



Connections

Information + Support

Families of Children with Special Needs

Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, & Yancey counties

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**An Affiliate of
Family Support Network™
North Carolina**

With Support From

Appalachian State University

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Network™—High County

Partnership for Children from:
Avery
Mitchell-Yancey
Watauga
Wilkes

~Embracing The Journey~ written by Janessa E. Shelton

Spring is finally here! It's that time of year that rolls around and I find myself wondering where the time has flown off to?! Springtime means celebrating the births of my daughters, as they were born in April and early June. Now after a decade, both of them have finally reached what my youngest daughter proudly refers to as the "double digits" It does not seem possible, and yet it is! There is so much truth to the Latin expression "Tempus Fuget" time certainly flies!

On the afternoon my oldest child was born, a tornado touched down in our little mountain town! This rare event was sure to be a metaphor for my daughters introduction to the world. She was reluctant to be born closer to her due date, so my doctor felt an induced labor was in order. After 32 hours of labor, Jackie was delivered by cesarean section. Bright eyed and full of spirit she was finally here. The next couple of months were filled with bonding, relishing all her little coo's and smiles. Soaking in all the awe and nervousness that comes with being a parent for the first time. Nothing could have prepared me for how much our lives would drastically change in an instant.



I distinctively remember an urgent feeling to peek at her in the middle of loading my clothes dryer. I popped my head around the corner to find my 2 month old infant having a violent seizure. Time blurred by and she was in its grips for nearly the entire ride to the hospital. After examining Jackie in the ER and the doctors not finding any evidence of what I described, they considered releasing her to go home. Then they witnessed her have another prolonged seizure. This hospital stay would be the first of many days and nights spent pacing hospital floors. There were so many times that I helplessly watched my daughter slipping away...repeatedly paralyzed in fear that her seizures would not stop. We tried many medications to no avail in attempt to control her debilitating seizures. We made the countless rounds to see a variety of very puzzled specialists. We exhausted every therapy and intervention available to Jackie. The intense search for effective treatments and learning how to navigate the medical maze has proven a very humbling experience.

Nearly eight years passed before Jackie was diagnosed with a catastrophic form of epilepsy called Dravet Syndrome. Given the often treatment resistant nature of this complex condition, Jackie has developed other co-morbid complications typically associated with Dravet Syndrome. Despite not having solid answers for those prior years, we were very fortunate to learn about early intervention services. Having access to a variety of services opened up so many other opportunities for her and our family as a whole. Those experiences early on, surely helped Jackie develop the confidence & skills that she has today. Our family has eternal gratitude for the massive village of amazing people who have become a part of our lives. The Family Support Networks of the High Country and Western NC were a tremendous source of support and encouragement for me back when I felt as if I was searching aimlessly for answers. They continue to be an integral presence in our lives today. Through attending their workshops and trainings, I have gained tools and much needed strength to be a better advocate for my family and others facing similar struggles. We have also been blessed to form long standing relationships through attending their support group meetings. The demands of raising a child with significant health care needs can be very isolating. When you're continually faced with so many obstacles, sometimes the best medicine is knowing that you are not alone. It is a very bittersweet feeling at times.

Learning to accept the roller coaster of grief that we as parents often find ourselves riding has been one of the most healing parts of this journey for me. I know that it is okay to take on the world today if I want to and it is perfectly fine if I am unable to. I understand now that less can sometimes mean so much more. Acceptance has many faces. We all deal differently and at our own pace. Learning to be okay with where we are today and enjoying these moments together makes a real difference in our quality of life. My daughters are teaching me so much about life. No matter where you are on the roller coaster, there is true healing in simply enjoying this chaotic ride. Holding Hope. There is real beauty in spirit when you find yourself embracing the journey.

To learn more information about Dravet Syndrome please visit Dravet.org & Dravet Syndrome Foundation

Join us on Facebook @ Jackie's Journey
YouTube Channel : hope4dravet

Tips for Shifting from School Year to Summer Break

- * If you and/or your child thrive on routine, build as much of it into your summer schedule as possible and REVAMP—but don't eliminate —your child's daily routine.
- * Prepare your child for his/her schedule
 - ◇ Have your child contribute to the family calendar and post on refrigerator
 - ◇ Review with your child frequently to prepare for the day or week
 - ◇ Involve your child when preparing for family trips and activities
- * Be prepared to be spontaneous: Make a list of place to visit and things to do when the mood strikes.
- * Don't succumb to summer stress! When stress strikes, try to shrug it off and find humor in the situation.
- * Encourage summertime learning: Visit the library, museum, or even explore in your backyard. There are mountains of opportunity to learn about history, geography, and nature in the summer.

Spring in a Bottle

What you'll need

- * Clear 2-liter soda bottle
- * Small flowerpot
- * Potting soil
- * Seeds
- * Saucer
- * Craft stick marker

Directions

1. Cut the top from a clear 2-liter soda bottle.
2. Find a flowerpot that fits inside the dome. Fill the pot with potting soil, then plant the seeds according to the packet directions.
3. Place the pot on a saucer and poke in a craft stick marker. Slip the dome over the pot. Be sure to water the soil when it looks dry.



Love and Logic: One-liners

Remember: The "one-liners" are only effective when said with genuine compassion and understanding. These are never intended to be flippant remarks that discount the feelings of the child. If an adult uses these responses to try to get the better of a child, the problem will only become worse. The adult's own attitude at these times is crucial to success.

"Probably so."

"I know."

"Nice try."

"What do you think you're going to do."

"Don't worry about it now."

"What do you think I think about that?"

"I don't know. What do you think?"

"I'll let you know what will work for me."

"I bet it feels that way."

"Thanks for sharing that."

"That's an option."

"I'll love you wherever you live."