

When Christopher Sings

By Tom Williams

I can recall that day in the spring of 1997 as though it were yesterday. Christopher, my six-year-old grandson, and I were having one of our frequent chats together in his backyard, which bordered on the Pacific Ocean.

It was fun having conversations with Christopher. He had a variety of interests, an inquiring mind, and what seemed to be a zillion gigabyte memory. Any topic was fair game: animals, astronomy, prehistoric creatures, toys, games, and occasionally just nonsense. But on this day we had a serious matter on the table. Christopher and family were going to be moving soon, from the shore of the Pacific Ocean to the mountains of western North Carolina.

The thought of Christopher and his family moving almost three thousand miles away prompted conflicting messages between my mind and heart, and it soon became obvious that Christopher was coping with similar conflict in his own remarkable way. My mind reasoned it would be best, under the circumstances, for his family to relocate to a place of more potential and new opportunity for him, but my heart was unable to echo that theme.

Christopher had thought a lot about the coming move. As he talked, it seemed to me he was trying to make the move a

bit less painful, the separation somewhat easier, the distance not so far.

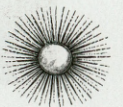
"Grandpa," he said, "You know, even though we're moving to North Carolina and we will be far apart, we will always be together."

"How's that Christopher?" I asked, recalling the many times I had held this once-fragile infant on my lap and read to him the popular story of Pooh Bear and Christopher Robin.

"Because you will always be in my heart, and I will always be in yours, so we will be together," he replied. Surely the magnitude of what Christopher had just spoken was beyond the comprehension of us both.

While I attempted to plumb the depths of those words of encouragement my little grandson had just offered, he began to sing to me. I can no longer recall the lyrics of the song, but I will remember forever its theme and sentiment. It expressed so beautifully our need for love and the value of treasuring its blessings in our lives.

Christopher had experienced a full



measure of love from his birth. Indeed love had made the difference between life and death for him, and now his song from the depths of his experience was a moving tribute to the healing power of love.

Listening to Christopher sing that day was like hearing the voice of an angel. As I looked at him sitting on the branch of a small magnolia tree, I beheld a miracle. It was a miracle that had its beginnings six years earlier at Christopher's birth.

During his delivery it became immediately clear to attending staff and Teri and Mark that this tiny infant had very serious medical problems beyond the scope of the large medical center where he was born. Within hours, he was transferred to the neonatal intensive care unit of CHOC, the Children's Hospital of Orange County.

Medical personnel were hesitant to permit his adoptive parents to see him before the completion of a three-hour major surgery during the first ten hours of his life. They were told he might not awaken from that surgery, but he did. His prognosis was uncertain. Would he survive? Would he ever be able to eat or eliminate? Would he be brain damaged? It would be months, even years before the answers to these questions would be known.

The Children's Hospital of Orange County was to be Christopher's home for many months. Here highly skilled professionals provided an environment where the latest medical technology blended with skillful and loving care to mend an infant's body. Here also was the place where Christopher began to bond with his adoptive parents, Mark and Teri Muir. They had eagerly and happily anticipated his birth from the time his birth mother and biological father had agreed that Mark and Teri would be the parents of the new baby immediately after he was born.

Christopher's birth parents were high school students who were not prepared for the obligations and responsibilities of parenthood and were, as the unfolding story revealed, incapable of providing for the many needs of a gravely ill infant and supporting him in his fight for life. Their love for their unborn son, coupled with their circumstances, led them to choose adoption so that he could begin life in a stable, secure, and loving home.

Mark and Teri were a childless couple who longed for a baby to love and bring completeness to their family. They were upwardly mobile professionals whose many talents and skills, it turns out, were dwarfed by their capacities to provide love and commitment to a baby boy named Christopher William Muir.

Christopher's medical condition was rare and serious. He was born with only 25 percent of his small intestine,

and the quality of those 37 centimeters of vital organ was very poor. His large intestine was of normal length but so tightly constricted it would not function. His large and small intestines were not joined. During his first two years Christopher would face seventeen additional surgeries to reconstruct his body and sustain his life.

Because his digestive system was incapable of absorbing nutrients, Critty, as Mark and Teri later affectionately nicknamed him, was fed through a broviac catheter. This feeding tube was used to drip miniscule amounts of



predigested formula with the goal of increasing the absorption rate of the small intestine.

This type of feeding method resulted in numerous septic infections within his system. Coli infections, liver damage, and kidney damage repeatedly threatened to take his life. But Christopher was a fighter who would not give up.

Month after month Christopher would be on the receiving end of tubes for nutrients, antibiotics, and blood transfusions, the latter provided by both Mark and Teri, who had the same blood type. The proverbial shedding of "blood, sweat and tears" was taking on new meaning. They gave their own blood to help him in his fight for life.

Their bodies often glistened with perspiration as they responded to the dreadful pain so unremittingly experienced by their little boy. Their tears of joy over having a little son mingled with tears of sorrow because of his suffering and struggle to stay alive. Teri and Mark received much encouragement and support from family, friends, and associates, and they gained strength and faith through prayer. Time after time they were found waiting in the chapel to get the results of Critty's latest surgery.

Family and staff celebrated Critty's first birthday in the hospital. Each holiday he experienced during the first year of his life was in the company of nurses, doctors, fellow hospital patients, and, of course, his parents. Although he still had to be tethered to two tubes twenty-four hours a day to receive his nutrients, the day finally came when he was able to remain home and hospital stays became less frequent.

He grew some and was a happy baby. This was a significant accomplishment for a little boy who had spent 200 of his first 365 days of life in hospitals.

We, his grandparents, marveled at the medical technology that helped Christopher win his battle for life. Children born a few years earlier with his condition had virtually no chance for survival. Yet we now also stand in awe of the influence and power of love in sustaining and encouraging human life. We could read the language of love and caring in the hands and faces of the medical staff. We could hear it in their voices. We saw it in their work.

As Christopher grew stronger we would visit him frequently and see him sitting with the nurses. His eyes sparkled with life as he gurgled and bubbled with joy.

We also saw the devotion and love of Mark and Teri in their eyes and heard it in their words. Who they

were, and what they were, to their little boy gave him the edge he needed to maintain his fragile hold on life. Through the miracle of love, Christopher lives today.

It was a real highlight in his life when the time came that Christopher's feeding tube and central broviac line could be disconnected for a short time each day. Prior to this time he could be seen carrying his pumps in a small backpack or pushing them in a stroller. By this stage he was walking and talking. Our hearts were warmed to see him run and hear him shout, "I'm free! I'm free" as he was disconnected from the tube that fed life into his body.

Over the years he began to eat small portions of special food and by the time he was four and one half years old he received all his nutrients by mouth.

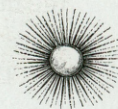
As he grew older, Critty astounded us with his ability to learn things that were of interest to him. He demonstrated a remarkable memory for many different kinds of information. Once while visiting a museum he was able to identify various kinds of dinosaurs by name and specify their distinguishing characteristics. He could do the same for certain species of sea life, such as whales.

At two years of age he could read numbers on license plates. When he was three he could repeat Disney books and videos word for word from memory. At five he could sing on nearly perfect pitch.

He was active, energetic, buoyant, and happy as a preschooler, but during that time some behaviors surfaced that concerned Mark and Teri. Christopher seemed to lack a concept of personal space—maintaining an appropriate distance between himself and someone to whom he was talking. It was difficult for him to sustain cordial relationships with peers in social settings.

He demonstrated a high sensitivity to bugs, spiders, and other insects. He reacted very positively with adults but, frequently, negatively with children. It seemed very difficult for him to perceive the feelings of others. Although he could learn many facts on a variety of topics that interested him, learning facts in a formal setting at school was extremely difficult.

Conventional forms of discipline, such as time-outs or deprivation of a cherished item or activity, seemed generally ineffective. He sometimes did not perceive



pain. Frequently Christopher was not able to control or contain emotional outbursts, a characteristic behavior of his disorder, often considered by uninformed adults to be related to lack of appropriate parenting.

He could play by himself for hours with a simple string. He was fascinated by computers and could play the same educational games over and over for as long as he was permitted to do so. It was almost as though comfort and safety were assured for him as he stayed with the familiar and avoided the new and untried.

Christopher's home had two big-screen television sets used for viewing selected videos. He enjoyed playing his favorites over and over within the time allotted for that activity. It could be traumatic for him if a video unfamiliar to him was suggested.

In sports, Critty struggled with coordination. He could, however, swim like the proverbial fish. He became an excellent bicyclist only after a month-by-month struggle that lasted over two years. He greatly enjoyed the trampoline and was adept at swinging, climbing, running, and jumping.

During Christopher's preschool years and kindergarten in a private school his parents continued to seek out the best in medical care for him. Leading pediatric specialists in medicine, psychiatry, psychology, and neurology examined and followed him. Diagnoses varied over time and included Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Deficient Disorder (ODD), and Tourettes Syndrome.

Mark and Teri arranged numerous psychological and psychiatric consultations. They attended conferences and parenting classes and purchased a small library of books and journals to study. Although there were many uncertainties surrounding his life, it slowly and painfully became increasingly evident that a cure for Christopher's condition was unlikely and improbable.

Medication would help for a while and the dosages would have to be increased. The best that could be hoped for was to treat and control the symptoms and to provide a complementary and supportive environment that would benefit Critty within his potential to respond and mature.

It was in their quest for this type of environment that Mark and Teri decided to relocate to a place where they and Christopher and Chantel, his four-year-old sister, could live in a setting that would benefit them to the maximum. They wanted a rural environment with more time for both father and mother to be home.

They wished to devote more time to the family and

less time to the fast track. They needed an environment where Christopher could be under less pressure and where individual differences might be more readily recognized as unique gifts from God rather than oddities that needed to be fixed or changed.

So they took the step; in fact, it was more of a giant leap. It was a leap that exposed again the love that had locked Critty into their hearts from the time he drew his first breath. Theirs was a compelling love holding them and their hopes together through, as it were, the very depths of hell. This was the measure of love that fashions miracles and it carried them through and sustained them.

Perhaps by now you have a clearer picture of what I am trying to convey in saying, "When Christopher sings, I hear an angel," and "When I look at Christopher I see a miracle."

The angel voice I hear is not the kind some might envision: one that emanates from white robed beings with wings and harps who inhabit heaven. No, the angel voice I hear is that of one of God's little children, now a boy and soon to be a young man.

It is the angel voice of a child in whom God's spirit lives. It is the voice of a little boy who struggled and fought a long and difficult battle to survive and live in a world that is different, in so many ways, from the world that you and I know. It is a sweet melodic voice born of the pain and struggle of one who faces obstacles and battles known to few.

It is the voice of a child of God who emerged victoriously from one battle that was won through love and medical science, who is now engaged in yet another battle as formidable as the first.

When I look at Christopher I see a miracle. I see the miracle that results when human minds, hearts, and hands, infused with divine love, minister to, and in behalf of others. This is not the type of miracle expected or required by some—that of full and complete restoration of one's body, or a new and unimpaired persona.

Christopher's miracle is not a direct intervention from the "hand of God" sidetracking the natural laws of the universe in order to bring healing to a selected one who is being favored over others. His is not an immediate and complete cure of his disabilities in a manner that skirts logic and defies reason. But it is a miracle.

It is true that some miracles do seem to represent

full and complete cures. These miracles bring wonderful results, but for many often foster a host of questions such as: "Why was my loved one healed and yours not healed?" "Why did leukemia take the life of my child while his friend with the same illness was spared?" "Why did the storm, fire, accident, disaster strike down so many others and leave me unharmed?" "Why Christopher?" "Why not someone else?"

"Why fuse his small and large intestine and not attend to his neurological deficiencies?" "Am I, are we, in God's special favor when the good things (healing) happen?" "Am I, are we, out of that special favor when the harmful and hurtful things happen?" "If God, in order to save my life, intervenes to keep me from boarding a plane that later crashes, killing all the crew and passengers, what did he have against those who were not spared?" "Were they all out of his favor?" "Why protect one and not the many?"

Of course, there are answers to these and similar heart-wrenching questions, but so often these explanations are personally unconvincing and unsatisfying to those who are hurting. Yet in spite of the bold certainty of some and the uncertainty of others on these matters, those who are wounded and in pain never cease to long for comfort and hope, and perhaps a miracle.

Christopher's life and his experiences have helped me immeasurably to understand what I believe to be the real miracles that continue to bring health and life and hope to one of God's family.

When I look at Christopher the miracle I see is the miracle of a life that would not now exist were it not for the love and care that nurtured and sustained him from infancy to the present. In the absence of modern medical science, love alone would not have brought Critty through. In the absence of love, medical science alone would not have been enough.

Christopher lives by a miracle of love. His life

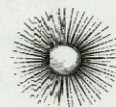


stands as a testimony of the reality that where there is love, there can be hope. The organs of his body that held him hostage between life and death as an infant have healed quite well through his tender years. He has made monumental progress in his struggle to survive, yet his life continues to be a formidable and frustrating challenge for him, and sometimes for others close to him.

Christopher and those who love him are engaged in a continuing battle. It is a battle fully as difficult, complex, demanding, frustrating, and draining as the battles that went before. The weapons are the same: love, in its many ramifications, and the best of medical science.

Shortly after Christopher's family moved to a log cabin in the mountains of North Carolina, Christopher was diagnosed at Chapel Hill with High Functioning Autism or Asperger Syndrome. The diagnosis of autism, which is a developmental disorder, brought insights to Mark and Teri, helping them understand some of the behaviors that had been so puzzling and distracting to them and others.

These behaviors and symptoms included uncon-





and frustrating road. For those close to him, unconditional love is the magnet that keeps them on course. The love that has indeed given Christopher life itself and sustained him has become an essential and inseparable part of who he is, so often enabling him to touch and brighten the lives of many others. Love is the difference that can make a miracle.

We are unable to count the many moments in our memories when Christopher's loving ways have endeared him to us and to others. How strengthening to recall these moments at times when he is out of

controlled body movements, obsessive thoughts, compulsiveness, and erratic emotional outbursts. He was treated for bipolar disorder, which is characterized by wide mood swings, depression, low self-esteem, and frequent highs that had him bouncing off the walls at times.

Essentially, Christopher's battle now was with conditions characterized by having a hard time understanding others, as well as difficulty in being understood by them. Knowing the diagnosis does not set the stage for a cure, although it does help the caring people in Christopher's life better understand what he may be experiencing. Having the diagnosis is also helpful in relating and responding to him and in assisting him in structuring his life in ways that are best for him and others.

Christopher attends a private school, Veritas Christian Academy, which has a wonderfully caring and supportive staff. Mark and Teri provided a coach to assist the classroom teacher and work with Christopher on a one-to-one basis.

In looking at Christopher's experience today, one senses that the same quality of love so vital to his very life in the neonatal unit at CHOC is supporting him now in a classroom in the mountains of western North Carolina. There is love in the Muir home in the East, just as there was love in the Muir mansion by the sea in California. Love is the miracle that makes the difference.

For Christopher, it is a long, difficult, confusing,

touch, out of control, or out in his own little world—a world totally unknown and unvisited by you and me.

We cannot know what it is like, but our own memories of beautiful moments with him make it so much easier to try to understand the world that has been given to Christopher and to feel some of the difficulty and frustration he experiences in his world.

It has been over six years now since Christopher sang to me on that beautiful spring day by the ocean. Though he and his family have moved a continent away, both Christopher and Chantel have visited us in our home numerous times.

Christopher still sings. One of the last times I heard him sing was at his Aunt CeCe's wedding reception. In his tuxedo Christopher confidently walked to the front of the large reception hall, took the microphone in hand, and sang "Love You Forever."

Once again, this time with a lump in my throat and a brimming heart, I heard an angel sing. And through glistening eyes, I beheld a miracle. A miracle of love.

Tom Williams's grandchildren visit him in Loma Linda, California.