



Complex Child E-Magazine

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Fully Rely on God: Christopher's Story of Hope, Faith and Healing by Kristi Pena

I started writing this article and then decided to start over. I have always been told since I was a child that I have the gift of writing, but on the subject I am about to approach, it has proven to be a challenge. I know how to place facts on paper, and though it is a fact that I am a believer in God, it has been difficult to tell you in words something I feel so strongly in my heart and soul.

I have been a child of God since right about the time I hit puberty. I have always prayed and thanked God for my blessings. I have always known during financial struggles, God will and has always seen us through. However, it was not until my youngest child was born that I learned about a term I would like to introduce to you:

F.R.O.G. Fully Rely On God

Christopher's Story

We had prayed for a child for a long time and after a missed miscarriage at five months along and waiting for years, Christopher came along. When Christopher was born and the knowledge that he had a heart condition was shared with my husband and me, there was no explanation of how it would be fixed to follow. We were told there was nothing the doctors could do and to take him home and enjoy him for the short time we were going to have him. The only option for him would be a complete heart transplant. As his parents, we undeniably wanted the medical team to try everything possible. After Christopher gave them some signs of instability, the criteria were met for him to transfer to a transplant hospital.

I think all too often we look for answers around us, forgetting to see the simplest ones. We neglect to realize that just asking God to help us fix a problem so big is the best thing to do. He is much better at problem solving, anyway.

After a lot of time on our knees and watching our son deteriorate before our eyes, it became evident that a heart transplant was just too risky for Christopher. His chance for survival even with a new heart was slim, forcing us to make the most difficult decision of our lives. We decided to take the advice of the very first doctor and just take him home

and let him be as comfortable as possible for as long as God would allow us to have him.



Most simply put, through our faith, we knew the situation was a win for him either way. If he were to die, he would be granted a pass straight to Heaven. And if we live the rest of our lives right, we would get to see him again. In our hearts, putting Christopher through the risky transplant at that time was for us, not him.

A lot of people questioned our decision, including family members. We were told that they hoped we could live with ourselves later. Of course some people did not come out and say what they were thinking, but they thought we had lost our minds. I want everyone to understand that this decision did not mean we were giving up. This only meant that we were taking it out of the hands of the doctors and placing our son's fate at the feet of Jesus.

In God's Hands

The moment I came to this decision the biggest weight was lifted from my heart and I knew it would be okay. If God decided to call Christopher home the next hour, life would go on. I was the one who needed the prayer more than him, because I would need the strength to carry on, a strength that I knew would only come from God.

At a mere 45 days old, Christopher was admitted into hospice, and given a prognosis of six months or less.

Some called it denial, some called it a tremendous act of faith and I tend to agree with the latter. I also followed the motto, "It's not the number of breaths that you take that's

important, but those that take your breath away.” I wanted Christopher to know his brother. I wanted him to see his home, the blue sky, the green grass, flowers, and animals, smell the fresh air outside, the small things most tend to take for granted.



Every moment we had with our son was precious. We celebrated his birthdays weekly, cake and all, as we were determined to make the best of our time given with him. We celebrated Thanksgiving, Christmas, and the New Year. None of his firsts passed without celebration. We were asked how we slept at night. Truthfully, in the beginning the pulse oximetry machine, which beeped through the night, let us know his heart was beating and was a huge help. But eventually the machine grew dusty and we relied totally on what we saw, which was a happy, visibly healthy child.

We Walk By Faith, Not By Sight

I cannot tell you how true the Footprints prayer was for me, because I truly believe God carried me through all of those uncertain times: “but those who hope in the LORD will renew their strength. They will soar on wings like eagles; they will run and not grow weary, they will walk and not be faint.” Isaiah 40:31.

We had routine check ups and they always said the same thing, no improvement, but Christopher was still continuing to defy all odds by just still hanging on. His “expiration” date came and went. His first birthday approached and we were filled with the most tremendous joy to ever celebrate this day with him! I made sure all of his invitations included, “To God be the Glory,” because we wanted all to know why we felt this day had come.



When Christopher was 15 months old, we got the most unexpected news, that his heart had improved so drastically that he was to be discharged from hospice. We truly believe that the great Healer wanted everyone to see what the power of prayer could do and was using our family as an example. I believe God still is in the miracle business. “I tell you the truth, if you have faith as small as a mustard seed, you can say to this mountain, 'Move from here to there' and it will move. Nothing will be impossible for you.”
Matthew 17:20

When Christopher was 21 months old, we got a call from his geneticist telling us he had discovered what caused Christopher’s heart failure, a rare genetic disorder called Barth syndrome. With this diagnosis comes the knowledge that there is a possibility that we will have to face heart transplant again due to the unpredictability of his disease. We still cherish every day and don’t take any of them for granted.

One of the lessons we learned through Christopher is when each of us wakes up, we do not know if it will be our last. Always remember to show love to your loved ones and say it too! Hug your little ones tight, because even if you aren’t facing the reality that you may outlive them, the days of each childhood are numbered. The time goes by so fast.



Give thanks and glory for your blessings. Just because the doctors give up, doesn't mean God gives up. May we continue to understand in faith that God's love, as a Father, will not cause us a needless tear throughout our journey of blind faith. Though we have the knowledge of Christopher's possibility of going into heart failure, it is still all in God's hands. God has blessed us with a miracle and I still claim it.

To learn more about Christopher, visit his Caringbridge website at <http://www.caringbridge.org/visit/cj08>