

## **The Voice of Experience**

By Annette Alve, mom of Eliza

### **Eliza Turns Twenty-Four**

It has taken me twenty-four years to write this. I'll tell you the end of the story first, so you don't have to wait. I know about waiting. When your baby is born different, you wait for the results of blood tests. You wait for CAT scans and MRI's, praying they will put an end to the fear that's filling your lungs. You wait for the doctor to hold up the films and say with a smile that, after all, everything is going to be all right. And then you wait, with each subsequent test, each new medicine, you wait with hope that, soon, all will begin to be the way you thought it was going to be.

I am sitting here with two photographs. On my left is one I have carried in my wallet for over 22 years. It's my daughter Eliza at 17 months in her pajamas smiling up at me from the floor of the bathroom shower. She's wearing pink and gray slippers with goofy mouse heads at the toes. The left side of her face is a deeper pink than the fabric lining the mouse ears. I can see splotches of birthmark on her left hand and arm. Over the years, when I've shown people this picture, they inevitably end their remarks with, "It's not that bad."

But her father and I knew it could be "that bad." Her birthmark went deep into places we could not see.

On my right is an 8 x 10 photo of Eliza at age 24. It's her college graduation picture. To get this, I had to pull a guilt trip over the phone. "Okay, you refuse to go to graduation, so please do your mother this *one thing* and have your picture taken. I want to see you in the 2008 University of New Hampshire yearbook." She's a good kid. She'll make a great nurse.

I rode my bike around lower Manhattan just a few days before I went into labor with Eliza. I worked on Friday, went to the movies on Saturday night, and after two pushes on Sunday morning, I delivered a baby girl. The nurse took her away and within minutes I was surrounded by four doctors: my obstetrician, an ophthalmologist, a neurologist, and a pediatrician. I asked my husband what was wrong. He said, "Oh, just a little purple on her face." When a nurse put her in my arms, the doctors peered down at us and observed, pleased when she began to nurse. Finally, I was able to see my baby. The entire left hemisphere of her head was the color of a deep purple plum; her eye shrouded by a milky fog.

For many years I felt embarrassed by one of my questions to the doctors during those first few minutes of life with Eliza. I asked, "Will she be able to have children?" I remember one of the doctors saying I was getting a little ahead of myself. I felt ashamed for asking what appeared to have been a silly question regarding a child who was only minutes old. Now, when I remember that moment, I feel only tenderness for my scared, younger self. I also know that it was a perfect question. Because to pose that question was to seek an

answer to the more profound: will my child find love and a sense of belonging in this world?

I know there are children who have serious medical conditions that may prevent them from having the opportunity to climb trees, kiss on the back steps or give their mom a graduation picture. But if there is anything I have learned in all these years of raising a daughter at risk from a myriad of problems that can accompany Sturge Weber syndrome, it's that love and belonging and success are up to each one of us to define for ourselves. As soon as I expanded my ego-driven thinking beyond pom-poms and pink prom dresses, I embarked on my own sort of freedom walk. I began to see this child – not my imagined child, or a Hollywood-child -- but *this* child, the one for whom I was chosen to help grow up and find her voice and place in this world.

Nobody who grows up with differences has it easy. At one support group for people with birthmarks, I remember a woman in her early 20's rubbing at her cheek and lamenting, "I just hate this thing." That thing was about the size of a dime. I wanted to stick my baby's head in her face and say, "Well, how would you like to grow up with this?" I felt angry, life had been so unfair to my daughter and how dare this woman complain about that pitifully small red dot on her cheek? Yet, she did have the right; only she knew the full context of her pain.

Maybe the burden of difference is the gift of opportunity. Parents of kids with differences need not sit at Buddha's feet to know opportunity for enlightenment flows from suffering and acceptance of what is. The luckiest among us will learn that even a responsive blinking of the eye, grasping a spoon, or mustering up the courage to put on party clothes and hope for a dance partner can be as significant an achievement as receiving that proverbial piece of sheepskin. It's right there for all of us, if we can open our minds and hearts to follow that unusual path.

The first night after I brought Eliza home from her four days in intensive care, I dreamed I carried her into a tropical forest, feeling like I'd stepped into one of Gauguin's Tahitian paintings. I came to a dark pool of water where people were languidly swimming, bathing or brushing one another's long dark hair. I looked around and noticed they all had birthmarks. With trusting faces, they beckoned me to join them. I wanted to get out of there quick. I didn't want my baby to belong to them. They were different. I ran away, looking for the pool filled with all the normal people.

It's taken me all this time to find my way back to that first pool. Early on, Eliza began to lead me, and, step by step, I began to trust her sense of direction. She's the one who got me here. Really, I just followed. As for that pool, if I could have opened my dream-eyes on my first stop there, I would have seen what I can see today: hundreds and hundreds of worn paths connecting a million pools, a million people, and a million different, loving hearts. (*photos – please imbed these photos or overlap*)

*Annette Alve works in Westchester County, New York, coordinating programs to empower women and build healthy families. She welcomes your e-mail.  
Alve1@optonline.net*

## *Family Matters*

### **Sometimes It's Hard to Be a Couple with Kids**

By Annette Alve

The first time my husband and I took our daughter Eliza on an outing we ended up in a fight. All because of a stroller. Maybe we were just clumsy parents, but that stroller about did us in. It was one of those cheap ones you could fold into the size of an umbrella. He unfolded it and I gently placed the baby in and strapped her up. He hooked the backpack full of diapers, pacifiers and bottles on the stroller's handles.

Eliza cries. I rush to pick her up. Stroller topples back on its handles. Backpack was left unzipped. Bottles and diapers scatter across the sidewalk. We glare at each other.

You don't have to pick her up the second she cries!  
Well, you didn't zip the backpack!  
As if I had time.  
You had time to light up a smoke.

We stumbled around town silently worrying: "He cares more about his needs than the baby's." "She's overprotective, just like her mother." Our marriage began to feel like that stroller, going all off kilter with the ups and downs of the baby. But soon enough, like all other couples, we learned how to keep the stroller upright. It was balancing marriage and a child with medical issues that wasn't so easy. Sometimes it brought out the best in us, other times, the worst.

The divorce rate is higher among couples who have a child with a disability. A study in the *2006 Journal of Marriage and Family* found that fewer than half of disabled children live in a married two-parent home, while 62 percent of children without disabilities do. In divorce, primary responsibility usually falls on the mother -- children with disabilities are more than five times as likely to live with single mothers as with single fathers.

Perhaps even more frightening is a report by the American Academy of Pediatrics in 2001 indicating that violence against disabled children (perpetrated by parents and outsiders) occurs at rates at least 1.7 times greater than their non-disabled peers. High levels of stress and hardship can lead to child abuse. And let's face it, who hasn't felt the urge to hit something when pressures feel unbearable?

It may be that this article is an exercise in "preaching to the choir." Most likely, the parent who can benefit most from exploring his or her feelings regarding the birth of a child with a disability or difference is the one *least likely* to pick up an issue of *Branching Out*. Avoidance is a common coping mechanism, and sometimes, it's a form of survival. It takes a bit of finesse and lots of patience to help a person go where they are afraid to go. A supportive partner and a good therapist can do wonders.

Other couples have been through the stress and strains of raising a child with medical, physical, mental and social challenges. If you are struggling with feelings toward your child, partner or marriage – here is a list of Stress-Preventers other parents of kids with disabilities have told me worked for them:

## 8 Stress-Preventers

**Share Your Dark Feelings** – From parents of babies to those of grown children, they all said the same thing: When they dared to share their feelings, especially those causing the most guilt and shame, they felt relief and closer to their partner. One father said the burden of what he felt on the day the doctor disclosed a hopeless-sounding diagnosis of Sturge-Weber syndrome almost crushed him. He had hoped the infant would die in her sleep that same night. Much later, in healthier times, he could no longer contain his guilt and he confessed what he had felt to his wife. That brave conversation strengthened their bond as a couple and as parents because, finally, his wife felt the security and freedom to confess that she had hoped for the same thing that same night.

**Don't Judge Your Partner** – Everyone reacts to disability and difference in their own unique way. Some mothers become super moms, feeling everything must be done perfectly and the child always comes first. Some men (or women) may not feel that way. It doesn't mean they love their child less; they just cope in a different way. Identify what a parent struggling to cope *can* give and *can* do well, then build on that. There are parents who become ever-vigilant for signs of illness or disability. Allow them to express their fears, then help them assess the situation and develop a plan of action.

**Get Outside Help** – Be aware of your stress levels. One mother admitted she sometimes felt close to being rough or even hitting her relentlessly crying, needy baby. Admitting and acknowledging it enabled her to put the child safely in her crib, close the door and walk away. She had a cup of tea and didn't return until she was calm. Many parents have the urge to be rough with their child – it doesn't make them bad parents. It makes them parents who need a break from parenting and some tools for coping with stress. The happiest couples had extended family near them to help with childcare. Find help in your community if you don't have family to lend a hand. Become involved in an outside activity so you interact with others and won't feel isolated.

**Honor Your Partner's Need for Time Away** – One father said he looked forward all week to the Friday night poker game with his buddies. His wife made sure she was home Fridays so he had his night away from the kids to just be a “guy” again. And he was certain to be on kid duty when she played basketball once a week or needed a long, solitary walk. Another dad needed to go on a fishing trip every so often. His wife recharged her batteries with a day of shopping and dinner with friends. Time for moms and dads to be away from home enjoying themselves was respected and deemed just as important as their time parenting.

**Shed Your Parenting Role** – Remember you fell in love with an individual, not a parent. It's easy, especially for mothers, to begin mothering 24/7, losing themselves to that

singular role. Make it a priority to occasionally step out of that role and spend some lighthearted time with your partner – and for heaven’s sake, when you do, don’t talk about kids and doctors and broken appliances.

**Go Easy on Fathers** – Support services are often focused on the mother and child while the father is left out or bears the brunt of bad news. Some will work longer hours to avoid their fears at home or in an effort to reduce worry about their child’s long-term financial needs. Conversely, some discover a positive, profound and transforming depth of feeling. Others report overwhelming fears; an inability to accept the disability, and stress that drains and disorients them. An atmosphere at home of disappointment and criticism of their parenting skills will distance a father still more. Seek outside support if a father, or mother, is becoming distant and detached.

**Live in the Present, Have Faith in the Future** – One father said he stops himself whenever he begins thinking too far into the future. Train yourself not to imagine all that *could* go wrong. Practice imagining positive outcomes. In times of stress, one mother chants the phrase, “This too shall pass.” She said it gives her a calming strength to endure a tough, temporary situation. Belief in a higher power gave everyone strength.

**Connect with Other Parents** – Joining the Foundation’s on-line support group or talking to other parents on the telephone or in person helped moms and dads feel less alone on their journey of raising a child with problems. Some felt left out of community and social activities, stigmatized or afraid of how to handle the public’s reaction to their child’s birthmark. Having other parents who could relate to those feelings and share how they coped gave them comfort and reduced feelings of isolation.

Nurturing and maintaining a relationship can be stressful even in the best of circumstances. But for most couples, and their kids, the long term benefits of staying together far outweigh the short term wear and tear on their hearts and minds. When stress is building all around you, take a minute to step back, breathe deeply and remember that wise mother’s chant, “This too shall pass.”

### **A couple of good reads:**

“Growing Together or Drifting Apart? Children, Disabilities and Their Parent’s Relationship,” at: <http://www.oneplusone.org.uk/publications/growingtogether.pdf> is a 2007 study from the UK.

A good book, especially for fathers, since it’s written by a father who’s been there.

### **Special Children, Challenged Parents**

**The Struggles and Rewards of Raising a Child with a Disability, Revised Edition**

By Robert A. Naseef, Ph.D. 2001

*Annette Alve has been with the SWF since 1991 when her daughter, who is now an RN, was 7 years old. Eliza’s photo and story are in the previous issue of Branching Out. Annette works with the Westchester County (NY) Division of Women’s Services.*

*In preparing this article she spoke with several SWF families who were willing to share their hard-won wisdom. Thanks especially to Mary and Sam Dalton, parents of 3 year old Gabriel, and Larry and Fran Layman, parents of 38 year old Chad.*