

## 'Semantics ~ Words Play a Part in How Families Perceive and Deal with a Chronic Disorder'

One year after Kristen died suddenly from what they initially called Reye's Syndrome, Kevin was born. Kristen is NOT here because **her MCAD was UNDIAGNOSED** and Kevin IS here because **his MCAD was diagnosed AT BIRTH** ~ which is **when ALL children should be tested!** At age 13, Kevin is strong and intelligent and very active being a teen! We all KNOW how THAT can be! And we have Brian (11.5, MCAD carrier) coming up quickly on the teen scene as well.

And to think **it could have been so different if 14 years ago we KNEW about MCAD!** Because it was, and still is to some degree, an unheard of disorder among MANY professionals, when we heard Kevin's diagnosis we were devastated and frightened because we immediately thought it was another 'death sentence.' We felt Kevin would get ill and die.

It wasn't until we gained more information by traveling to see Dr Roe and gaining daily experience of giving the Carnitor® and making sure he ate often that we moved from perceiving his disorder as a disorder and NOT as an illness.

After the shock of hearing his diagnosis finally wore off, **we CHOSE to view his disorder as a FAMILY CONCERN, not Kevin's problem.** We were going to deal with this as a family and not try to make Kevin feel like he was so different, even though his disorder IS different than what most have heard about.

Even though we as a family chose to perceive his MCAD this way, oftentimes the outside world had a completely different view. At first I would just fume when people would say "He doesn't LOOK ill." And I would tell them (taking deep breaths and trying to stay calm!) "He's NOT!" He has a disorder that we have to watch closely on a daily basis, but **it doesn't have to overSHADOW our lives as doom and gloom.**

**We CHOOSE to use ACTIVE**, not passive words ~ **words that TRANSFORM and ENLIGHTEN** ~ instead of darken and cause one to stay stagnant. I used to get upset (actually I still do!) when people would say parents should just ACCEPT their child's death (or diagnosis) and just move on. Yes, moving on IS important and it takes a great deal of courage and grief work, but I, speaking only for myself, certainly **DO NOT ACCEPT** Kristen's death! And I don't mean that I deny it.

If you recall from the last newsletter I referred to what I call '**residual grief reality**' ~ **I don't believe ANY parent ever FULLY ACCEPTS a child's death...that's part of their new reality. Accept is NOT an acceptable word to me** and for how I see my grief and working through it. It conjures up for me a "Get with it, Deb, and get over it" perception ~ not one that I will own!

I prefer to use the word **ACKNOWLEDGE** over accept. I **KNOW and UNDERSTAND** that Kristen died from undiagnosed MCAD (and I KNOW Kevin has MCAD). **That doesn't mean I HAVE to ACCEPT that in order to grieve in a healthy way!** People can argue and say that I'm playing with words ~ I'm not ~ I'm just trying to express

myself with words that have more meaning to me and grasp how I **SEE and HONOR my FEELINGS and THOUGHTS** about life and loss and death.

If you look at your own life, you can probably trace back where your own beliefs about life, adversity, loss and death were developed ~ and those early beliefs, role models, religious/cultural beliefs and rituals, etc. play a part in how you use language and how you act out those words in behavior. **My 'loss history' started very early...as a 3-year-old with 5 siblings under 10 years old and a mom dealing with the sudden death of her husband/my 'papa' at age 36!** I'm sure many of you have been there yourselves and it most definitely has an impact on how you SEE things as you grow up and how you grieve (if you allow yourself to grieve) when a child of your own dies or has been diagnosed with a genetic disorder.

**Kevin DOES have a chronic disorder** that will be with him for a lifetime, but that **doesn't mean he is ILL**, as I mentioned before. He may have some days where he gets sick, and we don't take those lightly, but we try to keep them in perspective. We make sure he gets what he needs, we know what we have to do and we do it! Overall on a daily basis **he is as ALIVE as any of us!** Ask his brother, Brian!

Don't get me wrong ~ I'm not trying to sugarcoat these disorders or reality by using "New Age" type words. I am just sharing with you how I **SEE** things and which words I **CHOOSE** to use to explain my vision of **MY** reality and how it's made a difference in how I cope with MCAD and the ramifications of it going **UNDIAGNOSED**. The point I'm making is that **no matter what adversities are 'thrown' at us, we STILL have a CHOICE in HOW we perceive those circumstances.**

It has been shown in research (in my own unscientific words!) that those that perceive the cup half full rather than half empty get through adversities in a more positive manner and are probably healthier for it! If you live in negative self- and other-talk ALL the time it takes its toll individually, as a family, and in all your relationships.

**We choose to see both Kevin and Brian as they are...**as individuals trying to grow with each day, making mistakes along the way (as we ALL do) and trying to have some fun in the process. It doesn't negate that we are serious about his disorder but it sure does lighten things a bit as far as stress is concerned. That didn't come overnight though. Those of you that are just beginning this journey, let me tell you that I DO understand where you are at!

**It IS a reality** in our family that we have already experienced one death due to UNDIAGNOSED MCAD and that **there will be illnesses** along the way for both our boys, but that **doesn't mean I have to think of Kevin as ILL all the time just because he happens to have a metabolic disease.** In fact, in order to defuse the 'medicinal' atmosphere of having to take the Carnitor®, we use the word 'vitamin' instead of medicine. To me, taking medicine is usually in the context of being ILL and Kevin is NOT ILL. So in order to promote a more uplifting atmosphere we use a word that signifies NURTURING HEALTH instead of trying to fend off ILLNESS.

After all my rambling, you probably get the idea that **words impact perceptions and vice versa.** Take, for example, how one views the percentages given each child for having an FOD. There IS a 25% chance of having it but there is a 75% chance of NOT

having it. Which do you CHOOSE to focus on? Of course, when a couple is trying to decide whether to have more children, it all depends on your very own individual circumstances. You may already have a child that is experiencing several difficult effects of serious episodes and requires a lot of care and energy on a daily basis, so you may make the personal decision not to have more children. Yet, even in that circumstance, **you still have a CHOICE of HOW you are going to perceive those circumstances ~ as a challenge or as a burden ~ it makes a difference!** Your perception will definitely influence your actions toward your child and the rest of the family. **If we as parents spend so much time in what we have 'lost' (i.e. the so-called perfect healthy child) we miss out on what we DO have ~ children that REALLY need us and love us and bring joy to us no matter what challenges are ahead!**

If you recall the book reviewed in our January 1998 newsletter, ***Special Children, Challenged Parents***, Dr Naseef stated that point in a similar way ~ acknowledge that your child has medical concerns but try and meet him/her where he/she is at and move forward from there.

Try to **be aware of your own use of language when talking with others or even within your own self.** It carries over to all aspects of your everyday living. By changing your words your overall perspective can be transformed from feeling victimized, burdened, and destined for years of pain and sorrow to a life where **you learn to control what you CAN control, you view adversities/obstacles as challenges, and you make a commitment to always advocate for your child/children.** And in so doing, you not only make a difference in your own life, but in the lives of your children, family, friends and others that come into your life! All by envisioning new ways of using words positively and actively.

**I would give anything NOT to have to deal with Kristen's death and Kevin's disorder and I wish there was no such thing as an FOD ~ but the REALITY is, in MY eyes, I have CHOSEN to deal with them, as much as I don't want to ~ I NEED to!**

What it comes down to is this...You can choose to be DEFEATED by having to deal with these disorders or you can **CHOOSE to be an ACTIVE ADVOCATE** for yourself, your children, and children yet to be born! I have **great FAITH and HOPE that the LOVE you have for your children, both living and deceased,** will show you the way and give you the strength to **NEVER GIVE UP!**

Deb Lee Gould, Director, FOD Family Support Group  
July 21, 1999  
Kristen's 14th 'anniversary'