

# Julie Jones

Life's lessons

Rolling on with a positive attitude!



**J**ulie Jones is a mother and blogger who contributed to this issue's "Real Moms Share" section. We asked her to give us an insight into herself, as well as into her life raising her son, BJ. We asked her a series of questions; some serious and some "just for fun". See what she said...



**PARENTING SPECIAL NEEDS: Tell us a little bit about yourself and family.**

**JULIE JONES:** Our family is what would have once been described as a “typical family”. There is a mom, dad and two children (a boy, BJ, 18, and a girl, AJ, 11). But, there is nothing typical about the way we function as a family because our son was born with Cerebral Palsy. We believe in approaching life with a positive attitude, but there is no denying that having a child with a disability affects most aspects of our life. Our family has been shaped by a determination to find solutions to problems as they arise, and a positive attitude. Travel and weekend outings are something that have also bonded us. Having fun times as a family has been the key to our strong relationships. Our son, BJ, has made huge improvements in the last six months. He is a happy, social and determined teen.

**PSN: Tell us a little bit more about your child’s diagnosis and personality.**

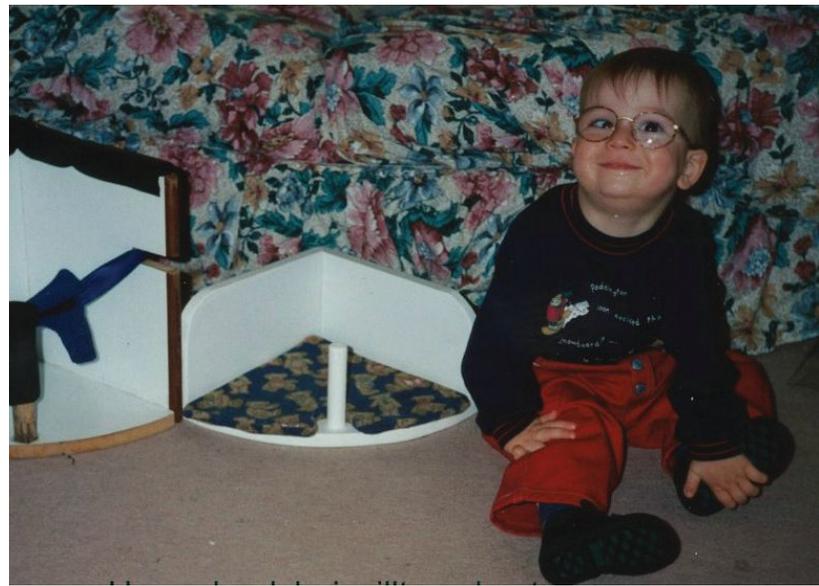
**JJ:** I had an uneventful pregnancy and birth with BJ. When I left the hospital, I was unaware there was anything “amiss”. It was only when he didn’t have good neck control at the same stage as other babies that I started to ask questions and seek advice. At 5 months of age we were sent to a physical therapist to “help him improve his muscle tone”. After a few visits she suggested that he may have Cerebral Palsy. BJ was a happy baby but his determined streak was evident early on.

**PSN: Share with us something YOU, personally, had to overcome by being a mother to a child with special needs?**

**JJ:** I like to find solutions to problems and Cerebral Palsy cannot be solved. Throwing us into every kind of therapy (speech, physical and occupation therapy) was my “solution” of sorts. It became abundantly clear after a few years of embracing all therapies that having a child with Cerebral Palsy was a marathon, not a sprint. I was going to burn myself out.

**PSN: What have been some of your biggest obstacles/challenges raising your child?**

**JJ:** Determination is a fine quality and that is the reason BJ has reached so many of his goals and continues to do so. However, his determination to



work against me at times was a challenge. I learned early on that he had to see the purpose (or rather what was in it for him) in order to put the effort into working towards a specific goal. I have had to be inventive with my approach and work with this trait; always reminding myself that it will help him achieve more.

**PSN: What is something your child does that you’ve come to appreciate as a gift?**

**JJ:** BJ learned to hug a few years ago. It was a great thrill to see him use two hands and to squeeze with all his might. It is a real show of his love and affection. Each evening he won’t go to bed without giving everyone a hug including his Grandparents who are usually visiting to help.

**PSN: What has school/education been like for your child?**

**JJ:** BJ has been very happy throughout his schooling. It certainly met his expectation...but not always mine. He is very social and has been popular with staff and students. He welcomes everyone like they are a “rock star” and that is a lovely feeling for everyone.

**PSN: Will you share with us some life lessons you’ve learned on your journey raising your child with special needs?**

**JJ:** I have several lessons learned. As parents we are BJ’s best advocates. No one else has the same vested interest. Choose your battles, not only with your child, but also, with school staff. Pick what is the most vital issue or goal and follow through with that one. Accept that you don’t know what the future holds. Work in

the “here and now” with therapy and goals related to therapy. Celebrate the small achievements: milestones like sitting, standing and walking may or may not happen but every little step towards any one of those goals is important. BJ learned to turn on a light switch – it may seem tiny, but, it empowered him to control his environment. This made him happy AND I knew he could then isolate one finger. That was an important step towards using augmentative communication. Try to find solutions to problems yourself. Have confidence to trial things and take your ideas to therapists. Take time out for yourself: everyone needs to have time to refresh and reenergize.

Spend time as a family having fun. Laugh and play together. Some of BJ’s progress would come after a holiday. Our therapists felt that the time out gave him time to consolidate the skills he had been working towards.

**PSN: What do you know now that you wished you had known earlier?**

**JJ:** I now know to trust my gut. If I feel a therapist or doctor will not suit BJ’s way of learning then I

would swap within a few weeks. I should have had more confidence in myself earlier on.

**PSN: Do you have a proud moment about your child that you would like to share?**

**JJ:** When my son was diagnosed with Cerebral Palsy I remember my first question was “will he walk”? At that time it seemed like the most important milestone. As time went on, I realized that walking wasn’t the main goal I should have. The fact that he was non-verbal created far greater frustrations than not walking. My main focus became being verbal or having good hand function to be able to use augmentative communication. Our focus shifted and we accepted a wheelchair as a part of life. We continued to do standing practice and walked BJ up and down the hallway to the bathroom and his bedroom. BJ continued to walk in a pool to strengthen his muscles. Quite unexpectedly last year BJ took 16 unaided steps at the age of 18. They were not “falling steps” but very clear, well defined footsteps while he maintained a tall straight body. He was proud of his achievement and the reaction from everyone spurred him on and he has

continued to walk around our home with supervision in this manner. It is hard work for him but I am proud of that moment and the fact that we never gave up.

**PSN: What kind of life do you envision for your child’s future? Or does your child have a dream he would like to reach?**

**JJ:** I learned early on not to look too far into the future. I am a worrier so I find that I get myself tied up in knots about what the future will hold. BJ has made so many unexpected gains in the last six months that I wouldn’t want to limit him by envisioning too much of his future because hopefully the improvements will keep on coming.

My main wish for him is that he





is happy, healthy and having his needs met. He has just started a post school program that he is thrilled about. He is excited to greet each new day. More than anything I want him to keep this enthusiasm and joy over his day-to-day life.

#### **ADVOCACY:**

**PSN: What was your impetus with regards to starting your blog and sharing about traveling adventures with your son and family (Was there a specific moment that made you decide to take action)?**

**JJ:** We returned from our second successful trip to the US in 2012 and I had so much information that I had researched. I asked questions, emailed attractions and airlines to find out as much as possible to make our trip smooth. I had found some great accommodations, activities to do and access to information. But, it seemed a waste that only my friends would hear about it. I decided to write about our trip and then it was pointed out to us that we were always doing things, even in our hometown that may be of interest to others, so the idea kept growing.

**PSN: As a blogger, please share about your advocacy "Have Wheelchair will Travel".**

**JJ:** When BJ was young, I went to an information session at a Cerebral Palsy organization. I started

talking to a lady who was the parent of a twenty year old with Cerebral Palsy. I was shocked when she said to me "you are so lucky, you just don't know how much harder it will get. You are in the honeymoon period". It was an awful thing to hear and I vowed to always encourage other parents to share the positives and the solutions we had found.

Have Wheelchair Will Travel is really the combination of my former life as a travel consultant and my current life as a Mom of someone with Cerebral Palsy. I have never lost my love of travel and I feel passionate about making life easier for others and providing encouragement.

**PSN: Do you have goals, or a mission, you are trying to achieve with "Have Wheelchair will Travel"?**

**JJ:** I think there is a residual feeling that people with a disability don't travel and it is taking a while for the travel industry to catch up to the idea that people with a disability try to live their life without barriers. People now expect that they can do what everyone else does (within reason) and with certain adaptations. I would like to see airlines take greater steps in the direction of making sure everyone can fly. Many people are very limited in their ability to be comfortable, or even sit without the support of their wheelchair seating system. It seems logical, to me at least, that in the future

airlines should be considering having wheelchair seating on their aircrafts. At the moment there are FAA accredited seating systems for children up to the age of 11 but the need doesn't magically end at 11. This needs to be addressed. We were even surprised on our last trip to Los Angeles to find that the new terminal lacked a stand-alone (unisex restroom). If there is a person in a wheelchair needing assistance from someone of the opposite sex (ie mother helping son, husband helping his wife) there is only the option to go into either the ladies or men's restroom. This is a bad oversight and one which makes a traveler feel self conscious and uncomfortable.

In all areas of travel I feel there is a need for education. As we travel we try to educate hotel staff and others (in a positive way) about what is needed and what a difference it can make to us to have our plans work well. We find that people are keen to know more when they see BJ enjoying his travel and he is so social he tends to build a good rapport with people and this tends to make them receptive to our ideas.

**PSN: In conclusion, is there anything else that you would like to share with our readers?**

**JJ:** I feel that approaching every situation with a positive attitude is the best influence you can have on your children. It isn't always easy, but I notice even when something does go wrong my daughter will say "well at least....." and point out the positive of the experience.

I have had down periods, I have been overly tired and feeling like it is all just too hard BUT taking time out either by myself or as a family helps me clear my mind and get back on with day-to-day life. I have been very fortunate to have family support and a Mom who recognizes when I need a break.

Lastly, have fun with your child. It will keep them positive and create precious family memories. ❤️

**PSN: Julie, thank you so much for sharing your experiences with us, as well as the lessons you have learned raising BJ. We look forward to hearing more from the adventures of "Have Wheelchair will Travel!"**



Just for  about Julie

**What do you do to find time for you?**

I love the escapism a movie provides so I will head to the movies with my Mom or friends. When I really need a pick me up I have a facial. I arrive at the salon and find it hard to stop thinking of all the things I should be doing but very soon the magic kicks in and I am off into a dream like state.



**Mommy timeout: Dream vacation?**

Hawaii is my dream vacation. The last time I visited it was before children and our flight was the last to land before Hurricane Inniki hit so I would love to revisit it without the drama. I would love to sit with a cocktail in hand at the beach..

**Favorite treat?** I love my chocolate. It has been my friend through many a tough time

**Your one makeup essential?** Mascara. I'm totally addicted to mascara and won't leave home without it.

**Do you drink Coffee or Tea?**

English breakfast tea.

**Are you a dog or cat person?**

Having grown up with them as a child, I'm a dog person

**Favorite wacky word or phrase?**

My daughter is a fan of the series Junie B Jones and if I am having a moment of praising myself over something I've done for her she quotes Junie B by saying "don't forget not to toot your own horn" It always brings a laugh.