

Finding Glory in the Thorns

EXCERPT

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ISBN 978-1-932307-87-0

Chapter 1:

Surviving the Island

The afternoon sun that late July day tried its best to penetrate the tree canopy overhead. The heat and humidity combined with our brisk pace to make for a sweaty trek across Stockton Island. Our uncertainty and anxiety over a garbled voice message on Lisa's cell phone drove us on our quest for a consistent signal. My hope was that the far southern tip of the island would bring clearer access to the mainland. But I knew that there was no guarantee.

It was the summer of 2003 and we were enjoying our seventh annual sailing excursion in and around the Apostle Islands of Lake Superior. Our good friends Ron and Nancy hosted us aboard their thirty-four foot Catalina sailboat, *Second Gift*. Every year, we looked forward with great anticipation to our adventures in the islands. The weather and wind were always an unknown, but the fellowship, food, and time to relax and recharge away from the realities of our regular lives never disappointed.

After a great day of plying the waters of Lake Superior, we had reached that point in the afternoon where we needed to determine a safe anchorage for the night. We tuned in to the maritime forecast to see what the wind direction would be for the night and reviewed the island maps for suitable options. Our conclusion was that Julian Bay on Stockton Island's southeast shore should provide us with a protected place to comfortably anchor. We brought in the sails and

motored off toward our destination.

On our way down the eastern side of Stockton Island, Lisa realized that she had a cell phone message. Her mind immediately raced to our three daughters back in the suburbs of Minneapolis. Alex was ten years old and Erin was eight. Carly, five years old, had been diagnosed with Angelman Syndrome, a genetic condition severely affecting all areas of her development. The girls were in the care of our loved and trusted friend Katie. Since Katie had accepted the call to become our primary caregiver support for Carly, she had accumulated much experience responding to seizures and other issues that could arise due to Carly's condition. She knew well our need to get uninterrupted time away so any phone call from home could be an emergency in nature.

Cell coverage in the islands was spotty at best. As Lisa attempted to retrieve the message, what she heard was Katie's mostly unintelligible voice. The only words that could be clearly made out were "Carly" and "seizure." Since Carly had experienced several grand mal episodes, Lisa's thoughts immediately focused on the need to make contact quickly. With panic in her eyes, she called me to the bow of the boat to tell me of the message. We stood there pondering the possibilities as we were suddenly swept back into the realities of life with Carly. Her first five years of life had been filled with challenges and trials and stresses that no person or family should have to face. Our mental state as parents had often teetered on the precipice of doubt and despair, which made a rare weekend away much sweeter and more important. But none of that mattered now.

We had to decide what to do. One option was to abort our plan to anchor in Julian Bay and make the two-to-three hour voyage back to the marina instead. Once on land, we would have access to a reliable phone and be able to leave at once, if necessary, for the five-hour drive home. But if we were misinterpreting the message, we would be forced to stay in the marina overnight and lose our last night of the gentle rocking and quiet solitude of an Apostle Island bay anchorage. I weighed our intense need to be away against the possibilities of a medical emergency at home. My parenting instincts waged war with my self-centered thoughts of personal preservation. I decided on an alternative course of action.

We would continue on to Julian Bay to anchor the boat. Once there, Lisa and I would swim to shore and then hike to the far southern point of Stockton Island where we would have the best

chance of establishing a cell phone connection with the mainland. With the boat securely anchored, Lisa jumped into the frigid waters of Lake Superior to begin her swim. Due to the depth of the keel, it was necessary to anchor quite some distance from shore. I am not a great swimmer, so I normally take a flotation cushion along with me to use under my chest. But we weren't sure how to keep the cell phone dry during the swim, so Ron volunteered to paddle me in to shore in Second Gift's dinghy. Once we were on the shore, Lisa and I began our hike. Ron was to stay with the dinghy at the shore prepared to ferry us back out to the sailboat.

That Saturday had been one of those picture perfect days for sailing on Lake Superior—eighty degrees with a steady wind and not a cloud in the sky. But as we began to walk along the trail that led to the south end of the island, I quickly noticed that the thick tree coverage took away the Lake Superior-cooled breezes that made it quite comfortable on the boat. Instead, it was humid and sticky on the island. I began to imagine that I was somewhere in a rain forest jungle rather than on an island in the largest fresh water lake in the world, a lake that has an average summertime surface temperature of fifty-four degrees! Dressed only in a swimsuit, the sweat quickly began to drip off me, and the black flies made their presence very apparent. Lisa and I found ourselves swatting each other's backs as we walked even more briskly to shorten their feast.

In those infrequent times when we broke out of the trees into a clearing, we began to notice clouds gathering overhead. Initially, they were fluffy white, beautiful clouds, but they didn't stay that way for long. Our view to the west was completely obscured by the trees so we had no idea what weather was to come. The trail we were on was fairly well maintained alternating between hard-packed dirt and small logs placed end-to-end. But, in some places, the hard-packed dirt was replaced by a couple of inches of thick mud. I began to wonder what else might be in the mud as I imagined all of the deer that must be on the island. I have also since learned that Stockton Island has one of the most concentrated populations of black bears in the world. I'm glad Lisa didn't know that before we left the beach!

The composition of the mud was perhaps more important to me than to the average person. You see, I have lymphedema in my right leg below the knee. This means that the lymphatic fluid my body produces tends to pool in my lower right leg, providing a warm, protein-rich environment for infections to rage! I also have

eczema on the bottom of that foot, which means that I often have the perfect entry points for bacteria and fungi. What I was walking through with bare feet as we headed south could have a big impact on my health. Lisa tried to make jokes about the mud but I could tell she was concerned. I didn't have time to worry. We still had no cell phone coverage!

We knew there were campsites and a ranger station at the south end of the island, and Lisa let me know that she was hopeful we would find a bathroom there. Just about then we heard the first rumble of far-off thunder. This wasn't quite working out as I had planned. I knew Ron would not be pleased, as he was always extra cautious about the weather when sailing.

It seemed to take a long time to get to our destination. It was probably only a matter of fifteen or twenty minutes, but it seemed much longer. When we arrived, we found the ranger station closed. The sun that had been so strong all day was now completely masked by a thickening layer of clouds. The thunder, still off in the distance, became more frequent. We walked to the far south point of the island. I pulled the cell phone out of my pocket and saw what I had seen every other time I had checked during our journey—no signal at all. Our trip had been for naught. The emotions that flooded through me were a high-intensity mix of frustration, anger, humor, and panic. I looked up at the sky and saw that the storm was quickly approaching.

Trees, water, and lightning are a deadly mixture. At that moment, the folly of my decision hit me like a slap in the face. We had come a long way for nothing, only to face a daunting, dangerous return trip to the relative safety of Second Gift. There would be no walking on the way back.

Trying to mask the deep concern I felt inside, I told Lisa we were going to have to jog. Neither of us was in particularly good shape, and the air was still warm and growing even more humid. I no longer made occasional checks for a cell phone signal. There was no time. The thunder was getting close.

At one point in the middle of a densely wooded area along the path, Lisa told me she could go no farther without a bathroom break. "You've got to be kidding me!" I blurted as I looked through the treetops at darkening clouds.

"I HAVE TO GO," my wife growled. In an instant, Lisa's facial expression replaced death-by-lightning at the top of my immediate list of fears. Seeing no signs of either passersby or portable facilities, she dismissed any risk. Right there in her swimsuit, she squatted on the

side of that path holding my arm and took care of her business.

Not more than a minute later, we met a park ranger hurriedly heading in the opposite direction.

I asked the ranger how far it was to the beach at Julian Bay and he replied that it was just up ahead a few minutes. He also confirmed that there was no telephone land line available.

We continued running—the sweat now pouring off of me, the thunder crackling overhead, and the first drops of rain falling from the sky. We were both exhausted but I could see in the distance an opening where the trail met the beach at Julian Bay. Maybe we were going to make it after all!

When we came up over the rise where the land meets the beach, we found a sight that we were both completely unprepared for—no Ron, and no dinghy! I looked out at the Second Gift and saw the dinghy tied up to her stern. Ron, not knowing what had become of us and understandably fearful of the bad weather, had rowed back out to his sailboat without us and was hunkered down with his wife in the cabin. Lisa walked right out into the water to begin the swim back to the boat. She turned around to see me, dumbfounded, standing on the shore.

“How had we come to this?” I asked myself. I was facing a swim of a distance I wouldn’t normally even think about trying without a flotation device of some kind. And I was already completely spent from running about two miles from the south end of the island. But staying on the shore was not an option since the lightning overhead was becoming more frequent. There was no shelter to be found. I decided I would have to swim for it.

I still had our cell phone in my pocket and I knew I had to do something with that. After scanning the shoreline, I found a long-overturned tree whose roots might provide some protection from the rain. So I hid the phone as far under the roots as I could and scrambled out into the water.

The cold water took my breath away as I dove in. I swam for a while and then rolled over onto my back to float while catching my breath. I hadn’t gone far when I looked up to see Ron untying the dinghy and climbing in to come for me. The lightning flashed and the thunder crashed all around. The rain poured down. I was terrified. When Ron finally got to me, I was almost too exhausted to climb into the dinghy. He managed to help me in without capsizing, and he frantically rowed back out to the sailboat. Lisa was already aboard and, as I struggled to catch my breath, the three of us scrambled down into the cabin.

The journey was over, but we still didn't know anything more than when we had left. All the hiking, running, swimming, and praying had not resulted in any tangible progress.

It Wasn't Supposed to Be This Way

A couple of days later, I lay in a hospital bed running a high fever and being pumped with antibiotics for a potentially life-threatening cellulitis infection in my leg. The message from home turned out to be a concern related to Carly's seizure medications. It was not an emergency after all but an imminent issue that needed attention.

Lisa and I took stock. The whole situation left us realizing how critical it was going to be for us to stay more closely connected to the kids on future getaways. Nothing seemed simple any more. Our island experience was just one more crazy example of what a dramatic adventure our life had become.

We remembered the days after bringing Carly home from the hospital. She was born screaming. At first, the nurse called it a "Nubaine cry" and assured us that the pain medication Lisa was given during delivery would run through her system in a couple of hours. But four hours later when she was still wailing, another nurse dismissed it suggesting that it often takes ten to twelve hours for babies to settle down after a mom receives pain medication during the late stages of labor. That was Wednesday night. By Thursday morning, Carly had calmed down a little bit but would only suckle fitfully at Lisa's breast. She really only remained quiet and calm for a few minutes at a time when being held in a very specific way that Grandpa discovered and was teaching the rest of us.

At home on Friday Lisa was still struggling to get Carly to nurse and she rarely slept. When Carly did sleep, the slightest sound or movement would wake her. None of it was making sense. We had two children already and so the fear crossed our mind that this might be what severe colic was like. But I think we just hoped it was the lingering aftermath of a chaotic, unexpected labor and delivery.

We had expected Carly to be born by cesarean because of her transverse (crossways) position. The night before the procedure was scheduled, some very dear friends prayed over Lisa surrendering the surgery to God but trusting with us that God could still cause the baby to turn. Labor started three hours later and the baby turned to the proper position shortly after we arrived at the

hospital. Our heads were spinning as the plan suddenly changed back to a natural childbirth and, admittedly mentally unprepared, Lisa begged for pain medication without realizing delivery was imminent.

It was into this lack of post-natal bliss that the issue of a severely irritated bottom got inserted. We'd spent most of the night Saturday trying every trick we could think of to soothe her oozing skin but to no avail. Now she was in pain and there was nothing we could do to fix it. In those hours, we became forever convinced that there are few life experiences as emotionally overwhelming as seeing your own child hurting yet knowing of no way to help.

Sunday morning, Lisa sat on the edge of our bathtub sobbing, feeling altogether lost and heartbroken. We wanted to be heading to church bearing that well-known new parent glow and sharing our precious newborn with friends and loved ones. Instead, Carly was screaming again and this time the obvious source was pain from a serious diaper rash. During the night, a bowel movement had eaten through her skin like acid and caused large oozing wounds.

I asked Lisa's mom to go talk with her in the bathroom hoping she might give her some comfort. She knocked on the bathroom door and quietly walked in to find Lisa sitting there on the edge of the bathtub in her pajamas, crying through complete exhaustion. She carefully began to explain. "Dad and I think we should take Alex and Erin with us up to the cabin for a few days. Maybe that would give you and Larry a chance to relax and get some rest so you can try to get on top of things with Carly."

Although we appreciated their compassion, Lisa was overcome with frustration. "I don't know what's wrong with her and I can't make her feel better!" she practically screamed. "This isn't the way it's supposed to be." She was getting really angry. "We're all supposed to be together having fun being a family! I don't want them to go. I don't want you to take my girls away. Why is this happening?"

As we looked back over those early days with Carly, it amazed us that the memories were still so vivid and raw. Disappointment and desperation hung over us like a cloud and it seemed that there was no clearing in sight.

Joseph must have felt this way when his fiancé Mary brought news of her pregnancy in Matthew 1:18-25. I shudder at the agony he must have experienced as he pondered a situation that presented no positive outcomes. If he chose to stay with Mary, he faced

living the rest of his life with a woman who had apparently been unfaithful to him, as well as the humiliation that would inevitably come when news of the pregnancy became public. If he chose to end the relationship, it would expose Mary to public disgrace and potentially death by stoning. “This isn’t the way it’s supposed to be,” he must have thought.

The disciple Peter shared a similar reaction in Matthew 16:21-22 after Jesus explained that He must go to Jerusalem to suffer and die at the hands of the religious and political leaders of the time. Peter knew that Jesus was the Messiah, the Son of God. How could it be that the most powerful man in the universe, the conquering King foretold throughout Scripture, the man he had come to love and worship with his entire being, would be killed by mortal men? “This isn’t the way it’s supposed to be,” he must have cried out in his soul.

For several very long weeks after that Sunday in the bathroom, each day looked at least as disturbing as the day before. The diaper rash was worsening, she wasn’t nursing well, and she rarely slept. She seemed starved and frustrated, even overwhelmed.

It also got hot. The air conditioning in our new home had not yet been installed. When Carly wasn’t sleeping, she was screaming. She seemed hot all the time too but had no fever. She only slept for forty-five minutes at a time in the best of circumstances (which involved someone holding a pacifier in her mouth at all times). If she was asleep, no one dared to move a muscle or make a sound. Just imagine that challenge with a five year-old and a three year-old, especially with no yard to play in outside since our sod had not yet been laid!

After several doctor visits and nurse phone calls, emailed suggestions from friends, and numerous trips to the pharmacy, we had exhausted every rash remedy known to man. As Lisa’s dad described it, “she looks like she was dragged on her bottom behind a car going forty miles an hour!” We finally figured out that what worked the best was leaving her bottom open to the air and rinsing it under clean tepid water after every couple of hours. Carly spent all of her time in only an undershirt or entirely naked without diapers on the floor of our family room. The area was layered with bath towels and receiving blankets over plastic trash bags to protect the carpeting.

During a desperate late evening trip to a lactation consultant, even the expert wept out of frustration that she couldn’t figure out why Carly wasn’t nursing. She simply could not coordinate the

suck-swallow thing, something that should be reflexive and intuitive for a baby. Her final suggestion was to express my own milk and give it to Carly in bottles after testing various brands to find the nipple that worked best for her.

So for the next few months, Lisa pumped breast milk seven to nine times a day while I simultaneously fed Carly the milk in bottles. We discovered that enlarging the holes in the nipple with a hot needle allowed Carly to receive trickles of milk without having to suck. She stayed intermittently calm enough to drink if we didn't hold her. Instead, I lay beside her on the floor while holding the bottle and trying to keep myself awake.

In some strange ways it was like a team building and bonding exercise yet I started to feel like Lisa and I were going to go through the rest of our lives on some sort of strange parallel pair of treadmills tending to Carly's needs. One thing was certain, our brains were aching from all the creative problem solving we were doing.

Carly would suck a few times then scream, suck a few times and then scream. Towards the end of a bottle, she might start to doze off. I mastered the art of making a covert and oh-so-gentle switch from the bottle nipple to a pacifier so that she would stay asleep for a little while.

That routine wore on for weeks.

Alex and Erin were big sisters who wanted to help but they quickly grew impatient taking their turns holding the pacifier for Carly. The trick for all of us was keeping ourselves awake or undistracted because, if we so much as twitched, all peace was lost and the crying-feeding-rash management cycle would start all over again. The full cycle — which took between one hour, forty-five minutes and two hours, fifteen minutes — was repeated over and over again twenty-four hours a day until Carly was several months old.

It wasn't until Carly was nearing six or seven months of age that she started to seem more comfortable. Her rash was intermittently under control and she was taking medication for acid reflux. But it was a laborious task keeping ahead of it all. One tiny stool in the middle of the night would trigger a recurrence and have both of us wide awake trying to soothe Carly through a bath and our own tears of frustration.

There were a few bright spots. Our friend Sandy came on two different occasions and spent the night with Carly so that Larry and I could get a few hours of uninterrupted sleep. And there was the day Carly was dedicated to the Lord. No one in the service could hear

our pastor praying for her because her screams found no pause even for the Almighty. But by that time, most of our church Body was well aware of the challenges we were facing so they were graciously and sympathetically composed through it all.

Fortunately, Alex and Erin have little memory of those early days. What few memories they do have are of missing opportunities to hold their baby sister and of eating dinner alone at the kitchen table holding their hands over their ears to quiet the sounds of Carly's screaming while Larry and I worked in the adjacent room to get her fed and calmed down.

It wasn't supposed to be this way.

A Different Reality

We celebrated our fifteenth wedding anniversary in my hospital room that summer. The girls brought me a picnic. Afterwards, Lisa and I had plenty of time to hang around in that cold, bland room and ponder our situation. Was it really possible that life had forever changed for us? Was the weekend's collision of our most challenging circumstances just the first in what would become a lifetime of juggling fears and worries, weighty decisions and life-threatening crisis?

Angelman Syndrome and now lymphedema. Neither of these things was curable and each had already shaken our lifestyle to its core. Just a few years before this we had been running a successful consulting business and writing custom training for companies all over the world. We were doing well financially and enjoying the flexibility of self-employment while raising our two little girls.

Our appreciation deepened for people who experienced health conditions that were turning their lives upside down. Nevertheless, we desperately didn't want to be one of "those" people. If this is what it was going to mean to be parents of a handicapped child, then we wanted none of it. And at only thirty-eight years old, I was already feeling like I was living in an old man's body.

I lay in that hospital bed for four days wondering. Would we always feel so consumed by our health issues? Would much of life feel like a lot of waiting around for God to release His healing touch? It certainly looked that way.