

# The Gift Of An Open Heart

the struggle from birth to graduation  
for a young heart patient

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# Contents

Foreword .....	8
Acknowledgments .....	10
1 It All Begins With the Heart.....	13
2 The First Open Heart Surgery .....	21
3 Year Two/Surgery Two .....	27
4 Getting Wheels .....	37
5 A Wish for the Fontan.....	47
6 The “Sick Freak” .....	61
7 Fontan Revisited.....	69
8 Eighth Grade.....	81
9 “You Need a Heart Transplant” .....	94
10 Ninth Grade—Just When There’s Normalcy .....	101
11 Watching My Funeral .....	117
12 The Trade.....	123
13 Dr. Stone and the Bovine Gift.....	135
14 High School With a Different Stroke .....	140
15 A New Stroke of Fortune .....	153
Epilogue.....	162



# It All Begins With The Heart

*"Mom, I have been working on this speech for a week," I half-heartedly complained. "Can you help me out a little bit?"*

*My mom walked from the kitchen into the dining room and stood over me as I sat at the dining room table. "Nick, you wanted to be senior class president, and now you have to write a speech for graduation. I didn't run for senior class president," she teased.*

*"I know, I know...can you just help me with the wording of a few things?" I asked in my most desperate voice.*

*She sat down next me and began reading what I had written down. I watched her lips move as she read the words, and I beamed as she read over some of the lines I was particularly proud of.*

*"You know, I just can't believe we're finally here," she said with an emotional pause. "You're graduating! I just can't believe we made it...eighteen years ago I would have never thought either of us would make it." Her voice trailed off as she went back to reading.*

*"It's a boy!" the doctor announced. He wrapped the bundled baby up in several blankets and presented him to his proud parents.*





Mom with Nick, born December 15, 1980

“Ten fingers and ten toes!” Tom announced, assuring his wife that their baby was healthy and normal.

Tom and Chris were excited with the thought of having a baby around the house again. When Nick was three days old Chris began getting things in order to pack up and prepare for the trip home. Before her baby was ready to be discharged from Mercy Hospital he underwent a circumcision.

As the doctor completed the circumcision Chris was surprised when she heard the doctors raising their voices.

“Oxygen, I need an O2 mask over here!” one doctor barked.

There was confusion and panic throughout the room as doctors and nurses began rushing in every direction. Chris yelled for her husband, “Tom! Tom! What’s going on? What’s happening?”

Tom went to his wife’s side and attempted to comfort her. The head doctor quickly regained control of the situation and continued to deliver orders to a waiting army of doctors and nurses. “Get him on oxygen and call Children’s and tell them





Dad and newborn Nick

we will have one enroute," he ordered. "Call downstairs and ready an ambulance. Lets go! We need to do this quickly!"

Tom looked in between two doctors frantically working on his son, Nick. He was horrified when he saw that his son had turned a dark, bluish-purple in color. Tom hugged his wife and prayed for everything to be okay.

Chris was nearing a level of hysteria as she saw the nurses begin to wheel her son out of her hospital room. "Where are you taking him? Where is he going? Please, someone tell me what's happening!" she pleaded with the nurses.

Finally, a nurse grabbed both Tom and Chris and pulled them into a corner of the hospital room. As Nick was wheeled out of the room, the doctor who had been working on him the most walked across the room towards Tom and Chris. He began speaking, "Mr. and Mrs. Zerwas, my name is Dr. ..."

"Where are they taking my son?" Chris demanded as she cut the doctor off in mid sentence. "What is going on? What happened? Where is my baby going?"



“Okay, Nick is being transferred to Minneapolis Children’s Hospital. Once he arrives he will be evaluated by several specialists to determine what the problem is.”

“What happened? Why did my son turn blue? Is he alive? Is he breathing?” Tom asked rapidly. “And where is he now? Should one of us be with him? Can we ride with him to the other hospital?”

“Your son is alive. He is still breathing, but I don’t know what’s wrong with him. Once he arrives at Minneapolis Children’s Hospital they will begin some tests to determine what the problem is. As far as the ambulance goes, you two will have to follow it to Minneapolis. There will be too many people inside working on the baby.”

As the ambulance quickly left with sirens screaming, Tom and Chris shuddered and attempted to regain their bearings.

Tom followed the ambulance as best he could. As they reached traffic the ambulance weaved through the cars ahead flawlessly, while Tom did his best to stay on the road. Chris sat in the passenger seat of the station wagon, her mind racing. She didn’t really understand what had happened, and how her family was going to make it through this. As the ambulance carrying Nick pulled out of sight ahead of them, Chris wondered if she would ever see her baby alive again. Tom and Chris didn’t quite know what to say during the ride to the hospital, so neither of them said hardly anything. Tom wiped tears from his cheeks and cleared his throat loudly. Chris slumped over and softly cried to herself.

By the time they arrived to the hospital, Nick had already been admitted through the emergency room and transferred into the pediatric intensive care unit. As they walked through the door into the emergency room they both supported each other. They leaned in, each using the other one to stay upright. A tall, thin man with thick, curly hair was standing in the doorway. Tom and Chris stopped and looked around trying to determine where to go to find their son.



The thin man approached Tom and Chris and introduced himself. "Hello, I am Dr. Frederic Stone. I am a pediatric cardiologist. I am taking care of Nicholas," he told them with an intense look on his face. Dr. Stone escorted Tom and Chris to a private room and began explaining what he knew about Nick.

"Mr. and Mrs. Zerwas...I have some news that will be difficult for you to hear."

With that Chris began crying again, and Tom held her closely. Dr. Stone continued, "Your son Nicholas is not the healthy baby you thought he was. Nick was actually born with a very rare and serious heart defect."

"Oh my God," Chris gasped, as Tom put his head into his hands and began crying.

Dr. Stone pressed on, "Nick was born with a heart defect called Tricuspid Atresia, and it is gravely serious. We will need to do two open-heart surgeries fairly early on, and hopefully those surgeries will allow his heart to pump enough oxygen for his body to sustain itself."

"What happens after that?" Chris blurted out. "After those surgeries will everything be okay?"

"Well, those surgeries will allow Nick to live several years; however, even with all the advancements of medical science your son will not live past seven years of age," Dr. Stone said as he leaned forward and looked into his hands resting on his lap.

"Oh, NO, NO, NO" Chris cried. "No, please, please don't say that!" Tom looked up with tears blurring his vision, and reached out to hug his wife. They sat holding each other, and as they both calmed down, Tom asked, "What are we going to do? How do we get through this?"

Dr. Stone looked at them and said, "By relying on each other and doing the best you can. There are two ways this can go. Either this will strengthen your marriage and make your family closer than you ever thought possible, or this will



destroy your marriage, your family, and your lives. You need to work together to survive this.”

Tom and Chris looked at Dr. Stone and listened to him intently. They held each other’s hands tightly, and promised to make it through this together. Chris thanked Dr. Stone for his help and support. “Could you explain our son’s heart defect again,” asked Tom, “and how it is different from a regular heart.”

“Nick was born with effectively a three-chambered heart, instead of a regular four-chambered heart. Nick’s heart is missing the right ventricle, which normally pumps the blood to the lungs. So, Nick’s heart has a unique blood flow with the absence of the right atrium. Blood is mixing in the left side of Nick’s heart and being pumped to the lungs and the body both by the left ventricle. This mixing of blood is causing a lack of oxygen and is the source of Nick’s bluish color and cardiac symptoms.”

Dr. Stone left Tom and Chris in that small conference room, and as they gathered themselves they promised each other to listen to Dr. Stone’s advice and work on making it through this together. Chris and Tom took up vigil along their baby’s bedside in the intensive care unit at Minneapolis Children’s Hospital. Chris stayed with her son in the hospital the entire time. She only left his side a few times each day to go into the basement of the hospital to the room designated for smokers. Tom traveled to the hospital each afternoon after work and stayed late into the night.

On the afternoon of December 24, Tom and Chris were finally able to bring their son, Nicholas, named after the patron saint of children, home from the hospital. When they finally had him home, however, they immediately thought of bringing him back to the hospital, where they knew he would be safe. The first nights were restless as their colicky baby with blue lips and ash-gray complexion cried until he lost consciousness.





Nick with brothers Tommy (left) and David (right), Christmas 1980

Chris sobbed as she held what she thought was her dead baby in her arms.

Middle of the night trips down to Children's Hospital was the rule rather than the exception. The doctors struggled to understand how or why the baby would not stop crying before he passed out. Whatever the problem was, the doctors decided the first surgery had to be done earlier than anticipated. With their baby just two months old, Tom and Chris drove to the hospital to bring Nick in for his first open heart surgery.

