

The Wrong Road

At some point or another we all find ourselves traveling down a road that terrifies us. We desperately try to change direction; we break down and pray, sometimes for the first time; and we seek release from the horrific place we find ourselves in.

Sometimes if we are lucky, further down that road we discover the reason we had to traverse the rocky terrain.

I can hear my brother's words like it was yesterday. He was speaking about his seemingly perfect daughter, a mere seventeen months old at the time.

"The doctor told us there is no cure, no treatment and no hope. 50% of the children diagnosed will die before their second birthday. Take her home and love her."

My brother's words made no sense to me. I thought my niece was perfect. We all did. She had met all her milestones on schedule, except walking.

The disease is called spinal muscular atrophy. SMA. We soon learned it was the #1 genetic killer of children under the age of 2. In simplest of terms, people with SMA lose their ability to crawl, walk, sit, hold their head up, swallow and eventually breathe. Even more scary, 1 in 40 people are carriers of SMA.

I hung up the phone with no concept of the journey that lay ahead. The thought of my niece dying, possibly before she turned two was so devastating that I wasn't quite sure if I could cope.

I cried. I got mad. I wrote angry speeches in my head about the unfairness life had bestowed upon us. We were good people, I would yell to no one. We didn't deserve this.

Kicking and screaming, I was dragged further along the wrong road.

Sometimes when we are faced with such pain and anguish, incredible opportunities are placed before us. I am the first to say that recognizing these opportunities is not always easy, as finding anything good in something so bad is difficult beyond imagination. Regardless, opportunities will present themselves.

As a way of easing my sadness and helplessness, I decided to host a little fundraiser. Invite a few friends. Maybe raise a few dollars for an SMA-related charity.

Little did I know then, the impact this fundraiser was going to have on my life, the disease and the SMA community. Little did I know that I could make such a difference.

This is the lesson for today. Whether we are dragged down a difficult road, or whether we are living a life of peace and contentment, we all have the ability to make a difference. Given the current state of the world, making a difference is almost a social responsibility.

Making a difference can be as simple as smiling kindly at the cashier in a busy check-out line, even though you yourself are tired and in a hurry. It can be through volunteering your time. Giving money to a cause that is near and dear to your heart. Or even something as simple as offering a hand to a friend or stranger.

For those of you that find yourself being dragged down the road of difficulty, whether through a diagnosis, a marital split, the loss of your livelihood, or something else all together, there will be a time during the journey where the opportunity for change presents itself.

You may not recognize it because of the circumstances, but trust there is a purpose to the pain you are living with and be open to finding it.

That wrong road I was dragged down – it turned out like this. With the help of friends and family we created an annual event that had a major impact in cure and treatment research. To date we have raised over \$1.2 million dollars and have seen incredible headway in the quest for a cure and viable treatments. So much so that the National Institute of Health declared SMA to be one of the next three diseases to be cured.

I would never have asked to travel that road. To this day I would trade everything in a heart beat for my niece to be healthy and disease-free, but it is what it is. And I am thankful that I have had an opportunity to turn something so horrific from my life into hope for others.

It's about accepting that there are reasons for the difficult things we go through. It's about being open to learning lessons from our journey along those wrong roads. And in this case, it's about finding a way to turn the negative into a positive and make a difference in the world we live in.

Good luck with your roads of difficulty. Remember you are not alone, and be open to the opportunity to making a difference.

Peace along the journey,
Louise

For more information on the event or SMA visit:

www.rebeccarun.com

www.CureSMA.ca

www.fsma.org

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