A Medal for Two

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by Krin Van Tatenhove

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There must be acceptance and the knowledge that sorrow fully accepted brings its own gifts. For there is an alchemy in sorrow. It can be transmuted into wisdom, which, if it does not bring joy, can yet bring happiness. – Pearl S. Buck, from *The Child That Never Grew*, written about her daughter with Down's syndrome.

It's the track and field regional finals of the Special Olympics. The stadium at the University of Texas, Arlington, is electric with the shouts of friends and relatives. An army of compassionate volunteers crowds the field, lining up runners, tracking the winners, cheering contestants in the spirit of the Special Olympics motto: "Let me win, but if I cannot win, let me be brave in the attempt."

I watch as these cheerleaders position themselves at the finish line of the 100 yard dash, one for each lane. When the gun sounds, they focus raptly on their athlete; for just a divine moment, that boy or girl, man or woman is the most precious human being in the arena.

The diversity is amazing, from preteens through adults, spanning a wide gamut of impairments. We shout our encouragement for all of them, especially a young man in his late 20s. Left in the wake of his peers, he jerks, not walks, towards the tape, his arms clutching a Woody doll from Toy Story. In any other setting his painful progress might be pitiable. But this celebration of life meets him with thunderous applause.

Parents are supposed to remain in the stands, but as the time nears for my son, Kristoffer, to compete, I rebelliously slip onto the field. Smiling like a seasoned volunteer, I elbow my way to the end of his lane. I can see him now, tall and lanky, lane four in a heat of boys that look much stronger, much more substantial than he.

Like most parents, my adrenaline is pumping, nerves on edge. The gun sounds, and with that flash of noise, my mind transports back to Kristoffer's birth...

October 22, 1997. Even as he emerged for his first breath, it was obvious: Kristoffer was different. The nurses cast surreptitious glances at each other and the doctor, then pasted on smiles for public consumption. But the masks had slipped and I'd seen beneath them. I'd glimpsed the looks of compassion and pity.

Facing the reality that you have a "special needs" child carries all the hallmarks of grief. Denial is pervasive as you await a diagnosis. Kristoffer's condition was not a known syndrome, which number over 750. He has a chromosomal translocation. I saw the dyed sets of his DNA, the blueprint for his life, so infinitesimally close to symmetrical. But there it was - that microscopic smidgen of genetic material that had broken off one side and attached itself to the other.

It made all the difference.

When the reality started settling in, I felt a wave of grief. I agonized that my child would not have all the possibilities of an "ordinary" life. As a Presbyterian pastor, I tried to buffer this grief, aware of a great paradox within me. The clarion call of my preaching is that the last will be first, and that ultimately the meek will inherit the earth. I have urged others to love outsiders, aliens, the disenfranchised. I have also seen firsthand that children with *all* their mental capacities are born every day into crushing poverty, intolerance and bloodshed.

But the litmus test of truth, the intimacy of grief, was now mine, and all the glib answers of my preaching failed me. I gave in to what I felt was a selfish reaction. My son would *never* receive a degree, let alone graduate cum laude. He would *never* walk the halls of power. He would *never* discover a scientific breakthrough, play in Carnegie Hall, or step to a podium to give a lecture. He would *never* start his own business, write a book, or excel in a recognized art.

Heck, I realized he might never learn to talk or read, make friends, or find a suitable woman to share his life with. And work? Where? At a Goodwill Store? Bagging groceries at a sympathetic Safeway? Sweeping floors at a State-run group home?

The geneticist wasn't encouraging. With the bedside manner of an IRS agent in need of retirement, he gruffly informed us that the prognosis was *very* guarded. Kristoffer might have to communicate using pictographs rather than words. Of special concern was the lack of a soft spot on his head, which was already on the border of microcephaly. If his skull did not expand to accommodate brain growth - a condition called craniosynostosis - he would require multiple bone-splitting operations and a plethora of stints.

Donna and I listened in numb silence. At that stage of my life, I was a worrier, conjuring every possible disaster. Though I preached Jesus' famous "Do not worry" passages from the Sermon on the Mount, I too often succumbed to fear. Donna, on the other hand, cut off dreaded thoughts before the tentacles developed, not because she had learned the art of letting go, but as a survival tactic. She'd been down so many times in her life that she just soldiered on. Somehow we balanced each other.

We needed that balance desperately as we walked through this valley together. I learned to let the expectations of normalcy be cremated in my mind. From the smoke emerged Kristoffer James Van Tatenhove, son of my loins, one of the loves of my life. I began to “Father” him as best I could, slowing down to communicate at the most elemental levels. I began to walk through the grief by walking closer to him.

For personal reasons, I had taken a break from being a pastor. However, I still assisted in mission and outreach at the First Presbyterian Church of Palm Springs, California

God knew we needed that congregation and put us there at just the right time.

Let me explain. In my decades of ministry, I have grieved for people who endure trials in this life without a community of faith to support them. The Palm Springs church wasn’t perfect; it had its own history of divisions and conflict. But they knew how to love us when we craved it the most.

One Sunday fresh after Kristoffer’s diagnosis, I tearfully asked for prayers for our family. The pastor, Jim Griffes, called the four of us - Donna, Kristoffer, my stepson, Keenan, and me - to stand in the center of the sanctuary near the Communion Table. He then called one of the elders, Jayne Humberger, to come forward and lead a *laying on of hands.*

Jayne was barely five feet tall and carried a lot of extra weight, but when it came to intercessory prayer, the woman was a lightning rod for the Spirit.

I held Kristoffer in my arms as the rest of the congregation flooded unabashedly down the aisles to gather round us. It was a circle of love, the communion of saints, and for the first time in months, I could feel the tightness in my chest begin to dissolve.

I don't remember Jayne's exact words as she laid her hands on Kristoffer's head. But here is what they meant…

…Loving God, you are the Great Physician, and anything is possible for you.

…we have heard the human prognosis, now we pray for a miracle.

…we know how much you love Kristoffer; we know you had a plan for his life even while he was in his mother's womb. Make that plan clear to all of us.

…most of all, we pray for your will to be done in this family, so that every trial they face will be shaped by your love and grace as a testimony to the world.

…give them peace, God, not as the world gives, but only as you can.

What constitutes a miracle? Each of us will answer that question for ourselves. But I left that service in a miraculous state of mind, full of conviction that God did indeed have a plan for my son, for me, for our entire family.

This certainty was cemented later in the week as I saw *Simon Birch*, the film adaptation of John Irving's *A Prayer for Owen Meany*. Simon goes to ask a critical question of his pastor. With his stunted growth and obvious disability, he enters the pastor's study, plops down on the other side of his desk, and speaks.

Simon: Does God have a plan for us?
Rev. Russell: I like to think He does.
Simon Birch: Me too. I think God made me the way I am for

a reason.
Rev. Russell: Well, I'm glad that, um, that your faith, uh, helps you deal with your, um...you know, your, your condition.
Simon Birch: That's not what I mean. I think I'm God's instrument - that He's gonna use me to carry out His plan.

Later, when Simon gets discouraged, he goes back to the same pastor.

Simon: I want to know that there's a reason for things. I used to be certain, but now I'm not sure. I want you to tell me God has a plan for me, a plan for all of us. Please.
Rev. Russell (*Finding it difficult to respond with a good answer)*: Simon...I can't.

I remember feeling infuriated at that pastor for his lame excuse of a faith. If he had been an actual character with offices nearby, I would have stormed through his door with a stream of invectives. For myself, I clung fiercely to my belief that Kristoffer would exceed the doctor's predictions. I vowed once again to have the patience and courage to seek out and nurture his gifts, no matter how small. I would help him carve out a unique future despite his limitations!

The spirit is willing, but the flesh is weak. Patience has never been my strong suit. Anyone who knows me will attest to that fact. As I tried to teach Kristoffer basic life skills, my frustration would quickly peak. It was *so* hard to separate the strands of what was happening. It still is. How much of his learning difficulty was due to his condition? How much was due to his stubborn lack of applying himself? How hard could

I push him? How would Donna and I balance our parenting styles? She was prone to over-protection; I was driving him, intent on helping him make the most of himself despite his disability.

Meanwhile, life happened. Like so many other parents around the world, we adapted to the daily realities of our new family constellation, many of which were stressful.

- Visiting specialists to help with Kristoffer's slurred speech.
- Confronting schools so they would not shelve him as hopeless.
- Searching for friends would who would overlook his disabilities and provide some sense of normalcy.
- Calming him at night as he cried out in his sleep, always at the crescendo of some crisis he could never articulate.
- Helping him interpret the onset of sexual feelings with realistic expectations.
- Gently leading him to basic self-sufficiency while others kids his age were preparing for college.

But there were also the surprises of joy.

- His vulnerable and fresh way of living in the present.
- The unexpected hugs he gave to people in churches I served.
- His impulse to give you a kiss on the cheek when you needed uplifting the most, led by uncanny intuition.
- His gentleness with other children.

- The discovery that though he was academically limited, he was nearly an autistic savant when it came to playing XBOX games.

Again I ask you, what constitutes a miracle?

It is now 2015 and Kristoffer has far surpassed that original grim diagnosis. Sure, he can only read at a limited level, but his receptive language - what he understands from others - is nearly at par. He communicates much clearer than we ever hoped for. Recently he graduated from high and attended the senior prom, milestones we had only dared to believe would occur.

But to me, the greatest miracle is how Kristoffer has brought acceptance to our family: acceptance of him, acceptance of others, and acceptance of our own inadequacies. It is deeper and more powerful than resignation. It is that life-affirming acceptance of sorrow that Pearl S. Buck spoke of. It is that acceptance that Kubler-Ross so aptly described as the resting place at the end of grief. And though it may not impart joy, it does pave the way for a new happiness and wisdom.

So, for any of you reading this, I urge you to consider acceptance as a foundation for your life. Listen to these words recorded in one of the stories of AA's Big Book.

Acceptance is the answer to all my problems today. When I am disturbed, it is because I find some person, place, thing, or situation—some fact of life—unacceptable to me, and I can find no serenity until I accept that person, place, thing, or situation as being exactly the way it is supposed to be at this moment. Nothing, absolutely nothing, happens in God's world by mistake. Until…I accept life completely *on life's terms, I cannot be happy. I need to concentrate not so much on what needs to be changed in the world as on what needs to be changed in me and in my attitudes.*

May I make a few suggestions?

- If you've been focused on trying to change someone else, accept them as they are and see how freeing it is.
- If you have a heavy load caring for a spouse or parent who is gravely ill, accept the task as a temporary privilege and see how your outlook changes.
- If you are agonizing over a failure in your past, accept it now as exactly what you needed to shape who you are today.
- If you are facing an illness of your own, accept the care of physicians, friends, and family. Let God redeem the moments of this precious day you've been given.
- Most importantly, accept the love of God, to whom you are infinitely precious. Let our Creator's inexhaustible grace give you the peace of self-acceptance, the peace that passes understanding.

Back to that day at the Special Olympics...

Kristoffer is racing towards me, his ungainly legs now striding like a gazelle. Will it be enough? I look to his right and left and it's impossible to see who is leading. Suddenly I want him to win so badly it's like an ache in my bones. I want it as vindication, as a justifiable revenge. It unsettles my soul. But just as quickly, the motto of the Special Olympics fills my mind: Let me win, but if I cannot win, let me be brave in the attempt. With a deep breath, I let go and revel in the celebration of life unfolding before me.

Ahhh, my son, my brave son, who has taught me the gift of acceptance, who has blessed me with a new knowledge of being human. Kristoffer, you will always be a winner to me.

He breaks the finish line and I give him a huge embrace.

"Way to go, Kristoffer. That was awesome! You're the man!"

One of the volunteers takes him from me and moves him towards the ongoing awards presented after each heat. I stand to the side and watch as Kristoffer nears the daises for Bronze, Silver, and Gold. I have no idea how he finished. I am simply basking in the joy of this event that elevates the dignity of being human.

They announce the results for his heat. The Bronze, the Silver…

"And for the Gold, Kristoffer Van Tatenhove."

He bends down to accept the medal and as he straightens up his eyes search the crowd and lock onto mine. I don't know who is prouder, him or me. I snap a picture that is now enshrined in my heart.

It's a medal for Kristoffer. And in ways that are still being revealed, it's a medal for his Dad as well.