

'Our Connection in Spirit...'

How important is it for humans to be connected with others while facing challenges in life? That may seem to be a simple question with a simple answer, but let me tell you, it's far from simple.

Many of us strive to connect with other families and professionals across the world dealing with these disorders, but there are some that choose not to. I won't guess at the reason for that or sternly judge anyone if they don't reach out to others, but what I **CAN** say is that **SUPPORTING EACH OTHER IS VITAL in ALL aspects of life**, not just when dealing with a rare disorder. **Yet, you can't be supported or even perceive that others are offering support if you're not open to receiving it.**

The FOD Family Support was not created to provide ALL the answers or invincible and proven suggestions to families. **Although we were painfully 'birthed' due to NOT having knowledge and answers about FODs, we chose to focus on offering the intangible and often 'inarticulateable' dimension of connection and emotional support, a connection that crosses all boundaries of space, time, and all other human characteristics and systems** (i.e. race, religion, politics etc) ~ a connection that is also presently being demonstrated so poignantly by men, women, and children across the world after the September 11, 2001 terrorist attacks. **PEOPLE NEED PEOPLE!**

[As a personal aside, it was encouraging, as well as inspiring to see so many men, whom often may feel in our society, that their masculinity is threatened if they express the emotional part of themselves, to allow themselves to fully feel and to hug another experiencing such horrific pain instead of cognitively 'staying in their head' in order to cope with the totally incomprehensible events. **It was and is an extraordinary example of how HUMAN SPIRIT and FAITH, HOPE and LOVE can be the salve that will 'heal one's fractured heart' over time and with much grief work. I HOPE that men, as well as women, boys and girls, continue this 'breaking of the shell' ~ it makes for a more REAL and TRUTHFUL and FULFILLING LIFE!]**

Just as there is a wide and varied spectrum of how children/adults **MEDICALLY** present and respond to an FOD, there is a **similar spectrum associated with how individuals/families EMOTIONALLY cope when faced with a rare metabolic deficiency.**

A while ago, I spoke with a new FOD mom that wanted to hear that things definitely would be okay and I couldn't 100% guarantee that. All I could offer was that most of the time once a diagnosis and specific treatment begins, and IF it's earlier rather than later, then the kids usually do okay and create their own kind of 'normal.' Then on the emotional level, **it's up to the families to work hard at**

living and coping WITH this challenge instead of fighting AGAINST it and themselves.

I mentioned the spectrum of how these kids present and gave examples of how some responded when diagnosed/treated from birth versus later on (i.e. refer to our Cost Benefit Analysis on our website's NBS page), some experiencing residual medical complications with seizures, gtubes etc., and **the anxious mom said, 'I don't need to go there' ~ meaning she didn't want to hear anything other than positive things. She didn't want to hear REALITY!**

I wish I could be ALL 'positive' when talking with new families, but that's not real life! Yet, being positive is a very relative state depending on your own context ~ to me, just **GETTING** a diagnosis is positive compared to having none!

Life is full of challenges and having a child (or yourself) with a disorder can present a family with spiraling ups and downs over time. Hopefully, **you'll CHOOSE to PROACTIVELY take on these challenges** rather than be frozen in denial and wish or pretend they didn't happen to your life or your child's life!

Soon after talking with this mom, **I had another call from a new family that demonstrated this proactive approach.** They had just gotten a diagnosis the day before and were already researching information on the Internet and making calls to other FOD Families with the same disorder.

I also mentioned to them the wide spectrum of presentation and they acknowledged that possibility instead of dismissing it as the other family had. I have yet to hear back from that first family. That's frustrating, but I can't make decisions for people. They have to **CHOOSE** for themselves how they are going to cope and deal with what's presented to them. **Some unfortunately prefer the 'head in the sand' way over the 'I Am/My Child IS WORTH ADVOCATING FOR' attitude!**

It's not about me, or anyone for that matter, stating cold hard facts in an in-your-face way (i.e. "Your child has an FOD, deal with it!") ~ it's about **CONNECTING COMPASSION and REALITY.** I call it **'Compassionate Realism.'**

It's about discussing a family's particular situation and what the facts are (i.e. results of tests, definite diagnosis, medical concerns etc), as well as combining that with **'listening for and hearing' not only the spoken emotions and fears, etc., behind the diagnosis and 'coping' with it, but also the unspoken ones, the ones that carry a lot of power, at least until they are voiced and validated and expressed in a constructive way.**

This is where the **importance of SUPPORT comes in.** Instead of struggling in silence, children/adults can connect and share those emotions, thoughts, and doubts etc., with other families walking a similar journey ~ diffusing some of the

power of those unspoken fears. **It can't take away your own personal and family challenges, but it sure does help to NOT FEEL ALONE on your journey.**

For those that are 'closed' at this time to support or connection or facing reality TOGETHER rather than alone, I will say, **there is always HOPE that someday you will feel safe enough to face your/your child's challenges HEAD ON and TOGETHER with others in our Family Support Group or with your family and friends. Just KNOW that we will be here when you are ready to experience that vital and vitalizing connection in spirit!**

Deb Lee Gould, Director
FOD Family Support Group
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