

**OUR SON HAS AIDS
A MOTHER'S PERSPECTIVE**

**THURSDAY, DAY ONE
OCTOBER 1992**

It started out like any other Thursday, doing the usual things around the house. I had a coupon for a free piece of pie with the purchase of one, and I have a good friend that I called to go and share some fun and splurge on pie. My sweet husband likes to have a special meal at home to eat all he wants, and this allows him that time unsupervised to pig out. My friend and I went and laughed and talked and had some girl time together which is a rare thing for me. My life is mostly full of men, having a husband, three grown sons and one grandson. We are also blessed with a wonderful daughter-in-law whom we all dearly love and treasure.

The doorbell rang later that evening and there stood Jim, our middle son, and his friend Mark. We were in the den relaxing and watching TV. Sam later said that when he looked through the door peep hole and saw Jim, he knew something was wrong. We began to talk, and he said he had something to share with us - he had been to the Doctor and had been diagnosed with full-blown AIDS. The Doctor had found Kaposy's Sarcoma which is a rare form of cancer, in the roof of his mouth. He knew he had to tell us. I immediately put my arms around Jim and held him as he cried momentarily. He shared with us that he had been tested two and one-half years earlier and had tested HIV positive. He had kept that terrible secret to himself all this time to protect us from pain. No greater love could a child have than to suffer in silence to protect us! He asked that his brothers be called so that he could share this all at once. I called each son and said, "I need you to come now". Since I had never done this, they each responded affirmatively, and we waited for their arrival.

When they arrived, Jim shared the news with them - and we were all in a state of shock and disbelief. We all told Jim that he had our unconditional love and support, and that we were all involved together. At one point I went to Mark and put my arms around him and thanked him for being there for Jim. I told him that we were there for him also. What a courageous thing for him to do - to be with Jim when he shared this dark moment with us!

We knew that Jim was gay, and we had dealt with th.at many years before. Our generation was taught that this was something that was avoidable, a chosen lifestyle, and not something one should be. Our first reaction was "let's get him fixed". In time, with much mental turmoil, we began to have a better understanding. We never rejected Jim and he always had our unconditional love, but I am sure there was a time when we made it difficult for him.

We waited to hear how our daughter-in-law felt, as she had stayed at home with our grandson when we were told the news. Our eldest son, her husband, said she was taking it all right. We waited to hear. Finally, the doorbell rang on Tuesday after her day of teaching school. There she stood, she put her arms around me, and we cried together. I told her how much I needed to see her, and she

asked why I hadn't called. I said that I knew she had to deal with this in her own way. She came in and we talked - she also supports and loves Jim, and we are a united family. We are so blessed!

Jim is a very special young man who has been a joy to us all. God has given him a very special artistic talent and inner beauty. He has said that when he was as young as five years, he knew he was different from the other boys. How profound from such a young child at this early age! I feel deeply that he no more has a choice than we do as to the color of our hair, or our height or our appearance. With all the discrimination against gays, why would anyone choose that lifestyle? They continue to research this issue and evidence has been gathered which confirms that there is a difference in the brain of gay men. Research needs to be done on lesbian women.

Jim dated in high school and tried to be someone other than his true inner feelings were leading him to be. What a struggle it must have been to find out that he in fact was different than the other boys.

FRIDAY, DAY TWO

We hardly slept. What a nightmare to face, our beloved son facing this life-threatening disease! The unknown - the painful recollections of men on TV diagnosed with AIDS - wasting away, crying out for help. How could we get through this? Throughout the day, first one son, then the other came to our home, and we talked and tried to make some sense of this devastating news. The feeling of being alone in the middle of the ocean, not knowing what to do or where to go. Our youngest son had a Doctor friend that he had talked to and he had picked up some things to read and also a book about AIDS/HIV. He brought us a pager and some books that he had picked up at a book store. He knew we would be home-bound waiting for the phone to ring, and the pager would give us some freedom to leave and not miss any important phone calls.

Finally, we each started to make some contacts to receive information to help us in helping Jim and ourselves deal with the dilemma we were all facing.

Still no sleep to speak of. How could we deal with the loss of a child? I remember my Grandmother telling me some time after my Father died at the age of 46, that she had lost her husband, but nothing was like losing a child. How those words had been etched in my memory as a young adult with a small child! Now we were facing the possibility of experiencing the loss of our beloved Jim!

SATURDAY, DAY THREE

My memory of this day is vague. There were people we had to tell something - and how could we say it and protect Jim's privacy? I had been responsible for contacting people to attend a gathering on Halloween evening. It was a get-together of five classes from my high school days. We had been trying to get a few people to stay in touch on a more regular basis, so that when a reunion was held it would be well attended. I had spent many evenings calling and felt some obligation to attend - although nothing could have been further from my desire. My best friend from high school called to make last-minute contact as to when we would be there. I had to say something - what could I say? I finally said that Jim had been diagnosed as having cancer, thinking that would suffice and she would understand if we could not attend. Immediately she asked where the cancer was. I was reeling - I had not thought it through, what could I say? I finally said I just couldn't talk about it, and that we would come if we possibly could. I hadn't expected any questions - how could I deal with telling anyone, when we needed to protect Jim, his job, his life.

Both my husband and my other sons said that we should go, even if only for a while, it would do us good. I protested but finally I agreed, there was after all nothing that we could do at the moment for Jim. We went and stayed a short time, acting as if nothing was wrong. Finally, when it was time for us to go, I shared with a couple of people that we were not really in the mood to celebrate, having just learned that our son had cancer. That opened the door for more questions.

SUNDAY, DAY FOUR

As is the custom on Sunday morning, my husband drops me off at the front door at church and I go in and get a seat and visit while he sits in the car and reads the Parade Magazine until time for him to come in for the service. As I walked in the door, I nearly ran over the Minister that heads the Care Ministries. I suddenly thought that he would be the person to talk to instead of the Senior Minister as we had discussed. I waited until he had finished talking with a woman and got his attention, I blurted out that our son had AIDS and we needed to talk. He asked if I meant today and I said no, Jim and Mark had been invited over for dinner. He said to call Monday morning and make an appointment.

Jim and Mark came over and we had a nice dinner. This was the first time we had ever invited Mark. Jim had brought him a time or two, but this was our first invitation. Jim had told us the night that he shared he had AIDS that he wanted his life to be as normal as possible. We laughed and talked and ended by playing a card game.

I had suggested that Sam make Jim a stepping box to strengthen him. He had all the signs, especially loss of weight - which he had explained away as an ulcer and actually he probably had one. He appeared gaunt, thin, and weak. Our home is tri-level and he could hardly walk up the stairs without resting, so we decided the stair

step box would help him develop his leg muscles which he certainly would need.

Jim had done some free-lance art work and earned some extra income. He had planned a trip to Paris for himself and Mark. These plans were made before the full-blown diagnosis. He was scheduled to leave January 8, 1993. We all wondered now how realistic the trip was, and yet he wanted to go so badly. All we could do was support him in whatever wish he had, whether we thought it wise or not.

Monday came and we met with the Minister. We asked if he knew anyone in our very large congregation who was dealing with the same issue. We were seeking someone who understood the seriousness, as we had been warned to be careful who we confided in. We talked awhile and he said he would call us the next day, he would have to get permission from any other parents. The next day came and went and no call was forthcoming. I stayed by the phone all day. With a large congregation it is certainly understandable that we never received the call, but days went by. Finally, a message on the recorder telling us the title of two books to read, and no mention of an attempt to contact any other parents.

We were rather overwhelmed. Where do we go for help? Who can we trust? Who is it safe to tell our secret? Days passed; fortunately, our youngest son heard about an organization called Other Options. He contacted Cookie Arbuckle who said she would come over and visit with us as a family. Friday evening came and she and her daughter spent the evening talking to us and educating us. Previously our son had brought literature which we had all read as fast as possible. So many questions, so few answers! Cookie brought comfort and a sense that there were wonderful people out there who really cared and had devoted their lives to helping in this terrible epidemic. She also left more literature and said she would help Jim fill out the myriad of papers necessary in this illness. She also said he would be eligible to go on medical disability. Somewhere in my mind this stuck. Here he was struggling to continue to work!

NOVEMBER

I mentioned to Jim what Cookie had said about applying for disability, he seemed so relieved. He is in a very frantic advertising arena with a stressful routine. We talked about it and he decided to apply for disability at the end of November. In the meantime, with our need to connect with someone who understood, we attended a couple of support groups but felt they were not what we were looking for. One was attended by HIV positive young men. No other family members were there. I will never forget something that was said during that meeting. The leader of the group asked, "Where will our Michelangelo's come from?" With this disease wiping out our talented, artistic young men and women, where will our artistic works originate?

We visited a second support group. These participants were parents and friends of lesbians and gays, people dealing with the issue of

homosexuality. We were already dealing with something much more serious. They were all very loving and caring, but there were no other parents whose children were affected with AIDS there, and we so desperately wanted to connect with people that had the same need to reach out and help one another.

In my search to connect with someone, I decided to contact a young lady that had been a Minister at our church and had moved to another church. She had also been our neighbor when Jim and our other boys were small children. In fact, Jim had a crush on Kathy and she was his first love. She very lovingly talked to me and felt our sadness for she too knew Jim and loved him. I had finally found someone who worked in the AIDS effort, someone who also knew our family and loved and accepted us. She was a wonderful resource and gave my name to another woman who heads the RAIN organization. Mary Catherine Smotherman, the founder, lost a son to AIDS. She called me one evening about 10:00 p.m. Words can never express the appreciation I have for her call and for the compassion I feel for her in her loss. She doesn't know me and yet she took the time to call and offer her support. God puts such wonderful people into our lives when we need them!

Days went by and I spent every moment I could with Jim. Happy times - like nothing had ever happened to change our world! We all had a compulsion to talk to him and see him - to soak him up like a sponge, yet he needed time to assimilate the news also. Since he had asked to live as normally as possible, I had to be strong for him and for the rest of our family. My time to cry needed to be in private for the most part. My need to make this a positive experience and to continue to have hope sustained me. I believe in miracles and perhaps my son would be that miracle! God only knows!

Thanksgiving came and I wondered if it would be our last as a complete family. I dreaded saying the prayer for fear that I would break down and cry. I rehearsed it over and over. Ironically, for some time I had been praying for strength and I wondered why - but never really questioned it. I had been doing so for almost a year. When I needed it most, God gave me strength. We had a nice Thanksgiving, although Jim did not feel well and spent most of the day on the couch in the den.

DECEMBER

Thanksgiving is past and now Christmas is to come. Many days were spent at Jim's house making Christmas wreaths, and just visiting and having fun. I had a great need to make our own house full of wonderful memories, extra decorations, and traditional goodies. Sam got sick near Christmas and it was a very busy time. Cooking, baking treats that all the family loves, shopping, wrapping gifts, and preparing for another family time that could be our last with Jim.

After Jim's November appointment with the Doctor she called and said his liver enzymes were high and that she wanted him to go to a

specialist. We finally persuaded Jim to allow us to take him, to make it easier for him. We had offered to take him to the Doctor previously, we really wanted to meet her and find out his prognosis, but he had declined our attempt. We took him to the liver specialist and in a few days the call came from the Doctor that he needed a biopsy on his liver. The day came, and we took him to the hospital out-patient wing for the biopsy. This took all day and we took him home knowing that the next week he had an appointment with his primary Doctor. Then we would learn the results of the biopsy. December 23 came, and we took him to the Doctor and finally met her. What a charming, caring, attractive, personable woman. She treated Jim like an old friend, telling him about her trip to San Francisco. Jim allowed us to go in the examining room with him. The nurse came in first and Jim asked if they had gotten the results of the biopsy and she said yes. He asked what they had found. When she said it was rather complicated and that the Doctor would explain it, I knew we were in for trouble.

In a few minutes the Doctor entered. They talked like old friends and she took all the time he needed. She said that he had CMV, a liver virus that can cause some terrible things such as blindness, mental dysfunction, as well as many other things. Jim would require daily intravenous treatment morning and evening temporarily, but once daily for the rest of his life to treat this condition. She asked if he understood what she was saying. He said yes as he took a deep breath and his eyes widened. She walked out of the room and I immediately said to him that he would handle it as he had handled all the other news. Considering the alternative, he would surely adjust to the IV's and life would go on. After a few moments I started acting like I needed to use the rest room and excused myself to find the little girl's room. I hoped to find the Doctor to speak with privately without Jim knowing. Fortunately, when I walked out of the examining room, there she stood at the nurse's desk reading something and discussing it with the nurse. I stood there planted in front of her until she had finished. Finally, she looked up at me and asked if she could help me. I looked at her and asked if she could tell me the progression of his disease. She shook her head and said no. I continued staring at her not accepting her answer and she finally said with an AIDS diagnosis the average remaining life is three years. With the diagnosis of CMV the average remaining life is six months. I was stunned. I thanked her and went out to the waiting room where I waited until Jim and Sam came out. With a big smile on my face I said something about not knowing which examining room he was in after going to the bathroom. We took Jim home after finding out that his treatment was to start that day. However, the Home Care Nurse couldn't make arrangements to come to Jim's house until the next day, Christmas Eve. Our plan was for Jim to come to our house after she came and we would visit and wait for the rest of the family to gather as we always do on Christmas Eve, for an evening dinner of turkey. Time passed and we hadn't heard from Jim, but he finally called and said that he would be over soon. When he arrived, we found out that the nurse had come and there had been a problem.

Jim relayed to us that this beautiful young blond woman came, and he thought how great to have such a special nurse. They got acquainted and she started the IV procedure. Jim has veins that roll, and she was having trouble finding a vein to start the IV. At some point she dropped the needle and it fell to the floor,

bounced up and stuck her on the top of the foot. She freaked out. Jim sat trying to comfort her. She excused herself and went to the bathroom, removed her pantyhose and bled herself which is what she had been taught to do, considering the communicability of the AIDS virus. Jim as a very sensitive, caring young man was devastated. What a way to start with this treatment! She called her office and they sent another nurse, Joni, who took over the treatment. We later learned that the first nurse went to the Doctor, who also happened to be Jim's Doctor. As a consequence, she has a three percent chance of contracting AIDS. Of course, she knew the risks when she went into home care twelve years ago. How sad for all of us. We told Jim he had to let it go, this was her work as is the similar case for policemen, firemen or any other dangerous occupation. Only Jim knows how deeply he was affected by this tragedy. I pray for her continued good health.

Christmas morning arrived and all the family congregated for a very special celebration. Nurse Joni had offered to come to our house for the IV procedure so that we could have our normal celebration. She came and obviously she and Jim have formed a very special bond. He loves her dearly. All the family had wanted to make this the best Christmas we had ever had - and they did. Much laughter, love, caring. Everyone had bought extra gifts for Jim - how could we not do this. He seemed to savor every minute. At one point he said, "let's slow down the opening of presents and make it last longer". Dinner time came and again the fear of losing it when I said grace. My God gave me the strength I needed. I got through it and we held hands and prayed. We will never forget this Christmas as long as we live. Our special time as a united family. How blessed we are!

JANUARY

My friend that went with me for pie on that fateful Day One was filling in for the Senior Minister's secretary while she took leave to have a baby. I had finally told her that Jim's cancer was not his only problem. She comforted me and understood. I discussed with her my feelings of emptiness over our meeting with the Care Minister and she said she would tell our Senior Minister that we would like to talk to him. The Tuesday before Jim was to leave on his trip we went to the Minister's office. He was as kind as the other Minister had been and said that in February a new Minister would be on board. He would form support groups for such concerns as AIDS, heart disease, cancer, etc. It would probably take some time for him to get settled in and get started. I said we didn't know if we had that long to wait with Jim's prognosis. As before I asked him if there were other families in the church that were going through what we were, and if we could connect and help each other. He finally said he would make some phone calls, and we left. We didn't hear from him again either.

Now we are in the process of getting Jim ready for his trip to Paris. It was decided that they would put in a pick line since Jim's veins weren't holding up well. Jim asked me to be there as he was uncomfortable about the procedure. During the week before, his blood count was very low, and he had to have two pints of blood and

sign a release due to the possible danger of a transfusion. It was a lost day for him because he had to have his daily infusion, then blood transfusion and they had given him some medication that made him drowsy. During this time the nurse had talked to him about a living will. He tried to comprehend but said he wouldn't sign anything in his present state of mind. How wise he was to wait until the medication wore off.

He was able to skip one day and then had to have two more pints of blood. He only had one day between the last blood and his departure to Paris. Jim has a fear of flying and had asked his Doctor to prescribe Valium. which she did, to help him with the apprehension of flying. The morning came when they were to leave for Paris. We picked them up at Jim's house to take them to the airport. Jim seemed tense and said, "I don't want to go". I ignored the comment. I had asked myself many times if he really wanted to go, or if he felt that he owed Mark this trip for all his help and support. We will never know. The airport security was very tight that morning, since the Iraq situation had erupted again. Jim seemed very weak and we got him through the gate with his cane. When I started through the buzzer went off. I took off my jacket and shoes which had brads on them and tried again. It went off again. I took off my belt which had brads and tried again. Still buzzed. They said to put my arms forward with palms together and go through. Buzzer went off. Finally, they said take off the earrings - I made it. I grabbed Jim's carry-on, my shoes, jacket, belt, earrings and headed for the waiting room. It was not until I heard my name on the loud speaker that I realized in all of the commotion I had left my purse at the security gate. I retrieved it.

Jim and I have a very special connection and sense of trust. We had taken a course together many years ago and had learned to relax and reduce stress. On the way to the airport and also after we arrived, I took him mentally to a relaxed state of mind. The relaxation and the Valium helped him to depart. I couldn't help wondering if I would ever see Jim alive again. He looked so frail, so delicate, so sick. I prayed for a safe trip for them and put them in God's hands. Off they went down the ramp to the plane. I was compelled to stay until the plane taxied away. Here was my baby leaving the country, facing God knows what. Would he be OK?

We had decided to use the eight days while Jim was gone to refortify ourselves for the days to come. I started to feel under the weather for a few days, some better than worse. My worst day was the day before Jim was to return from Paris. I worried that I might have been around him with cold symptoms and he might have contracted something I was carrying. I wondered if I would be able to go to the airport the way I felt. I tried to stay busy but it was hard not to think and wonder what was happening.

He left on Friday and when we came home from a movie Sunday afternoon there was a message from Jim on our recorder. He couldn't imagine where we were because we always went to church and brunch and then home. We had decided to do something different and skip brunch and take in a movie and eat later. I had missed talking to Jim. He said he might call later. I prayed that he would, and he did call about four that evening which was ten p.m. in Paris. He said the flights had been fine and that they were very tired and had slept

most of the day Saturday. The weather was bitterly cold and windy. They had room service for meals and would start Monday to take in the sights. I thanked God that he had made the trip all right and that we had heard from him. We saved the message on the recorder, I was afraid we might never hear his voice again.

The day finally came when Jim and Mark were to arrive. I had called the airline after each flight to see if it had arrived on time. The flight from Paris to New York had arrived a little late but could still make connections with the flight to St. Louis. We later found out that they had stayed on the runway for over an hour waiting to take off from New York. When they arrived in St. Louis late, they had missed the flight to Oklahoma City. We called and found that they were scheduled to stay overnight in St. Louis, arriving at ten the following morning in OKC. Mark's parents were planning to pick them up. I couldn't wait to see Jim and knew I had to also be at the airport when they arrived. We later got a phone call from Jim in St. Louis and he said Mark wanted to talk to us. Mark said that Jim had been sick, and he felt Jim had to get home. He had been able to get a flight to Tulsa that would arrive at 11:00 p.m. and asked if we could pick them up in Tulsa. We said yes, we would be there.

Our cars are several years old and of questionable dependability on a dark night when a quick trip was needed to transport our sick child. I called our neighbor next door and to keep an eye on the house as we would be out very late. We always look out for each other. They come and go a lot, so this was a usual thing to do. I told her that Jim was sick, and we didn't know what kind of shape he was in. She asked if we would like to use their van. What a Godsend! We didn't have to worry. They needed a few minutes to empty out some things and we could leave. Our youngest son called and wanted to go with us. How glad we were to have him, not knowing how we would find Jim. We filled the van with pillows and blankets, went to fill the gas tank, and left for Tulsa after 9:00 p.m. Not knowing where the airport was, we studied the map and off we went with our youngest son as the co-pilot.

We barely had time to make the arrival of the plane. With one wrong turn we were five minutes late. We went into the airport and immediately saw Mark. We looked around for Jim. There seated in an almost horizontal position was Jim. He looked up and said, "Now I can almost smile - I'm so glad to see you". He looked even worse than when he had left. I hugged him and told him how good it was to see him. We tried to find a wheelchair to help him to the van. No wheelchair was available, so Sam and Bob supported him on each side and to the van we went. I hurriedly spread out blankets and pillows. Jim got in and went immediately to sleep. We put Mark on the back seat and I sat beside Jim on the floor of the van while we drove back to Oklahoma City. We immediately knew we would take him to the hospital emergency room, which we did. We arrived at the hospital at 12:50 a.m. They took him to an examining room

where we stayed until 7:00 a.m. It wasn't until about 5:00 a.m. that they decided he needed to be admitted. Jim's Doctor was out of town and another Doctor was on call. About 5:00 a.m. we convinced Mark to let Bob take him home for some rest. Mark had endured their long trip and the strain of Jim's condition. He was exhausted. After it was determined that Jim would be admitted, Sam went home to rest. We waited for a hospital room to become available. Finally, at 7:00 a.m. Jim was wheeled to his room. He had slept fitfully in the emergency room. He had not been able to sleep well in Paris. He had overextended himself, having fever and diarrhea. He looked so ill.

As is the case in the hospital, someone came in every time he would settle down to rest. The on-call Doctor finally came in and said Jim definitely needed to be hospitalized. Jim was not happy with us for bringing him to the hospital instead of taking him home. He said all he needed was some water and rest. He had become dehydrated. What a long day! By then his lips were full of blisters and he could only breathe with his mouth open. IVs were installed and we waited. They had given him liquid Tylenol for the fever, but it made him nauseated. The family came in one by one for a period of time, but no one had much rest. I said I would stay the second night and go home the next morning to rest. What a long night! Jim mumbled all night long, had diarrhea, nausea, vomiting and generally a bad night. When they would change the bed, he would get chilled. At one point I had four hospital blankets over him as well as one doubled, and I also leaned over him to warm him. I was exhausted. When he would try to talk, I would get up and lean over to hear. His mind was spinning. He had so much he wanted to say. He acted as if he stopped talking that he would lose control, and he so desperately wanted control of his life! He was trying to figure everything out. It was Monday morning, I had been up for forty-eight hours. I was exhausted, both from the ordeal and from being ill for the better part of two weeks.

Sam came to pick me up to take me home and Bob stayed with Jim. I was exhausted by then and emotional. The realization of Jim's condition was etched in my mind - would this be his demise? I rested, unable to sleep, quietly sobbing sporadically. I just wanted to be held, consoled. Bob had called to say Jim was sleeping, mostly non-responsive, even to nurses. They gave him blood enhancer and more medication. Bottle after bottle of IV containing various treatments. They did the M.R.I. and scrubbed him for the port installation scheduled for Tuesday. They also gave him antibiotics. Sam stayed all night with him. More of the same. I stayed home and Bob stayed with me for reassurance. God blessed us with three wonderful sons. Everyone looked out for the other as well as for Jim. Together we would get through this ordeal. Our daughter-in-law called her friend from college, who is also our Doctor. She explained our situation and asked for medication to help me get some rest. Bob picked up the

prescription and they insisted I take it and sleep. It is so nice to be cared for by people you trust and love. I will always remember their care and love for me. We suddenly realized that no one knew Jim was in the hospital except Mark and the family. We started contacting friends. Flowers and cards began to arrive as well as visitors. Jim has so many wonderful friends and we have become better acquainted with them through this time. Some hugged me and held me in their arms and asked if we needed anything, and they meant it. We are so lucky! Tuesday Jim had periods of being wide awake, and periods of deep sleep, increasing periods of quiet sleep with mouth open, temperature normal, some difficulty swallowing, minimal talk, incoherent. By afternoon diarrhea had stopped, but there was some bed wetting. Dr. Brown visited and remarked that Jim was very sick. He had a seizure as we stood beside the bed. She just held his hand and waited until it was over. She reassured him. She also reassured us later as we walked out into the hall to talk privately with her. She said they really didn't know what was going on, but it appeared that Jim had some neurological problems. She wanted to do an EEG and a chest X-ray. How difficult it must be for her, so much is unknown about this disease. Our former neighbor, Kathy, now Minister, came to see Jim. They talked and I left the room to give them some private time together. She came out into the hall later and we held each other and cried, consoling each other. She had told me when I initially visited her that she had met and sat with many AIDS patients, but that Jim was the only one she had known and loved before, and that it was so different. She was so touched. He had told her that she was his first love and how beautiful she is. At one point he had gazed into her eyes and said, "I may never get to look at you again". These words caused her to have to leave the room.

Much of the day and night, when Bob was there, Jim was both incoherent and hostile. He gave Bob a hard time and seemed so confused about things. He thought we were all against him. We were all so fearful that we had lost the rational Jim and we would have to deal with this new person in his body. How much I remembered back to the days of my Mother's illness after a massive stroke. Her personality changed and she seemed to turn against the person that loved her the most. That person was me, her only child, my father was deceased. Dr. Brown came to see Jim at 10:50 a.m. She said the present difficulties were a result of the CMV and possible overdoing. She prescribed various medications and said he would be scrubbed to disinfect for the installation of a port Tuesday. This method is easier for long term IV use and reduces the possibility of infection. Jim was lucid and visited with Dr. Brown about the trip to Paris. An M.R.I. was scheduled. During Dr. Brown's visit a nurse peeked in and said I had a visitor. I stepped out and saw the female Minister from the church. I later learned that our former neighbor Kathy had called her and asked her to visit with me. She said she would wait until the Doctor had left. When I returned to the hall there, she was

waiting for me. We went to the reception area and she hugged me, and we talked. God sent this very special woman to me when I needed her. I felt so empty and felt that my church had somehow let me down. She made up for everything! She knew when to let me ramble and when to say just the right words. She concluded by saying "I am also here as one Mother to another." I am so grateful for her comfort and care. I pray she is blessed for the work she is doing.

Bob had made arrangements for Jim's financial adviser to meet with us at the hospital to go over Jim's financial situation, and to take care of the many things necessary in his incoherent condition. We met in a conference room and discussed this as well as any ideas anyone had regarding Jim's wishes for burial, living will, etc. The only time I broke down was when I asked the advisor if she knew that we had lost our jobs almost nine years ago and we were financially at rock bottom. That hurt worse than anything to openly acknowledge that we didn't have the resources to pay for private duty nurses or help Jim financially. That was one of the saddest times of my life. We were there for Jim emotionally and lovingly, that was all we could do.

Wednesday Jim seemed to show some improvement, although he was having chills after his fever broke. Dr. Brown said she felt that the neurological problem was resolved and that it was instead fluid from his left ear that was swollen and had put pressure on the brain. She had sent an ear, nose and throat Doctor to check on him and he had relayed this wonderful news to Dr. Brown. She said perhaps Jim could go home by the weekend! I'm not sure just when I let my friend know that Jim was in the hospital, but she contacted the Senior Minister and he called at 10:00 p.m. one night and said how sorry he was that Jim was so ill. He also said that he had called a family or two, and that one family was in the same circumstance as we with a son in the hospital. I felt a little detached, too little - too late. The female Minister at our church had been there for me when I needed someone. How grateful I am for her love and concern!

By Wednesday evening we were all exhausted. We asked Dr. Brown if she would order a night nurse since that seemed to be Jim's worst time. She agreed and the call came later that they couldn't find one. We wondered if this was an AIDS problem or if the request had really been too late to secure one.

Sam stayed at the hospital, and Bob and I went home. A friend of Bob's had brought two huge boxes of food to him for all the family. We had invited the rest of the family at the hospital to come to our house and eat. One by one the family congregated. Bob got on the phone and called everyone he knew from his past contacts when he worked in the emergency room at the hospital. Finally, his efforts paid off and they found a nurse for the night. Our eldest son insisted that I take the prescription to rest well, and they stood over me lovingly. Our daughter-in-law massaged my back to relax me and the love in that room was felt by all!

It is amazing what a difference it makes when you rest at night. Thursday morning brought energy and optimism. Jim had his first

good night since he had been in the hospital. However, he was still having fever and talking incoherently. We still had much concern. Dr. Brown said it still seemed that he could go home on the weekend. Mark's mother and sister visited Jim. Jim was still having seizures. We desperately wanted to take him home where he wanted to be, but so much had happened. Could we manage him? So many unanswered questions. The unknown can be fearful if you allow it. They finally brought liquids to Jim for the first time, Jell-O, grape juice, ice cream. He managed a sip or two. He hadn't eaten in eight or nine days. Flowers, cards, company poured in and out. Bob had taken off work the entire week that Jim was in the hospital. Our eldest son and wife had to work and came evenings to relieve us. Our grandson, would sit in the reception area and draw and watch TV. It made long days for them as well. The nurse came again that night.

Friday Jim was having sweats, requiring a change of linens. He was running a slight fever but slept well. The nausea continued and they gave him a shot. Dr. Brown still felt that if he would get up and walk behind a wheel chair down to the nurse's station that he might go home Sunday. He was overjoyed.

Jim has such a large circle of friends, and they were so supportive. His room was full of cards, flowers, visitors and family. I asked one of the nurses if there were any other AIDS patients on the floor. She remarked that the man next door had AIDS. I asked if he had family or company. She replied that no one had been to visit. I asked if we could go in and visit him for a short time. Sam and I took some flowers that we had sent to Jim and went to the next room. We introduced ourselves and I told him our son was hospitalized next door and had AIDS. We also wanted to share some of the flowers that Jim had received. I asked where he was from and he answered Enid. I reached down and took his hand and softly told him that he was not alone, that someone cared about him. He smiled and thanked us, at which time a nurse came into the room with medication. We visited with him a few more minutes and left. My heart went out to him. No one should ever have to face this ordeal alone. My prayers are with him. I later learned that he had been in the hospital during the Christmas season for a couple of weeks. He apparently had no visitors, but someone had brought a small tree. Later, the evening of our visit, we learned his sister came into Jim's room with tears in her eyes. She wanted us to know how much our visit meant to him as well as to herself. We were not at the hospital at that time, but it filled my heart with gladness that we had been able in some small way to offer kindness to someone else. There is so little that any of us can do and yet this small gesture was greatly appreciated. If we could all repay kindness extended to us by passing that kindness on to others, this world would be a better place.

Saturday Jim's fever was higher, and he slept most of the day. He cried and said that he was never going to go home. Jim has not seen me cry the entire time and it was all I could do to handle this. We didn't see how he would be able to go home. He was so weak and unable to eat. Amazingly he awakened at 4:00 a.m. Sunday and his nurse had helped him walk down the hall as the Doctor suggested. When I visited Saturday, I had told him that I would shop and spend time preparing his favorite foods for his enjoyment at home. That

seemed to make him happy, so I left the hospital and went shopping. It was the first time I had done anything else for a week and I really enjoyed the outing. I cooked all day, putting all the love in the food that I could. Sunday, I continued to cook, and our plan was that Bob and I would meet at Jim's house to greet him. Sam and Mark would check Jim out of the hospital and bring him home. When the car pulled in the drive and he got out we were overjoyed. He slowly walked in and sat on the couch to rest. You could see him drink in the beauty of his home. This was the first time he had seen it since he left for Paris. The color in his face seemed to improve. He smiled and we thanked God for his return home! The Doctor had said he needed 24 hour-a-day attention. Not a nurse, but someone with him at all times. Mark was off Monday and had to return to work Tuesday. He works long hours and we needed to schedule someone. We provided a list of friends and Cookie helped with the scheduling. We took turns and happily the first three days went better than we could have imagined. Bob said at one point that we needed to find joy in each day. Bob was right; we look for and find joy in every day. We are truly blessed!

Jim came home from the hospital on Sunday, January 24th. Bob's birthday was January 18th, Original plans were to celebrate Bob's birthday the Monday after Jim's return from Paris, but Bob insisted that we forget about any celebration with Jim so ill. Happily, Tuesday evening now January 26, Jim felt like having a time to be together. We all congregated at his house. We ordered pizza delivered, spread out a sheet on the floor of his den and had a picnic on the floor. We celebrated Bob's birthday and what a happy celebration, one more with the entire family!

The big issue now is the fact that Jim has lost so much weight. He weighs 105 pounds. He is working very hard to eat but after so many days of not eating, it is difficult. He is working at doing his part and we are all proud of him. He is still running a fever and has night sweats which interrupts his sleep. We were able to see the Doctor seven days after he was released, because of the fever. On the appointed day, we picked him up, helped him dress and helped him in the car. It was a beautiful day to be out and he enjoyed the ride. We secured a wheel chair to lessen the fatigue. The Doctor saw him quickly and she spent all the time he needed. It had been recommended to her from the nutritionist that he be tube fed because he was not able to consume the 3,500 calories needed daily just to sustain him. His attitude is wonderful, and he said he would do whatever it took.

During this ordeal he has for the most part been cheerful, loving and tends to cheer up his visitors instead of the reverse. Except for the time that he was irrational, he is strong, positive and determined. The greatest lesson we have learned is to take one day at a time. God sustains him and us and all who love him. We are truly blessed and if I had it all to do over, I would choose Jim to be my son. I am honored that God allowed me to be his Mother and share my life with him. He has brought me joy, laughter, beauty, insight, serenity, understanding, tolerance, and I hope wisdom. If I could only give him half what he has given me I would be overjoyed!

A very good friend of mine said to me, as I rambled on about the

situation with Jim, that I should record some of my thoughts. How wise he is for telling me! He and his adorable wife have lost a daughter in an automobile accident and they understand our pain. Writing this has helped me and I pray that it may help someone who is also walking in this path.

During one of Jim's worst days at the hospital I received a card in the mail from a woman that I didn't know. She had heard about us from one of the AIDS organizations. She had lost a son to AIDS. It was the most poignant card and message, and I was overwhelmed with her capacity to love and care for a stranger. I have since talked to her by phone and expressed my gratitude to her. I will treasure her card as long as I live.

There have been cards and calls from numerous people, some longtime friends, church friends, school friends. They have all meant so much to us. One very dear friend from school has been so caring. She sent me a card in which she wrote, "The people in your life are like the pillars on your porch. Sometimes they hold you up, and sometimes they lean on you. Sometimes it's just enough to know they're standing by". True friendship, caring, love is what life is all about. Without caring people, we would feel so alone.

Our daughter-in-law said to me that God works in mysterious ways - that perhaps the fact that we were not employed and had the time necessary to care for Jim was in fact a blessing. I agree. Jim has blessed our lives and we feel enormous pride in him.

JANUARY 1994

In my need to keep this story open ended, with hope in my heart for that miracle, I chose to stop writing more than a year ago. Something compelled me to write again early in January.

We have now had one more year with Jim and he has survived yet another hospital stay. The Doctor told him that she didn't expect him to leave the hospital either time - alive. Jim is our "Miracle Child". Also, he has been diagnosed with MAC. Any of the three diseases he has, KS (a rare form of cancer), CMV (a viral infection attacking major organs, in Jim's case his liver is affected) and MAC (AIDS related Tuberculosis which is not communicable) can be fatal. Every day we feel blessed to have him with us. He has had pneumonia, staph infection, transfusions, nightly feedings through his port, removal of his port due to infection. A temporary port was installed and finally a new replacement. His nurse changed jobs and the nurse that got stuck in the foot with the needle began taking care of Jim. What a wonderful relationship he has established with each of them! One more nurse entered his care and he bonded with her also. He still keeps in touch with all of his nurses. Once you form a bond with Jim you can never forget him. He has this wonderful ability to get around the polite facade and sneak into your heart. Every day we have with Jim is a blessing. Some are easier than others, but none the less we have been allowed to enjoy them. Jim has good days and

bad days, but he still keeps fighting. Never give up, for as bad as some days get a new dawn opens up a beautiful new day. Our family has had the pleasure of sharing birthdays, another Thanksgiving, and another Christmas with Jim. Only God knows if there will be others, but we don't really know that much about our own lives. We have come to terms with this disease as well as one might. We are all more relaxed and there is a certain serenity that has come to us. This is not to say that we don't worry, pray, have bad days, and cry many tears. I recently saw a sign which said, "If you worry, why pray". I have been trying to follow this sage advice.

A friend of Jim's is on a RAIN team (Regional AIDS Interfaith Network) at our church. Their team had lost their client. He called me to see if Jim might be interested in associating with a RAIN team. I had called the RAIN office headquarters earlier to see if we could set a team for Jim, but the waiting list is very long, and they didn't give us much hope. I was delighted and told Jim's friend I felt Jim was ready for a team, so he called Jim and told him they would like him to be their client. Thankfully this has worked out and the love and care these dedicated people have offered Jim, Mark and our family can never be adequately acknowledged. As I have said before, God puts wonderful people in your path when you need them most. Life goes on, one day at a time. Words could never express the love and gratitude I feel for the privilege of having Jim as our son. He is a delight and has brought tremendous joy into our lives. If, as it is, said, the Child chooses the parent, then I am even more blessed. His sensitivity, humor, strength, talent and charisma have brought many friends and loved ones into his life. the days ahead, I will continue to be at his side in all that he does.

More than likely Jim was exposed to the AIDS virus ten or eleven years ago when the emphasis on AIDS education had not begun. Jim is a very moral, spiritual young man. Any one of us could choose the wrong person to love and suffer no long-term consequences. In Jim's case loving the wrong person could cost him his life. We feel no shame or guilt, but compassion on those who have and will continue to give their lives for loving the wrong person.

We have more days to face uncertainties. Jim is working hard at living and we are all working hard at making his life meaningful. Only time will tell the outcome of this story, and we are prepared for whatever comes our way. We truly feel blessed for all the wonderful people we have met, and the strength their caring has given us. We still have not shared our story with all of our friends. We now believe that if they are true friends they will understand and love us all. My prayer is to find a cure and prevention of this terrible disease, if not for Jim then for those who will face this ordeal. Continue to have hope and God will give you the strength to take each day as it comes. God bless everyone who reads this story and walks this long path into the unknown.

Edna Rogers

This story is a celebration of the life of Jim Rogers, our beloved

son. Born James Alan Rogers, July 10, 1959.

The AIDS support group was formed at our church and I attended a couple of times. They had no facilitator and only two other families in attendance. At the time it was formed Jim was very ill and we just didn't have time for a support group. My feelings of being let down by the church have been softened by the love and care of many individuals at church who have certainly made a difference in our lives. We still have not connected with any other parents at church who are walking this long walk, but we are at peace.

The most difficult part of watching your child deal with a life-threatening disease is that it goes against God's natural order of life. We more easily deal with and accept losing someone dear to us that has lived a long and fruitful life. Watching a young man at the prime of his life, fighting for his existence, is against the natural order and more difficult to accept. I have to believe in life hereafter and being together again or this terrible ordeal would surely overwhelm me. Jim has still not seen me cry, a miracle in itself. Being a very sensitive person, tears and I are not strangers. I have held Jim in my arms and comforted him through his tears, knowing the only way this is possible is with enormous help from my Creator. My prayer for strength has been answered over and over again. There have been times in my life when I questioned if prayers were answered, but I now have proof, again and again. Sometimes the answer to our prayers is not what we want, or think is best for us, but accept we must. I still pray for a miracle and I believe in miracles. Jim to date is our miracle, thank God!

My thanks go to so many wonderful people; my wonderful and loving family, Mark, AIDS organizations, Cookie Arbuckle, Mary Catherine Smotherman, The wonderful Health Insurance carried through his Employer, Mothers we met at the support group who had lost a son, Jim's Doctor and staff, home health care nurses (Joni, Judy, Laura), RAIN team members who give of themselves so unselfishly, hospital staff, friends of Jim's who constantly call, visit, send cards and just love him. Friends of ours, old and new, comfort us with the same love and care. I have never felt more loved nor more appreciative in my lifetime. God is with us, let us never forget, even in times of crisis. All of these people are helping Jim live the best possible life he can enjoy.

JANUARY 1994

It is now time to write the final chapter of this story. I have prayed that the ending would be different, but God called Jim home to share his beauty with other loved ones who have also been called home. What a privilege we have had to share our lives with our beloved Jim!

Jim had planned to go with Mark, sister and spouse, and his parents on a ski trip to Powder Horn. He was not feeling well and had a Doctor's appointment at which time she arranged for a chest x-ray. We talked about the advisability of going on this trip and

Jim said he really wasn't excited about it, but he would miss Mark so much and he could be sick at home or sick in Colorado. The day before they left, he was informed that he still had pneumonia and had to have a series of antibiotics. When they called from the Doctor's office to relate this, they said Dr. Brown said, "Have a great time on your trip". That was all he had to hear. The medicine was delivered, and another supply would be sent to Colorado. This trip required two days; a twelve-hour day and one eight-hour day. He was exhausted when they arrived. He called once and said they were housed in a lovely condo with fireplace. He only became excited about the trip when he thought about a sleigh ride. He told me before he left that he hoped to take a sleigh ride before he left this earth. He did get to have the ride and he enjoyed it greatly. They decided to stay an extra day and drive home in one day, instead of two. They were on the road for twenty hours driving straight through. He was exhausted when he called Sunday about 11:00 a.m. He said they would sleep most of the day and would call later.

We didn't hear from him that day and I thought they were resting. He called Monday and said he wasn't having a very good day, and the reason he had not called back Sunday was that he was in a great deal of pain. He cried a lot and felt that he needed to see the Doctor. He said something felt different. His Doctor was out of town and the Doctor covering for her said to go to the emergency room. He decided to tough it out and wait and see Dr. Brown that Monday afternoon. I asked Jim if his Dad could take him to see Dr. Brown as I had picked up a "bug". Mark was off work because he had hurt his knee on the trip. Mark took him to the Doctor. I was afraid to be around Jim as I was running a fever and nauseated. Not feeling well, I certainly couldn't be around Jim. He said he was having trouble getting around. Sam took care of me, fearing that he might also be a carrier of this "bug". We talked to Jim daily and by Thursday Sam went to check on Jim. After talking they determined that he possibly had a pinched nerve from the long car ride. Sam called our Chiropractor and he suggested cold packs every other half hour for a while then followed by heat. They tried that and Jim seemed to feel better. We were all sure that the long trip had caused a nerve to become pinched and this treatment would clear things up. I was better by Friday and went to visit with Jim. He could not walk by then. I called Sam to see if we could get a walker and wheel chair from Cookie at Other Options. He came later and brought them. When Jim tried to walk, he only had use of his right leg. It took both of us to support him and I had to physically move his leg. Later when I talked to his nurse, she said the problem was probably caused by the CMV. The good sign was that the problem was only in one leg, and if that continued, they would probably do some testing to see if it was in fact a pinched nerve. By the next day he had lost the use of his right leg also and he was paralyzed up to his waist. At that time, we were told he probably only had weeks to live. We were stunned. We had fifteen months to prepare for this moment and yet we were not prepared. At that time our main concern was that he not suffer.

We decided that he would not be hospitalized. We would allow him to pass on to the next dimension with family and friends and as

much dignity as possible. Bob made a call to his nurse and told her our wishes. We wanted him taken off of all medicine except that which was given for seizures and pain. The nurse relayed our wishes to Dr. Brown, and she agreed to allow this. We were told that normally patients have to be hospitalized before they can be taken off medicine. Our prayers were answered.

We spent every moment we could with Jim. He worsened every day. By Monday he was not expressing himself well. Understanding him became difficult. We knew our days with him were numbered. By Tuesday the insurance company had approved an in-house nurse. At 1:00 p.m. his nurse arrived. He lovingly and thoughtfully cared for Jim and made his last days as good as they possibly could be. By Wednesday it was obvious that Jim needed more care. We talked to his home health care nurse about having another nurse for the balance of the day/night. She received approval from his insurance company. Mark seemed in denial and felt that he could manage. We were afraid that Mark would not know when to notify us to come. Mark works a very long shift at his job. He doesn't get home many times from work until midnight or later. We knew he was exhausted from loss of sleep, caring for Jim and we didn't want to miss being with Jim at his final hour. By the time the existing nurse arrived for his shift, Jim's condition had worsened. His home health care nurse came and brought a pain pump and hooked it up. During the day we each laid with him and stroked him and kissed him and told him that we had released him into God's care. He didn't need to hold on for us, we didn't want him to suffer any more. His RAIN team and Minister friend were notified, and they came to add support. We piled onto the bed, taking turns when there were too many there. One by one we would have to leave the room and cry, regain our composure and return to him. During the day he communicated with us even though he could not speak.

He only had use of one hand by then and he reached up and made a heart, enclosing it with a square. We interpreted that as, "I love you, all of you". He took Bob's hand and held two fingers together

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This was our learned signal and trigger in relaxing him to take him to his ideal place of relaxation. He held up the fingers toward Heaven and looked up, indicating that he was going to Heaven. Then he gestured with his thumb and forefinger, to indicate "in just a little bit". He lovingly looked into our eyes, one by one, our moment had come to say goodbye to our beloved son, companion, brother and friend. His labored breathing became more relaxed and soon it stopped. We all cried and told him to go to the light. We cried for some time, then hugged each other and cried. Somewhere between seven and nine or ten minutes elapsed. Suddenly he snorted and started breathing again! We snickered, relieving the tension, and comments were made that only Jim would make a curtain call. He has such a wonderful sense of humor, and he always liked a little drama. Certainly, he had provided that for us all. We laughingly said that we were glad the Minister was there to validate our story, or surely people would not believe us. I asked her if she had ever experienced anything like that and she said no. We then realized that we had been given a special blessing. We had one more chance to say goodbye. Tenderly we stroked him, told him how much he was loved. We told him we would miss him but that it was his time to be set free. He had suffered for so long. Probably thirty minutes or so elapsed and he drew his last breath. There was a tear in his eye, and we knew he sadly departed his loved ones. He was now in God's loving care and free from pain and suffering. Our tears were tears of pain, loss and joy for his release from this terrible disease. He has blessed our lives with his love, tenderness, sensitivity, artistic talent, sense of humor and tenacity - that great will to live! He fought for his life to the bitter end. This terrible disease finally mastered his spirit and he passed into the unknown. We have been comforted by loving friends and family. Our pain and sorrow overwhelm us, but Jim would want us to go on with our lives. Our precious memories can never be taken from us. We cherish every breath he took. My one prayer was that Jim not lose his eyesight, since as an artist his life and career was centered around visual experience. Thankfully his CMV took another avenue and our prayers were answered.

I have asked myself if I will ever get over losing Jim. As a mother I carried him in my body, breathed for him, ate for him, labored for him. We have shared life in the greatest sense of the word.

God has truly blessed our lives with this great gift, our beloved son, Jim. Although he has departed this Earth, he will live in our hearts forever.

James Alan Rogers, born July 10, 1959, told us of his AIDS diagnosis October 29, 1992. He departed this earth surrounded by loving family and friends at 8:10 p.m., January 19, 1994. May he rest in peace.