suctioned. Since we started talking to TSA ahead of time, things at security have gone VERY smoothly and they thank us for helping them too.

5) We are always first to board (a few minutes ahead of time) and last to get off the plane. We still end up waiting for our bags though.

6) Of course it is important to bring some back-ups of supplies in case anything gets damaged. Jeanna has a nice list that I cross check with.

7) They almost always offer us FREE snack boxes, headphones and even FREE alcohol drinks to my husband. We have almost always been treated VERY nicely by everyone.