

IN BODY ONLY

by

Michael Mason
(1966-1998)

The Story of One Young Man's Struggle with Muscular Dystrophy

Written in loving memory of:

Homer Fairchild
(my grandfather)
March 16, 1920 – December 17, 1993

Kevin Godwin
(my cousin)
April 13, 1965 – June 10, 1989

Brad Stephens
(my best friend)
October 2, 1970 – December 24, 1984

PREFACE

If you saw me on the street I would be just another person in a wheelchair. Would you know how to approach me? Or, would you shy off in the other direction? What do you feel when you see someone in my condition – pity, animosity, guilt? Why? Do you have any friends that are severely handicapped?

If you tried to be friendly when we were introduced and held out your hand to shake mine, but I was unable to move my arm and could only slightly move my hand, what would be your reaction? Would you think that I was being rude? How would you expect *me* to respond under those circumstances?

These are some questions for you. Now some questions for me. When I see *you* on the street do I know how to approach you, or do I shy off in the other direction? Do I have many friends who are not handicapped? What do I feel when I see someone who appears totally normal but tends to complain about trivialities, as all normal people do – pity, animosity, guilt?

This book is intended to help us all learn to live together as fellow human beings. We can't do this if we don't understand each other. After thirty or so years of losing my physical capabilities one by one, I want to pour out what is in my mind – not only my thoughts but my feelings and emotions. *Here they are* for your examination.

I have Muscular Dystrophy (I will just call it MD from now on). It is one of the most debilitating diseases known to children. At age 31 I am only one out of a million who have survived this long. This disease has taken me from a perfectly normal (albeit somewhat ornery) child to a man who is now wheel chair bound and completely dependent upon others for almost everything. I have had to bear with the curses of this disease, *but I have overcome them*. Currently I have no use of my legs and very limited use of my arms – I can move my fingers enough to write and work a tape recorder, but I cannot move my wheelchair.

We often hear of celebrities coming down with some serious diseases or incurring some injury in an accident, such as Annette Funicello contracting Multiple Sclerosis, Rock Hudson dying of AIDS, or Christopher Reeve suffering a spinal chord injury. Suddenly a world of attention is brought to these particular diseases because we feel that these people are part of us. We identify with them, and we want to do whatever we can to fight their diseases. Between the efforts of the celebrities themselves and the attention that they bring, considerable progress is often made. And this is good; we hope that cures will be found for all of these diseases.

But MD is different. It does not give its victims a chance to become famous. It affects the very young. By the time that I was 12 years old I was confined to a wheelchair, and I know many who had the disease who were in wheelchairs from age two or three. Therefore, in order

for MD to get any type of publicity it is necessary for some celebrity to take up the cause, such as Jerry Lewis does.

But as much good that he does, this is just once a year at the time of the telethon. It is not kept before the public like many of the other diseases which have ongoing celebrity advocates. This is one of the reasons when in 1996 one of my cousins became active in Miss Teen USA. They had a web page on the Internet where you could read about the background of the contestants. The day that I logged on to this web page to see what was listed on my cousin, I noticed that they had information on MD, and I realized how beneficial that was. I hope that this book will be helpful for both the handicapped and the non-handicapped, and I hope that it brings some recognition to the terrible nature of this disease and activate many more in the fight against MD.

But I am not just trying to advance the fight against MD. Diseases and handicaps will always be with us. I am not looking for sympathy, and neither should any handicapped person. There are a lot of people in this world with all of their physical facilities who seem to have handicapped themselves emotionally into not using the intelligence that God gave them. I might not be able to walk or even to move my arms, but I have not lost my mind, and *I have something to say*.

I have something to say to those who can identify with my situation and wonder how I handle it.

I have something to say to those who wonder how they can and should interact with handicapped persons.

I have something to say to the parents of special children who are unable to express for themselves.

I have something to say to those who can only see the physical aspects of life.

I have something to say to those like me who wonder why “normal” people seem obsessed with their trivial problems.

I have something to say to you – read it and take courage – there is far more here than meets the eye.

CHAPTER 1

BEFORE I KNEW – THE EARLY DAYS

My early life was much the same as most young American males. However, there are a few things that I would like to present to set the stage so that all of the rest of my experiences with MD can be better understood.

The year was 1966. Lyndon Johnson was president. US soldiers were fighting a war in Vietnam that was being protested at home. The Baltimore Orioles won the World Series. The Green Bay Packers were on their way to winning the first Super Bowl ever. The Beatles and the Supremes were entertaining America, and Bonanza was the most watched television program. It was into this environment that I was born on a Thursday afternoon on November 17, 1966, at Druid City hospital in Tuscaloosa, Alabama.

My parents (Barry and Linda Mason) had lived in the Druid City (as Tuscaloosa is called) arriving from Louisiana in August of 1963 so that my father could continue his studies in business administration at The University of Alabama. We lived in a two-bedroom unit apartment across the street from a Kwick-Chek grocery store; but having lived there only the first year of my life, I obviously have no memory of the place.

Later they rented a house in a neighborhood called Southwood. I only have vague memories of that house and would not bring it up at all, except that it was during this period (specifically, Aug. 28, 1968) that Mom gave birth to my sister Michele, who Dad started calling Missy. It was also at about this time that Dad joined the faculty at The University of Alabama, beginning his 30-plus-year career there.

In 1969 we moved to a three-bedroom house in Skyland Park, a subdivision on the southern edge of town. I look back with great tenderness on the seven years that I lived there, for those were the days of innocence. Looking back now, I realize that I did not know that there was so much hatred and bloodshed in the world. I did not understand the ramifications of the war and the people who were being killed in Vietnam. I didn't know that a president was being forced out of office. And I did not know what Muscular Dystrophy or its consequences were.

My sister and I were born 18 months apart, and generally we were very close and played well together. She was quite a tomboy, which led us to share much of the same interests. However, it did have its drawbacks. For one thing, we were very competitive – whatever one of us had the other wanted one just like it, if not better. When one of us would have a birthday, our parents would make sure that the other would get a small token gift in order to counter the green-eyed monster. For example, one year my sister got a Fischer-Price Castle for her birthday and my parents got me a Fred Flintstone finger puppet as a sort of consolation prize. It worked.

When one of us was having a birthday party at home, the other would try whatever was possible to spoil it. For example, I remember receiving a brand-new bicycle for my birthday, and when my sister came out to look at it she tore the back reflector off of it. But then there was the

time that she received a camper set for her birthday. It had weebles that wobbled but they didn't fall down. I don't know what a weeble was made out of, but they looked like hard-boiled eggs with eyes, noses and faces on top. Well anyway, the day that she received them, I went about peeling the faces off of all of them. Also, whenever one of us wanted to have a friend sleep over for the night we would have to wait until the other one could also invite a friend. Or, even if we were invited to sleep over somewhere else, we still had to wait until the other one could make similar arrangements. Neither of us are too proud of the way we behaved toward each other, but those of you who have siblings can probably relate to this, even if you are still in denial about your own participation. The competitiveness is a temporary thing that most normal children go through, and fortunately, it is now gone (even though she still has a better bedroom than I do).

In those early years my sister was very gullible. I could talk her into or out of anything. One time when she was running her bath water, I told her to let me in – I had to brush my teeth. Then, when I got in I had a game of keep-away with her pajamas. So when she cornered me, I threw them over her head and they landed in the water.

“Michael! Look now what you have done – I'm tellin' ...”

I could see she needed a cooling down period, so I blocked the door. “You really don't want to do that do you?”

“Why shouldn't I?”

“Well, for one thing, I won't let you out of here until you promise me ... I mean, after all, it *was* an accident ... I didn't mean ...”

“Yes you did. You did it on purpose.”

“Why would I do something like that, knowing you would tell mom? You know it was a accident.

Just then Mom heard us arguing and yelled through the door: “What are you kids doing in there – you know that you are not supposed to be in there together.”

“It's my fault,” I bargained, “I had to brush my teeth and Missy let me in.”

This came as quite a shock to Mom, who had never seem me so eager to brush my teeth before, and she never heard me confess to anything. Mom was in a dilemma. She could not decide whether to applaud or criticize, so she just let everything balance out: “Well, er, hurry and get done and get out of there.”

“OK, yes ma'am,” I said in a tone that she had to know we were covering something up. But Missy realized that she had missed her chance to nail me, and anything negative at this point would put her in a bad light. That night she actually went to bed in wet pajamas. Not exactly what I had in mind when I broke in on her. But then, I was not about to argue at this point.

Other examples of sister abuse could certainly be cited. There was the time when she was in a shopping cart and I turned it over with her still in it. On another occasion, I used her head to crack our back door window. You know how that goes – we were just playing around. Her head was OK, but the window wasn't. My parents replaced the glass, but every time it would start raining, the door would leak. Eventually they had to replace the entire door. Then there was the incident with the dart gun. I begged my parents to buy me a dart gun like the one that my friend had next door – the kind that had darts with rubber suction cups on the end of them. One time when I borrowed it from him, Missy was hanging around, so I aimed the gun at her. I only meant to scare her, not give her a black eye. So much for my chances of getting a dart gun.

The sport of sister-torment was not lost on me, and the art of talking her into doing things that would get her into trouble became a refined art. For some reason I always felt that the pleasure would be doubled when I got the chance to tell Mom or Dad the whole story according to Michael the archangel. Of course, when they heard her side of the story justice would prevail (why did I never realize that?).

One time this game went to seed, however, and it could have led to far more serious consequences. We were sitting at the table eating breakfast and Mom had placed our medicine neatly in front of each of us before going out to take care of some more important business. So it was just me, sis, and those evil pills. It was really unfair – I had to take four and Missy only had to take two. I was tired of taking all of that stuff, but I managed to hack down three of them.

“This one is yours” I said.

“No,” Missy replied, “I only had two.”

“Couldn't be. That would be unfair. It would make me get better quicker than you. Mom would not want me to get better quicker than you, would she? We both had three pills – one of yours rolled over here. I took my three – this one is yours.”

She bought it, and before I realized the full ramifications of what was happening, it was down her hatch. Oh well, too late now.

When Mom came in I could not resist: “Missy took my medicine!”

Missy and Mom both went ballistic at once. “HE TOLD ME TO!!!!”

“What do you mean, ‘he told you to?’ Do you just take pills because someone tells you to take them? When have you ever done anything just because he told you to? What is the matter with you?”

Somehow Missy's reasoning could not be properly articulated under these trying conditions, and it was almost worth it to see her take the heat. However, it was quite temporary, as it was clear to everyone who the real culprit in this situation was.

Mom went over to the phone and began dialing the phone. “I’m going to have to call the doctor to see what that is going to do to you,” she said. Suddenly this game wasn’t too much fun anymore. Missy and I both sat there holding our breaths – she imagining all kinds of intricate surgeries to extract the evil poison from the depth of her innards; me imagining what punishment would belie me to compensate Missy for the pain that she was about to endure. I was convinced that they would certainly feel sorry for Missy and give me the whipping of my life.

Fortunately, the doctor said that it was OK just this once, and we would not have to go in. But it was certainly not OK as far as mom was concerned. The punishment must have been pretty bad, however, because I fail to recollect what it was right now – I must be suppressing it. I do recall, however, that Mom closely supervised the taking of our medicine for several years after that.

While I can recall some whippings when I was young, I cannot recall what most of them were for. My parents were firm believers in not “sparing the rod,” but they never took things to extreme. The rod of choice for Dad was his belt – for Mom it was a paddle that was used to stir paint. Neither of these devices could cause any type of injury, but they had a high “sting” component. Needless to say, this got our attention.

Probably nothing is as catastrophic to the act of corporal punishment as a failure in the mechanism itself. For example, one time when Mom was giving it to me good with the light-weight paint-paddle, the thing broke off in her hand. These paddles are more for appearance (and paint stirring) than for inflicting pain. We would yell a lot, and maybe even imagine some pain; but you can’t do a whole lot of stinging with such a light slat. When it broke all she could do was laugh. The recognition of her anger was sufficient for that go-round, and it was at least a couple of days before I misbehaved again.

My mother usually worked at home, although occasionally she would take outside jobs or go to classes. However, for the most part she was at home when we were. Summers were especially fun, when Missy and I could sleep late, and then start off the day with Applejacks or Cheerios. Mom would usually have something planned for the afternoon. Often we would go swimming at Riverside Pool that was owned and operated by the University. At other times we would go to the movies. There was a theater near the house that had a children’s matinee for the first month of the summer, and we got in half price. One of the first movies I can remember seeing was Herby the Lovebug. Outside the theater they had a Volkswagen in the parking lot decorated just like Herby. Quite effective.

At other times we would just go to the mall or go shopping – sometimes stopping by the toy store while Mom went to the boring fabric store. Dad worked during the day Monday through Friday, so our activities with him were spent on weekends. Occasionally when he would come home at night he would read us a story either from a children’s book or from the bible. We always would enjoy these stories, especially like those of Moses and Joseph when they were young.

On weekends Dad would usually take my sister and me on a walk with him. There was one section of Skyland Park that had not been built up yet. It was hilly and overgrown with weeds. He would take us down there and let our imaginations run wild. Sometimes he would take our dog Charley with us, but he usually wanted to stay home.

On Sunday afternoons our parents would usually spend time with us, often playing one of those children's board games. As we grew older they taught us how to play checkers and dominos. Dad was excellent at both games and no one, not even Mom, could beat him at dominos. Occasionally I would get lucky and beat him at checkers; but I can only recall about two occasions when I beat him at dominos. It's a game that you have to count and remember numbers, and I realized at an early age that math was not going to be my strong suit.

Dad occupied much of my time in my early years, finding things in which we were both interested. His favorite activity was fishing, and he took me with him on several occasions. However, as time went by we soon realized that fishing was not going to be one of my favorite activities. He also took me to basketball and baseball games to see if I could get interested in that. I don't remember much about the basketball games – its kind of a mice-mash for long arms and legs. However, I do remember the baseball – they served great peanuts there. Eventually we did find one activity that we both liked, and that was watching football. And, later I got to understand and like basketball.

Most children probably think that their fathers are far too busy to have much time for them. So, whatever we did together tended to turn into a lasting, happy memory. For example, one night my father realized that the car was low on oil. He was going to the nearby gas station and he asked Missy and I to go along. The gas station was only about 200 yards from the house. We got there, added oil, and returned in no more than 15 minutes. But it was just the idea that he wanted us to go with him that enables me to treasure that memory even to this day. Years later when I heard that they had closed down that gas station and turned it into a bank, I always felt a twinge of sadness recalling that event.

Like most boys who lived in the country, Dad had a number of dogs while he was growing up. It became apparent that he wanted his children to have this experience as well. Of course, Missy and I were quite enthusiastic about this proposition. But, as usually is the case with most, it is the parents who end up taking care of the pets that “belong” to the children. Not that they minded that much. The first pet that we had was a beagle that reminded my mother of Snoopy from the Peanuts cartoon strip. She was inclined to name the dog Snoopy, but she thought twice when thinking about what the neighbors would think if she went about the neighborhood yelling “Here Snoopy!” So she settled on the name Charley, which I did not see was that much better. We had him probably about a year.

One Saturday morning my sister and I got up to watch cartoons. Even though we were told not to bring the dog into the house until our parents got up we went and brought him in anyway. Like all young dogs he would chew on anything and everything – this time the target

was the coffee table. I can still see the teeth-marks in that coffee table to this day – once there they don't really go anywhere.

Our yard was not fenced in and there was a road behind our house that was fairly busy. One day he wandered off and got struck by a car. We buried him across the street.

Shortly after that Dad decided to build a fence and close off the yard. It was wood in the front, but the sides and back were ordinary hurricane fence. It was clear that eventually we would get another dog, but we did not know when. Dad had seen an ad in the paper for this farmer's dog that had had a litter of puppies. One night, after my sister and I had gone to bed, Dad drove on down there and picked one up. He quietly entered my room while I was sound asleep, placed it in the bed beside me and as I awoke there, staring at me was a beagle puppy. He didn't look as much like Snoopy, but we named him Charley anyway – Charley II that is. Needless to say, I had trouble sleeping that night with all of the excitement.

Like all puppies, he also loved to chew on things. His habit was even more expensive than Charley I's. One time he chewed on the wire that connected the outside air conditioner unit to the house. Dad was not a happy camper that day. But that was not the worst of it. Dad partitioned off a part of the yard for a garden and fenced it in. One day when Missy and I got curious as to what was in the garden we opened the gate, went in and closed it. We were looking at the signs that he had made – carrots, okra, squash – you name it. As we eased back so proud of ourselves, one of us (the other one) forgot to close the gate. Needless to say, it took the dog less than a fifth of a second after we left to initiate his own exploratory expedition. He could not read, however, and so he had to dig the seeds up in order to determine just what was planted. It doesn't seem too traumatic at this point, but Dad had put in a lot of work on the garden, and he was steamed. Missy and I just got sent in the house and the dog had to dodge whatever was near at hand. We all survived – barely.

Charley II developed a habit of burying his bones around the yard. One afternoon when we were all out in the yard having a picnic, Dad asked Missy to see what the mess the dog had made up near the house. Missy started to inspect and uncovered a bone that he had buried in this shallow stash. Well, this did not go unnoticed by Charley II who began chasing Missy all over the yard. She figured that she could get refuge over by us, but all that had was the effect to get Charley II bounding all over our picnic paraphernalia.

“Just throw the bone to him,” Dad said trying to hold the table cloth on the table.

“But its covered with dirt,” Missy responded, holding the bone above of the dogs high-jump capability.

“That won't hurt ... dogs love dirt,” he replied, and with that she cast off the bone and the dog with one solid hurl.

Our pets give us a sense of control over nature, at least when we act in accord with their instincts. However, they also remind us of our own mortality. Like Charley I, Charley II was not

to have a long tenure at our house. He was particularly susceptible to the mange. We tried several treatments – really everything that the vet could throw at him. It was a heroic effort, including several home remedies of our own. But it was soon clear that the situation was hopeless. Dad tried to make it as easy on us as he could. That summer when we went to Louisiana to visit our relatives, we dropped the dog off at the vet. Missy and I did not know that my parents and the vet had agreed that it was for the best to go ahead and have Charley II put to sleep. It was not until a couple of weeks after we got back from Louisiana that I realized that we had not done anything with regard to picking up the dog. I finally asked Mom when Charley was coming home, and that is when she told me that he had been put to sleep because of the disease.

The hardest part of this was when we went to the grocery store – whenever I would go past the dog food section in the front of the store, there was one particular brand of dog biscuits that had a picture of a beagle that was a dead ringer for Charley. We had talked about getting another dog, but moving and one thing and another – it never came about. As far as the Mason's were concerned, the pet business had to wait another decade. While the parting from our pets is a sad thing, it is a small price to pay for the years of pleasure that they bring to us.

Like every boy growing up, one thing that I despised was taking a bath. After all, this took away valuable time that I could be spending watching TV, playing outside, or maybe even drawing a picture. I recall one time when I decided to draw the line in the sand. It started on a Monday. Mom sent me into the bathroom to take my bath. I went ahead and ran the water; but while it was running I would just take my clothes off and put my pajamas on. Once the tub got full enough I would shut the water off and leave about five or ten minutes, then pull the drain plug thinking that no one would know the difference. Then – back out to business. (Of course, I realize now that I did not save any time; but for some reason, this never enters into the reasoning process of most kids.) This went on for about a week.

There was one close call. On the second or third day of my scam my sister comes in right after I had finished my bath and yells: “Mom, where’s the soap?” A sudden shot of adrenaline hit my gut as I realized that in my concentration on deception I had omitted to make sure that there was soap in the soap dish. My career as a secret anti-bath agent was about to go down the drain.

Mom came back to my room: “Michael, how did you take a bath without any soap?”

“I just put water on the washcloth and used that,” I replied – a lousy fabrication, but all that I could think of at the time. I held my breath.

“Well, you be sure that you use soap from now on – how do you expect to get clean without soap?”

I couldn't believe it – she bought it.

I now realize that such a scam could not last forever, and a couple of days later (I actually made it until Friday) I was going to wash my hair in the kitchen sink. I took my shirt off and Mom saw that the dirt was caked into my shoulders. She then hit me between the eyes with the obvious question: "Have you been taking your baths?"

Somehow covert deception was not the same to me as straight-out lying, and I had to confess that I had been covering up. She took care of that real quick, as my punishment was to take a bath under her close supervision and interaction. She scrubbed my shoulders with the stiff brush taking off that outer layer of skin that was stained with all of your basic earth-tones. Needless to say, the humiliation of this incident was sufficient to assure that all future baths were duly taken.

Church has always played an important part in my life; more so now as an adult than as a child. Growing up as a child, church was not one of my favorite activities -- I did not view it as a pleasure to attend. I just viewed it as something that I had to do. Most children do not spend much time thinking about spiritual things -- or eternity -- or heaven or hell. Most children are just busy trying to have fun, living each moment to its fullest.

But, I can remember attending church for as long as I lived. Since before my birth my parents had been attending at the Oakdale church of Christ on the Eutaw highway, just outside of Tuscaloosa. Contrary to public opinion, most churches of Christ are not in a denomination (part of a larger organization). It is just a group of Christians who strive to worship God according to the examples found in the New Testament. They claim Christ as the church's only founder.

One of the first things I noticed about the building where we met was that it was more like a house than other buildings that most people call "churches." Later I found out that there was a good reason for that -- it was built to be a house. For about two years before my parents began attending with them, the Christians of this group had been meeting in the members' homes. They decided it would be better to obtain a permanent building. Not being large group at the time, they knew that they would eventually grow. One couple donated some land and they built the house on it. However, they did not complete it on the inside -- they left most of the walls out. The few walls that they did have served to partition some classrooms. But for the most part the house was an open area that served as an auditorium.

Right across the street from this building was an elementary school. It looked rather formidable since every time that I saw it the lights were turned off and it was empty. Being only 4 or 5 years old, I assumed that this was where heaven was.

Another thing that always stayed with me about the early years of church was when the preaches would proclaim that the church was God's house. But, whenever I was one of the last people to leave the building, I noticed that someone was always locking up the door. That really confused me -- if this was God's house, why do we have to lock it? ... and more importantly, how is He going to get back in? Well, it is hard to explain God to a four-year-old.

I can remember enjoying the bible classes a whole lot more than the actual worship services. You got to meet your friends, and the teachers would generally have some kind of fun activity planned for us. Then, there was always the chance that you might learn something before you got out of there.

One of the first “Sunday-school” teachers that I remember was Janice Ford, who seemed always to have a great rapport with the children. While I loved the singing in the worship, the 45-minute sermon was what I enjoyed the least. It certainly is the most difficult time for parents to keep their children still for that long while someone else talks. Usually they head off the problem by bringing books for the kids to read during the services. My parents just brought pencil and paper and let us draw -- *after* the preaching began, of course. On the fourth Sunday of the month they would have a singing service on Sunday night. Since most of the time was spend in singing praises to God, the 15-minute sermon was not so bad, and my sister and I always looked forward to the end of the month.

Of course, with every church you have to have a preacher. We had a couple of them, and, as I recall, they did not stay too long. (I was too young to remember any reasons for this.) The first one that I can remember was name Mike Tanner, and although I do not recall much about his sermons or him, I recall him coming over to our house for dinner one time. The first preacher that I really knew was a man named Aubrey Belue, who arrived at our church around 1972 (I was five years old). We had the tradition to refer to fellow members of our church as “brother” or “sister.” Well, I did not know what his first name was, and after hearing him called Brother Belue for so long, I got the feeling that his first name was brother.

I recall an occasion when our regular bible study teacher was not going to be there that his wife “Sister Belue” was going to take over the class. I got to thinking -- what a coincidence, a guy whose name is *brother* meets and marries a woman whose name is *sister*. Of course, later when I thought about it -- it seemed so ridiculous. However, as a kid, this was a perfectly reasonable conclusion.

Old brother Belue could really keep us awake during his sermons. He would start out slow and gradually raise the pitch and the tempo. Then, just when he was at the point of yelling, he would cut the volume and catch the real sleepers.

It was the summer of 1978 when I was 11 when he destroyed a misperception that I had held ever since I could reason about preachers. I had always thought of preachers as super people -- totally abnormal holy people. I remember going to my Grandmother’s house and above the table in a dark corner there was a picture of a man hanging on the wall. On the table was a bowl of unleavened bread and a bible. That’s what I thought preachers did all day -- sit in a dark room with a lamp on and read their bibles. One day in 1978 when I was attending summer school my father was out of town and my mother had surgery on her foot. So there was no one to take me to school and the preacher offered to take me to school. On the way he started asking me what programs that I watched on TV. To my great surprise and shock -- he watched the very same programs that I watched! This was the first step to my recognition that preachers are just like “regular” people.

The Oakdale church began to grow, as it should, and pretty soon there was not enough room to hold everyone. They bought some property in Tuscaloosa, on the south side of town, where they began a new building. Of necessity, we had to sell out old building before we could afford to build the new one and so they had to temporarily hold services at the YMCA. My sister and I were taught in a class that was in the hallway of the building. From time to time a wino would come staggering by. Not exactly conducive to the study of religion. Our teacher was furious that “her” children were subjected to such a show, and at one point she even took us down and held our class in her car. But this was only temporary, and we finally got our own classroom.

The thing that I really hated about the YMCA was climbing the flight of stairs to the top floor. Each step that I took convinced me that there was no way that I could make it to the top. However, I eventually made it. The room up there was not air-conditioned either, so it was a doubly painful experience. One time one of the young college students who attended with us just fell over and passed out from the heat. Fortunately, he was not hurt, but it caused quite a disruption.

Finally the church moved into a building that it acquired and became the South Tuscaloosa church of Christ.

One of the couples that attended with us -- Don and Carolyn Hill -- had two children -- Bill and Jamie. They were about the same age as my sister and I. Our before and after church interaction led to a close and long relationship. They would also come over to our house to visit, and we would also go to theirs. On one occasion we were invited to spend the night -- and we spent many afternoons in the summer at the University pool. Their father was a student at the university.

Once when we were visiting them Bill and I decided to build a fort in the carport using pillows and chairs. It was a great fort, but when darkness came we had to go and sleep inside. We did not recognize that the pillows were to be used that night, thus necessitating the destruction of our fort, and we were not happy to discover the destruction of our great edifice of defense the following morning.

We got along over at their house; however, when they came over to our place trouble usually ensued. One Christmas they came over and while our parents visited we retreated to the back of the house. My sister had received a dinner place set and a toy sink for Christmas, and for some unknown reason, Bill and I found our way into her room. We started pretending to wash dishes in her new toy sink when Bill got the idea that it would be far more realistic to use real water from the sink. He got an empty cardboard shoebox out of the closet and went in the bathroom, filled it about half full and brought it back into her room and poured it into the toy sink. Not to show inhospitality to my guest, I went along with the game, grabbed the other half of the shoe box and followed his example. Unfortunately, the shoebox absorbed the water, got mushy and water started leaking down the hall. We made several trips anyway, so it did not take long for this exercise to evolve into a watery mess all over the hallway and her room. When our

parents finished their visiting and came down the hall the mess was obvious all over the carpet from the bathroom to Missy's bedroom. The kitchen play set was not designed for water, so there was a great pool under it as well. Seeing this, Dad immediately hit the ceiling. He had to take all of Missy's new kitchen set and place it in the back yard to dry out, since they were afraid if it would get rust spots all over the carpets. Mom did not think it was nearly as big a deal as Dad did, but she agreed that it would be necessary to keep it outside until it thoroughly dried out. Once it was totally dried out it was ceremoniously placed back into its rightful home once again.

Before Bill came over the next time my parents drilled into me that, absolutely under no circumstances, were we to put water in the toy sink. I was totally convinced -- and convinced them -- that there was no way that I would do anything like that. But there was something about that sink that just was not complete without water. It was like a magnet and drew us to it. So when Bill got some water out of the bathroom to put into the sink, it just seemed to be the thing to do to give the experiment a second chance. Jamie (Bill's sister) and Missy had instructed me to go tell my parents what Bill was doing, and I proceeded to comply with their wishes. However, as I got to the bathroom I was compelled to get a cup and bring back some water of my own. Jamie asked me as I entered the room: "Did you tell your folks?" but seeing the water in my hand her query turned to frustration as she stated to Missy: "He went to get more water!"

We did not do nearly as much damage this time, for we were being monitored much more closely than before, and they caught us in the act. A parent has a very difficult time understanding when something is explained so clearly; how it is that a child will not follow through. I can assure that it was not out of a lack of love or respect, or anything like that. It's just that this time we felt that we really could pull it off without a mess. It was certainly doable. We just overestimated our ability -- both as plumbers and secret agents of the water brigade.

Eventually the Hills moved to Starkville, Mississippi when their father became a professor at Mississippi State. We only visited them there one time, but it was a trip that I will always remember. Their family owned a private plane and when we went to visit them, they drove us to the airport and offered us a plane ride. Mom and Dad decided to pass on it, but Missy and I were eager to jump in. Mr. Hill sat in the pilot's seat with Bill next to him, while Missy, Jamie and I sat in the back. When that plane first left the ground I was petrified, refusing to even look out the window. I began to regain my composure as we made a few trips around the airport. I first peaked and then opened my eyes and really enjoyed the flight from that point on. At this point I am really glad that I jumped at the chance, for this was to be my first and last flight. If nothing else, when I remember this incident it taught me to "go for it" since we do not know what tomorrow might bring. I was always grateful for the Hill family for providing one of the great thrills of my life.

Like many families, mine went all out for the holidays with decorations and a huge home-cooked meal. But of all the holidays I would have to say without a doubt that Christmas has always been my favorite time of the year. In the early part of December, my parents would take my sister and me to the shopping mall to see Santa Claus. A few days later we would all get

together and put the Christmas tree up. Then we would go outside and view the tree from the street.

We never did open our gifts on Christmas since we were always in Louisiana visiting relatives. Therefore, the night before we were supposed to leave, Santa would pay us an early visit and ring the front door bell. Missy and I would then rush into the living room and start going through our presents. Dad was always right behind us, but in all the excitement I never noticed that it always took Mom a few minutes to join the fun. She would secretly enter the house through the back door.

I remember one Christmas in 1975 when I almost spoiled everything by catching Mom in the act of playing Santa Clause. I was becoming impatient waiting for the doorbell to ring. Every five or ten minutes I would peak into the living room to see if St. Nick had paid us a visit yet. Finally, after 20-30 minutes of this I retreated to my bedroom in frustration. As I was passing through the den on the way to the living room Dad realized what I was doing and called me over to the couch where he was, and he began to ask me what I had done at school that day. After about 4-5 minutes of that conversation, the doorbell suddenly rang and I ran to the door and there were our gifts. I remember running toward the door to see if I could catch a last glimpse of Santa Claus ... but, of course, he had already gone.

Going to Louisiana was as much of a Christmas tradition to me as putting up a tree and visiting Santa Claus. We traveled to the Bayou State three or four times a year, but my favorite time to visit was during the Christmas season. I loved looking at the Christmas decorations at the different houses between Alabama and Louisiana on the way.

I always looked forward to passing through the town of Jonesboro in Louisiana. In the middle of what was the town square stood a tall lamppost. Every December they would somehow attach steel wires to this lamppost so that the lights at night would look like a huge Christmas tree.

Living in the South, we did not have to worry much about the weather spoiling our holiday trips. However, I do recall one Christmas when our trip was threatened. The night before we were supposed to leave, the weather forecast called for snow, but the next morning (much to our relief) we discovered that the snow did not stick and the roads remained open. There were patches of snow on the ground, but there was no ice on the roads, and we took our trip as planned.

On one of my early Christmas trips to Louisiana I was all bundled up because it was freezing cold. I was turning into an icicle in the back seat wondering just how I was going to make it. We had barely pulled out of our drive when Mom asked: "Do you all know that this is the first day of winter?" Thanks Mom, but that was a fact that I really could have done without at that point.

My father's mother (who we called Maw Maw Joyce) lived in Oakdale, Louisiana, as did his brother and three sisters. I do not know much about my paternal grandfather except that his

name was Rufas Crofford Mason, he was born in Mississippi, and he died in 1959. However, my grandmother had long since remarried to a gentleman named Eli Grantham (who we called Paw Paw Eli).

Twelve miles north of Oakdale up highway 165 was the small town of Glenmora. My maternal grandparents, Homer and Dimple Fairchild (who we called Paw Paw and Maw Maw Fairchild) lived here. Their house was used as our headquarters for these trips so naturally I grew close to this side of the family. My grandmother is a person of high energy, outspoken and strong willed. My grandfather was a great storyteller, and he could always find a way to make me laugh. Together they made a fun couple and provided me with a childhood full of pleasant memories.

Living next door to my grandparents was my mother's sister (my Aunt Bettye), my uncle and my cousins Kevin and Christy. I had other cousins on both sides of the family, but I would not be as close to them as I was to these two, and especially Kevin. Kevin was a year older than I, while Christy as a year younger than my sister. Sometimes we would all play together, but usually the boys would go one way and the girls another.

Kevin and I had a lot in common, and he introduced me to the hobby of collecting things such as records and matchbox cars. Meanwhile I introduced him to the collection of action figures that I had, such as GI Joe and Superman. We also enjoyed watching TV together, especially those police shows that seemed to dominate the airways at that time. And to the sorrow of both of our parents, we soon discovered we had something else in common as well.

Muscular Dystrophy (MD) is an inherited genetic deformity affecting the muscles. There are varieties of diseases called MD, but the one that I have is the most common (Duchenne). It gradually disables the skeletal muscles that affect the arms and legs as well as the working of the lungs and heart. It is also referred to as being in the category of a sex-linked inherited disease. For example, out of several thousand people born with this disease, only about one would be a girl. Females of the family are carriers, but they very rarely get the disease.

The effect of the disease causes the muscles to waste away. Therefore, it is a common mistake that my many that the victims of MD are just fat. In reality, it does not have much to do with how much you eat – it is the nature of the disease itself. Though you are born with the disease, the symptoms usually do not begin to show until around four or five.

One of the most definitive telltale signs occurs after the child has fallen down. When a normal baby falls down in the middle of a room, you will see them get up right there and then and just keep on going as though nothing much has even happened. When an MD child falls, they often will crawl to the nearest piece of furniture and use that to get themselves back on their feet again.

In 1968 my cousin Kevin was diagnosed with the disease through a blood test at age three. I was almost two years old at the time. When I was four I begin showing some signs of

the same disease, so they performed a blood test on me. However, it came back inconclusive. My doctor then ordered a biopsy that was performed in the spring of 1971. It was when it came back positive that my parents knew that my physical fate was certain.