hep

Everyday Life

June 22, 2015 By Kimberly Morgan Bossley

Found a note the other day in my journal I began writing shortly after learning my disease had advanced to Stage 4. There is so much today that I still feel here. I have cleared the virus but I still have the residual effects of a cirrhotic liver, including hepatic encephalopathy. I am not what I used to be but I am happy and I am a fighter wanting to survive.

The smile on my face is more for you than for me. The giggle you hear is put there to hide the underlying constant thought of fear and uncertainty that occupies my now everyday life.

Waking up with stiffness and achy feelings all over. The stomach growling in hunger yet you know when it is time to go eat the thoughts go immediately to "Can I have this or should I be eating this?" What is good for my liver? As I begin to eat what I finally believe would be a good choice, suddenly not so hungry anymore. As I stumble through my morning rituals I find as I climb out of the shower that my body is worn down as if I just ran a marathon. Grasping my breath as I get dressed I lay down on the bed to regain my strength. All while thinking, "How can I possibly do anything today?"

What feels like seconds was in reality 15 mins of being still; I am faced with kids hollering "Mom it's time to go…" I jump up and put my shoes on, as lord knows the sensitivity in my feet nowadays. Anything not protecting them causes extreme pain. I race to the car, get in and sit in a daze…"What am I doing?" The kids look at me like I have lost my mind. To me, I feel as though I have. Searching from side to side looking for my keys, my son points to my hands, which were holding them all along.

Off and running we go… making it just in time for the last bell. I kiss my son goodbye and wish him the best of the best for the day to come. I watch him run to the door and remembering back to the day I gave birth. This little peanut is now a young man. A young man whom has had to learn to live with a sick parent. Both he and his older sister now have become my primary caregivers. My eyes wall up in tears as the guilt of putting this burden on them is more than I can bear. My daughter is now off to college and still calls several times a day to check up on me. She is not really living the "college life" as she is worried more about me.

There are so many things about this disease I wish never had to happen, but my life and my reality is now. I am faced daily with choices and uncertainties that no human being should ever have to face; no family should have to endure. This disease not only wreaks havoc on the patient but truly changes the whole family. No more spur of the moment outings, having a large group of people over to visit and entertain. Attending my kids' sporting events are met with preparation. Lots of blankets for warmth, a soft chair, gloves, electric socks and most importantly...pain meds. Never did I ever think my life would revolve around ME, my comfort, my pain levels. After all, I used to be an ALL about my kids type mom. I did everything for them, about them and for us as a family. Now, it is my two angels who are the ones insuring my comfort, and that my endurance is met with ease.

How does a parent look at themselves in the mirror and feel good about any of that? Not this woman. I am ashamed, humiliated, discouraged, and angry. I hate what this disease has turned me into. It makes me want to fight that much harder. IT WILL NOT BEAT ME!!

So until the next day, I pray, I stay positive as that reflects down to anyone who comes into contact with me. After all, nobody likes to be around a doom gloom person. I repeat each day the same.... With a SMILE ~

We all must remember to be kind to ourselves, our caregivers and our doctors. Surrounding us is full of a team supporting us to be better, to be cured and to be healed. Give today your all and know that with each day, and focus just on that day. In time, life eases as you learn to accept what you cannot change.

Remember “Not Without A FIGHT! ~HCV~Â©”   Together WE are STRONG!

Kimberly Morgan Bossley

To read more about Kimberly Morgan Bossley’s journey and story you can find it at www.notwithoutafight.org Also a very informative video on Hepatic Encephalopathy visit www.hesback.com