

PONDERINGS ALONG THE PATH

By Nadine Boyd

Dear Compassionate Friends:

One of the life lessons I have really struggled to learn (and am still learning) is that life is not fair. When you are young and idealistic you have plans for the future and somehow you think if you are a "good" person you will have a happy life. You think if you try to follow the laws, pay your taxes, be a good employee, wife, husband, parent, (_____fill in the blank), kind to others, and work very hard your dreams and goals will come true and you will be rewarded and have a happy life.

Well-surprise! As we have learned, even bad things happen to good people. The worst thing we could imagine has happened in our life-the loss of our child. Almost every bereaved parent I have met expressed that they felt they must have done something terrible that their child was taken.

When our son Aaron died I felt that maybe my faith wasn't strong enough, that I didn't pray hard enough and then I was angry that we didn't get the miracle he deserved.

I have heard many bereaved parents also express "Why me? Why my child?" I also felt that. My husband wouldn't even allow me to drink coffee when we were expecting Aaron, and then he was born with an extremely rare recessive genetic kidney disease. We had no way of knowing we each carried a recessive gene for this hereditary disease.

Unknowingly, we genetically predisposed our child to be born with this disease. Parents with children with serious health problems have grieving issues of our own, especially when your child is born with a genetic disease. Even though no one in our families for generations back had kidney problems our child did. We blamed ourselves for his suffering and pain, even more for his loss. Each of us would have gladly traded ourselves instead of Aaron for all the medical procedures and tests, daily dialysis and finger pokes he had to endure. But we carried on; just knowing Aaron would get a new kidney and be healthy. We were called twice with the good news there was a kidney available for him. The first time he was suffering from pneumonia and was not able to go through surgery. The second time he got as far as being prepared for surgery before they determined it was not quite a good enough match. This was 25 years ago, before medicine made such wonderful advances in the field with better anti-rejection drugs and tissue matches. It was absolutely heartbreaking to be so close to our goal and then reach another setback.

In the meantime, Aaron grew sicker and sicker as we waited for another call. Donated organs are so precious many people don't realize there is a very fine line between deciding who is ill enough for a transplant but healthy enough to go through surgery and recovery. We did not receive another call before Aaron's little body finally could not go on any longer. We were so desperate for our child we actually became quite callous. My husband and I did not admit it to each other for a number of years, but each of us wondered what blood type a person was, or if he was an organ donor when we would see someone behaving or driving recklessly.

Around the time our family awaited "the call" and for a number of years after, there was a lot of controversy whether some people received preferential treatment due to their celebrity or income. Several celebrities received organ transplants shortly after we lost our son. Jerry Garcia from the Grateful Dead, David Crosby and Mickey Mantle all received new organs, despite the evidence they had destroyed their own through the misuse of alcohol and drugs. I have a lot of conflicting feelings about this. I know that addiction is a horrible disease, but it does make you wonder if you have to choose to give an organ to an iconic musician or amazing athlete, or a child who is their family's "everything" how they do it. I don't envy the medical professionals who have to make that call, but I still wonder.... It has been very hard to live with those circumstances, knowing your child grows more and more ill and you have absolutely no control of when or if he will receive a life-saving organ. The other heartbreaking circumstance is that another family must lose their loved one and voluntarily donate his or her organs so that your loved one can survive. Even all these years later, I remember and live all over again the pain and anguish of waiting for the call that never came, and the feeling that it just is not fair that Aaron never got his miracle. I continue to pray that science and medicine progress to the point that no family ever has to get "that call", whether it is to donate their loved one's organs or to get the call that an organ is available from a deceased person.

I pray that someday we all can receive that "peace that passes all understanding" to allow us to get past the knowledge that life is not fair and continue to strive to be loving, kind, and contribute to our communities.

In friendship,

Nadine