



FATHERS' PERSPECTIVES

EMILY'S LEGACY

By Ron Wells

Lisa has always been the “better parent”— she works with kids, has the natural motherly instincts, and sees things for what they really are— so naturally, she began to see problems with Emily’s development before I did. In some ways we were lucky with her diagnosis and doctors because of Katie Belcher, daughter of PPG members Dan Belcher and Mary Wermuth. After the initial visit with the neurologist and a trip to an ophthalmologist, they knew what we were facing. Our neurologist was very honest with us and we had both of our mothers with us in his office for the terrible news.

Our family is a strange mix these days, my parents divorced when I was 4 years old and I have had very little contact with my father. We told him about Emily’s disease but he never bothered to meet her. Lisa’s father died before I met her, so we don’t really have a huge male perspective. During the whole course of Emily’s life and death I tried to focus on the good times and make everyday count and be supportive not only to Lisa but to all of our family members. At times I could tell things weren’t spoken or opinions weren’t stated. I thought we handled things pretty well though.

I have always believed that our kids are more than just dying children, suffering this horrible disease for whatever reasons. It sounds cliché, but I would rather have had Emily live and die as she did than to have never had her at all. Our kids are indeed angels but here for a while, gracing our presence with their

immeasurable personalities, unconditional love, peacefulness, and uniqueness.

Having Emily in our lives did indeed change me, I find that I am more patient and understanding. I also try to look at the big picture and keep things in perspective more than I used to. As a police officer I find that I am less compassionate with stupidity however. We hear everyone else’s problems and I truly have to bite my tongue frequently thinking to myself, “buddy, walk a mile in my shoes once, you think you got problems!” I usually try to interject a little wisdom and reality when dealing with people, depending on the situation, like after two cars hit each other and someone is always crying about their beautiful car being smashed up. I remind them that they can always get another car, fingers and legs are harder to replace.

Emily taught us so many things in so little time that this letter could go book length very easily. As her father, I will always cherish my memories of just holding her or stroking her hair and of course I miss those moments every day. I found that our family pulled closer together in the most difficult of times and that you truly discover who your friends are.

We had a butterfly release for Emily’s anniversary. A group of us met at her gravesite, then read some poems and played some of our memorable songs. The “ceremony” ended with the release of 16 monarch butterflies. It was so cool!!!

The company we used was the Magical Beginnings Butterfly Farms
114 Royce St., Suite H, Los Gatos, CA 95030
www.butterflyevents.com

I would be remiss in not mentioning the other fathers I have met during the annual conferences. I always say that it’s the only place in the world you feel comfortable with wheelchairs, feeding tubes and bags, suction machines, and oxygen tanks. Our strange lives at home completely change at the conference, the playing field is leveled and the discussions are usually frank and honest. As much as it hurts to attend, I can’t put a price on the men’s group.

I guess our biggest mistake as fathers is assuming that we are the rocks, the pillars for the foundation of the whole family. Society is partly to blame, but in our lives and coping with our kids I have learned that we are all in this together. There were days when Lisa was the strong one and took charge and vice versa. Just because you’re the man doesn’t make you invincible, indestructible, and coated with Teflon. Share your feelings, lean on that shoulder when you need to, and when someone offers help, take it.

We show Richard pictures of Emily all the time and he now says “Emmy,” when he points to them. That is what being a father to me is all about, passing on things I have learned on to him and any other children we have, and keeping Emily’s legacy alive.