

'HOPE...in the eyes of a parent'
inspired by and in memory of Ryan

There is ALWAYS hope...it just may not be or look like we feel and think it **SHOULD** be!

Many of my articles are fueled by my conversations with parents, just as the 'Find the Light in the Darkness' article was (*on our site, Coping and Healing page*) ~ where a professional wasn't going to tell a new FOD Family about our Group because she felt our newsletter was 'too depressing' for the family to read. In other words, this professional was basically telling this family that it's **HOPELESS** to find any kind of 'good' support out there because there isn't any at this time! **She was making decisions for this family ASSUMING they wouldn't want to read about LIFE and REALITY and all because it was too depressing for HER!** Of course, there's support ~ it just doesn't 'fit' what others perceive as supportive ~ which to them may mean, "Let's not talk about death." **Trying to protect families FROM reality as well as DENYING them their right to decide for themselves what is supportive is WRONG.**

Just as wrong is when someone tells a family that, "It's no big deal, the treatment is very simple. We have this all under control.No need to overreact." What that does is **dismiss or minimize the seriousness of the disorder**, possibly leading families into denial or thinking that they REALLY don't have to be concerned. You may think that doesn't happen ~ but it has and it does.

Hearing that message from a medical authority, on another subconscious level, also seems to magically 'absolve' parents/grandparents for having passed on a defective gene. That may sound like a bunch of psychobabble but let me tell you, I've spoken to enough families over the last 11 years to hear 'guilt' even when the words aren't actually spoken!

None of us wants to think that we are responsible for our child's disorder. Of course, **when you put things in context and realize that NO ONE knows for sure which genes will be passed on and in which combination**, it's totally unrealistic to think we're responsible for knowing that we are carriers (*since diagnosis is often AFTER newborn screening, an episode or a death and BEFORE we know we're carriers!*) or even when we DO know, we need to remember that there is **MORE of a chance that EACH child WON'T have a disorder (75%) versus having it (25%).**

Waiting for some outside entity to tell us it's no big deal or to absolve us of guilt or fear is NOT what HOPE is about. However, **dealing with those issues of guilt and fear/stress** (*discussed in other Coping and Healing articles on our website*) **is a highly PERSONAL PROCESS that takes time and a lot of internal work and it CAN impact how you view hope for the future.**

Sometimes that can be done by yourself, but in some cases it may help to talk with a counseling professional if they are causing concerns in your life. This is getting away from my main point but in a strange sort of way, **this type of message almost skews hope at the other end of the continuum** ~ implying there's hope for your child and future children, because "It's no big deal!"

There's hope all right. It's just NOT because it's "No big deal!"

When a family hears a diagnosis of a rare disorder, the **initial hope may be for a cure**. However, as more information is gained and realizing that there is no cure, that hope may be **readjusted to being able to treat effectively**. And depending on the situation, that hope may need further 'readjustment' as time goes by and experiences change.

But what happens to hope when you hear that your child is going to die because there is no effective treatment so "Just go home and enjoy your child while you can." Statements like this have been made to some of our families ~ talk about blasting all hope (*according to the 'normal' definition/use of the word*) for this family into the stratosphere! That professional or any person for that matter may be stating a 'cold fact' based on what few cases have been seen of a very severe form of an FOD, but **HOW that 'fact' of inevitable death is conveyed has a HUGE IMPACT on how a family perceives hope!**

Having experienced **various transformations of hope** myself (*when we were given Kevin's MCAD diagnosis I/we IMMEDIATELY thought he was going to die suddenly as Kristen had, until we gained more information*), I try to compassionately convey to parents that have just been given that heart-wrenching prognosis that **hope can be perceived in different ways, for not only the benefit of their child, but for their own present and future coping and dealing with their child's (or other loved ones) condition, as well as death, whenever that may be.**

Parents often feel so helpless AND hopeless when they hear a prognosis like that ~ especially when it's given in such a detached and many times unemotional way. Parents have told me that **they feel as if the doctors and others have "given up" on the child and family**. Now, before you jump all over me about Drs sometimes being detached and cold, I realize that SOME may present that way to really 'protect' themselves from feeling too much and getting attached ~ if they get too attached they might not be able to do the kind of work they do. I understand that thinking ~ however, **that still doesn't mean that the content of a devastating message can't be given in a more compassionate and caring way. 'Bedside manner' DOES make a difference!**

I'm here to say that despite what the eventual and inevitable 'outcome' will be **HOPE IS STILL POSSIBLE, yet in a different way**. It's not a matter of debating whether knowing ahead of time is 'better or easier' than a sudden death ~ that isn't the point. The point is if you can work through your fear, anxiety, guilt, and other emotions of grief instead of focusing ONLY on the 'inevitable outcome' that was devastatingly placed before you, you can **take each precious moment in the PRESENT and cherish it NOW, so those memories will be with you to help you in the FUTURE.**

You can also try to make your child as comfortable as possible during this time ~ families have sometimes been 'advised' (*directly and indirectly*) from having certain procedures done (*i.e. gtube*) because "it won't do any good" ~ but if it makes your child more comfortable instead of fighting for every ounce of energy or strength for days or weeks or years, than it **WILL DO SOME GOOD!** If you can embrace your circumstances and your child from **THAT** perspective, **it opens you up for channeling some of your**

heartache in a more HOPEFUL way...and benefiting you and your child in the process. Hope CAN BE transforming for all involved!

Intellectually acknowledging that yes, a death may happen soon, LOOKS like all hope is gone, but it really isn't. **Saying that there's absolutely NO hope is a false statement to me.** There may be no hope for an absolute physical cure of some disease but that doesn't mean that ALL hope in ALL realms is nonexistent!

When you **perceive hope 'wholistically' you become more open to other meanings** for yourself. By not just 'staying up in your head,' and **experiencing what is happening with your mind, body, AND spirit ~ you will SEE how hope can be transformed from the darkest of darkness to a new kind of 'lightness.'** It certainly may not look or feel that way the moment you hear a shattering prognosis, but over time, **it IS possible if you BELIEVE it's possible.I KNOW firsthand it's possible!**

Hope comes in many 'colors.' I happen to be drawn to '**yellow**' (*as evident by our pamphlet, card, and 'my rose'*). For me, it brings me that light and strength when the 'shadings' of hope may not look so bright. Every time I see or think of a **small yellow rose, memories of Kristen flood my being and in a strange sort of way I draw energy and HOPE from that.** As odd as it may sound, THAT is what the true power of 'mystery' and spiritual connection is all about and it CAN have a transforming effect on the rest of your life.as well as your family's life!

On that note, I'll end this as I began ~ **There is ALWAYS hope...**it just may not be or look like we feel and think it **SHOULD** be!

Allow YOUR more enlightened vision of HOPE to transform your own lives.

Deb Lee Gould, Director
FOD Family Support Group
July 21, 2001
Kristen's 16th 'anniversary'
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