

# *The* **Journey** *Home*

Lessons from an experience with Childhood Cancer

## *The Journey Home*

© Dr. Kwame Aveh  
adevuu@gmail.com  
ghapacc@gmail.com

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SMARTLINE

# *The* **Journey** *Home*

Lessons from an experience with Childhood Cancer

DR. KWAME AVEH

## DEDICATION

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This book is dedicated to the memory of “Prof” Elorm Kobla Aveh  
December 21, 1999 - January 27, 2009



“If Roses grow in Heaven  
Lord, please pick a bunch for us  
Place them in ‘Professor’ Elorm’s arms  
And tell him they are from his family

Tell him we love him and miss him,  
Place a kiss upon his cheek  
And hold him for a while

Because remembering him is easy,  
We do it every day,  
But there is an ache within our hearts  
That will never go away

Adapted from Kirsten Preus

## COMMENTS

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This book, “THE JOURNEY HOME”, dedicated to the memory of ‘Prof. Elorm Kobla Aveh’, is a chronicle of the challenging times childhood cancer dealt the Aveh family and to others like my family who could only support as it were “from a distance”.

Although the experience was a difficult one, God has worked it out for good as He promised in His Word in Romans 8:28, “And we know that in all things God works for the good of those who love him, who have been called according to his purpose”. Indeed, from the difficult experiences of our son Elorm, this book will help countless families who at one time or the other may have to grapple with various forms of childhood cancer.

As we cherish the memories we were privileged to share with Elorm, others will benefit from his life experience and learn the early warning signs of childhood cancer and God willing, avoid the heartaches of not finding out till it’s too late. May this work compiled by my friend and brother, Dr. Kwame Aveh, be a source of blessing to all who read.

*- Ing. (Pastor) Theo Nii Okai, family friend of the Aveh family:  
For and on behalf of Okai family  
February 2016.*

I met (the father and son) Felix and Elorm in Cape Town at a time when I was the Chairman of CHOC. We shared great and difficult moments but what struck me about the pair was the confidence with which they carried themselves.

As a parent who knows all about childhood cancer, I can only congratulate Dr. Aveh for his courage in writing his experience and I know this would greatly benefit mankind.

*- Kenneth Dollman-Board Member  
(Childhood Cancer International-CCI)*



## NOTE

When you buy a copy of *The Journey Home*, you have made a contribution towards the establishment of a home for parents and their children who have been diagnosed with cancer and are on admission at the Korle-Bu Teaching Hospital. Proceeds from the sale of this book will go towards the construction of a 30-bed hostel at the hospital estimated to cost 2 million Ghana Cedis. This project is embarked on by the Ghana Parents' Association for Childhood Cancers (GHAPACC) in collaboration with the management of the Korle-Bu Teaching Hospital (KBTH).



## ACKNOWLEDGEMENTS

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For four years, I struggled to document the experience I am about to share. My eyes welled with tears at any attempt to write this story down. I had my fair share of emotional breakdowns but finally, with God's help, I have been able to do what I set my mind to. In just a week, I rushed through piecing most of these words together. I was aware that the longer I spent reliving this painful ordeal, the more my heart will ache. With a constant reminder that the goal was bigger than the challenges of the journey, I strived on. I believed that I owed it to my best friend and son, Elorm, to tell his story and to create the much-needed awareness for children with cancer. I take on the role as advocate, not only for children living with cancer, but for every single one of us.

I was first encouraged to write this book by Mr. Albert Ocran of Legacy and Legacy Consult. He was convinced after hearing my experience that others had to as well. I heeded to his advice, but I must admit, that my initial draft was just a distorted account. I have Mr. Theophilus Okai, a Director at the Volta River Authority, to thank for making my efforts book-worthy.

It has been a long and arduous journey and I would like to recognize the contributions of the following people who supported us. They indeed deserve special mention:

Dr. Lorna Renner, a Paediatric Oncologist at the Korle-Bu Teaching Hospital, who was with us from the beginning. Dr.

Ivy Ekem, also of Korle-Bu and the many other doctors and nurses there. Theo and Becky Okai and family, my late in-laws – Mr. Thomas Tettey Addy and Mrs. Juliana Chochoe Addy, The Vice-Chancellor of UPSA - Professor Joshua Alabi, Mr. and Mrs. Henrici and Oye Aboa, Mr. and Mrs. Emmanuel Arhin, Mr. and Mrs. Jones and Sylvia Ofori-Boadu, Sammy and Dr. Marian Korboe, Mrs. Grace Amartey and family. Evelyn and Joni Freeman, Professor Allan Davidson and the staff of the Red Cross Children's Hospital in Cape Town, South Africa. Professor Nicolas Novitzsky of the University of Cape Town Hospital, Mr. and Mrs. Sadie Cutland, Rev. Craig Andrews, Professor Yaw Amoateng and his wife, Mukhtar, Kenneth Dollman and family of South Africa, Christi and Lubi Koorts of the Childhood Haematology Oncology Clinics (CHOC), South Africa, Auntie Sarah of Chaplaincy House, South Africa, Clive and Ursula Baatjes of South Africa, Rashaad Davids of blessed memory, Mr. and Mrs. Ofosu Osei, Dr. and Mrs. Osei Bonsu and Dr. Antwi and Rose of the Komfo Anokye Teaching Hospital (KATH), Mabel Addy, Mr. Samuel Boateng, Dr. and Mrs. Owusu-Afriyie, Mr. and Mrs. Narh, Benjamin Fiifi Ocran, Mrs. Tina Osei, Nana Gyamfuaa, Pastor Mrs. Emily Buabasah, Mr. and Mrs. Juliana Quartey, Nana Ayensu, Lawrence and Agnes Sackitey, W/O Andrews Aveh (retired) and family and Kwame Jesus and his praying warriors. Uncle Ebo Whyte of Roverman Production and Kweku Sintim Misa(KSM) come in for special mention. There are many names I may have forgotten and for this, I ask to be pardoned.

To end with, my encouragement and motivation has always come from my dear wife, Naa and my two children, Delasi and Esinam. They have been my greatest support. I am aware that I have not been the easiest person to approach. I haven't always allowed you to ask the questions on your minds, but please bear with me, as we pray, time will heal our aching hearts.

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When you walk through the storm  
Hold your head up high  
And don't be afraid of the dark  
At the end of the storm  
There's a golden sky  
And the sweet silver song of the lark

Walk on, through the wind  
Walk on, through the rain  
Though your dreams be tossed and blown  
Walk on, walk on, with hope in your heart  
And you'll never walk alone  
You'll never walk alone  
- Michael Ball

*From the song, You'll Never Walk Alone (Carousel)*



# 1

## THE GENESIS

Just like my other two children, I had my second child at one of the country's top hospitals. I had always wanted two boys, so when we had Elorm after my first son, Delasi, I was elated. Elorm's chosen name came easy – it meant 'He (God) loves me'. God had once again demonstrated his love by hearing and granting me my wish. He weighed 3.5 kilograms and he appeared a normal child. As a baby, he participated in the WHO Multicentre Growth Reference Study for two years. This earned him a diploma certificate with the citation:

*I, Elorm Kobla Aveh, participated in the World Health Organization Multicentre Growth Reference Study. Although I am little, I have helped immensely in providing information to be used in developing growth curves for assessing the health and physical development of children in the world. Thank you, Mummy and Daddy, for allowing me to be part of such an important international study.*

21/12/2001  
Signed

Dr. W.B.O  
Co-Principal Investigator

Dr. A.L  
Co- Principal Investigator

Elorm had a huge personality. He lit up a room with his infectious and often mischievous smile. I don't think anyone who ever met him can forget that smile. He loved playing with his siblings and friends at school and he never turned down an invitation to compete in a game of football. He had decided Manchester United was his favourite football club even as a toddler. For a boy his age, the things he knew about the club would have surprised you. This love for 'Man-U' was a passion he shared with his Granddad, the late Mr. T. T. Addy.

We count our children first when we count our joys and blessings. In the midst of our joy, we realized that all was not well with Elorm. He often fell ill and our visits to the hospital became quite regular. He lost interest in food and looked weak most of the time. As a toddler, we noticed he had two lumps, one on his neck and another on his stomach just above his navel. In spite of all this, the doctors assured us that he was fine and there was no cause for alarm. They explained that Elorm's symptoms were only signs of a viral infection. This situation persisted until he turned four years old. At age four, he developed a condition that needed immediate medical attention.

One morning, as I was driving the boys to school in Tema, I noticed something unusual. There was a swelling on Elorm's neck. This was different from the already-existing lumps. I touched it and asked him if it was painful. He replied in the negative but added that he was feeling unwell. I suggested taking him to see a doctor but he insisted on going to school.



The boys attended different schools, and the norm was to drop Elorm, being the younger one, off first. On this occasion however, I decided to keep an eye on him for a while longer so he was still with me as I dropped Delasi off. Before we could get to the entrance of Elorm's school, the swelling had doubled in size. I rushed him to a nearby clinic in Tema where we were regular clients. He was soon attended to by a doctor. Again, the doctor said the swelling was only viral. He prescribed some medication for us and we left the clinic with little worry. The lump would disappear just as it had come, he assured.

The doctor was wrong; the swelling continued. It got to a point where Elorm's neck could not be separately identified from his jaw. Alarmed by this, we returned to the clinic. On the third day of observation, we were referred to the Korle-Bu Teaching Hospital. I however insisted that we go to the hospital where Elorm was born; our family doctor knew him better. Looking back, I believe this was my greatest blunder.

My preferred hospital was not equipped at the time to carry out a proper diagnosis of Elorm's condition. So, for almost a year we kept consulting at this hospital, experimenting with all kinds of drugs. His health was like a pendulum – better for a while and down again before long. This inadvertently affected his attendance at school. Elorm was unhappy when he had to stay home or visit the hospital instead of going to school. He enjoyed school immensely and had made great friends and excelled in class.

Ntemah Okai was one of his best friends. Elorm and Ntemah had managed to connect our families in the most interesting way. Having been absent from school for some time, Ntemah's family paid us a visit at home. While chatting, Ntemah's parents suggested that we seek a second opinion on Elorm's sickness. It had persisted for so long and they felt perhaps another doctor would give a different insight. They directed us to their family physician in Tema. I laughed at the idea in my head. If the second biggest hospital in the country was not curing my son, what could a small clinic offer? I thought. My wife, Naa, was however more accommodating to their recommendation and insisted on us going there. Reluctantly, I agreed.

After updating the doctor at this new clinic on Elorm's medical history and condition, he suggested some tests. He recommended one of the modern diagnostic centres in town and we obliged. The following day, we had all the tests done. However, we had to wait for two days to receive the results since the samples had to be sent to South Africa for examination. Forty-eight hours never seemed so long.

On the day the results were to arrive, I arranged with my wife, Naa, to pick them up as I had a seminar. It was during one of the seminar sessions that I received a call from her. Our lives were about to change with the words she uttered: **LEUKAEMIA, CANCER OF THE BLOOD.**

No, that cannot be true, I thought as I buried my head on the table in the seminar room in confusion and despair. I felt my world crumbling before me. A sharp knife was piercing through my heart. I was devastated. Without saying a word to anyone in the room, I packed my bag and left.

With the results in hand, I took my son back to our family hospital, the 37 Military Hospital, and showed them to the doctor. She in turn asked us to do a biopsy there. I wondered why she had not seen the need for a biopsy during all those months we kept visiting the hospital. We did the biopsy but the results were taking forever to come and I was determined not to waste any more time. I went straight to Korle-Bu Hospital with my son and my wife who was then pregnant with our third child. It was there that Elorm's battle for survival began.

### ***What are the known or suspected causes of childhood cancer?***

*The causes of childhood cancers are largely unknown. A few conditions, such as Down Syndrome, other specific chromosomal and genetic abnormalities, and ionizing radiation exposures, explain a small percentage of cases.*

*Environmental causes of childhood cancer have long been suspected by many scientists but have been difficult to pin down, partly because cancer in children is rare and because it is difficult to identify past exposure levels in children, particularly during potentially important periods such as pregnancy or even prior to conception. In addition, each of the distinctive types of childhood cancers develops differently—with a potentially wide variety of causes and a unique clinical course in terms of age, race, gender, and many other factors.*

*<http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood>*

### ***What is leukemia?***

*Leukemia is cancer of the blood cells. It starts in the bone marrow, the soft tissue inside most bones. Bone marrow is where blood cells are made. When you are healthy, your bone marrow makes:*

- *White blood cells, which help your body fight infection.*
- *Red blood cells, which carry oxygen to all parts of your body.*
- *Platelets, which help your blood clot.*

*When you have leukemia, the bone marrow starts to make a lot of abnormal white blood cells, called leukemia cells. They don't do the work of normal white blood cells, they grow faster than normal cells, and they don't stop growing when they should.*

*Over time, leukemia cells can crowd out the normal blood cells. This can lead to serious problems such as anemia, bleeding, and infections. Leukemia cells can also spread to the lymph nodes or other organs and cause swelling or pain.*

*<http://www.webmd.com/cancer/tc/leukemia-topic-overview>*

## FACT BOX

Elorm was admitted to the children's block that same day we went to Korle Bu. He was later fully diagnosed with ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL). The first step on the long and tortuous journey to seek a cure was for our little boy to undergo a form of treatment called CHEMOTHERAPY.

### *Are there different types of leukemia?*

*There are several different types of leukemia. In general, leukemia is grouped by how fast it gets worse and what kind of white blood cell it affects.*

- *It may be acute or chronic. Acute leukemia gets worse very fast and may make you feel sick right away. Chronic leukemia gets worse slowly and may not cause symptoms for years.*

- *It may be lymphocytic or myelogenous. Lymphocytic (or lymphoblastic) leukemia affects white blood cells called lymphocytes. Myelogenous leukemia affects white blood cells called myelocytes.*

- *The four main types of leukemia are:*
- *Acute Lymphoblastic Leukemia, or ALL.*
- *Acute Myelogenous Leukemia, or AML.*
- *Chronic Lymphocytic Leukemia, or CLL.*
- *Chronic Myelogenous Leukemia, or CML.*

*In adults, Chronic Lymphocytic Leukemia (CLL) and Acute*

## FACT BOX

Elorm's initial hospitalization lasted three weeks. I had to be with him for the entire duration, commuting from the ward to work. In the evenings I took over from my wife to enable her go home to look after our oldest boy. Unfortunately, we lived far away from the hospital so each morning Naa brought along a fresh set of work clothes for me to change into. I was a big nuisance to most of the female parents in the ward. We were forced to share the same room and facilities but I couldn't care less. My focus was on Elorm and I was prepared to do whatever it took to get him better. I remember one such mother being bold enough to ask me why I would not allow my wife to come and sleep over with my son instead. I wanted to tell her to mind her own business but I

restrained myself. I just gave her a dry smile and pretended to be absentminded. She did not end it there; she kept on nagging about how uncomfortable she was in the room. She complained about every little thing, indirectly throwing shots at me. I was aware that many of them gossiped about me as I moved up and down the ward, cleaning my child, washing plates and feeding him, but I paid them no mind.

We were two weeks into Elorm's chemotherapy at Korle-Bu, when I got a call from our family hospital. The results of the biopsy were ready. When I went to pick it up, I met a young lady who told me her boss wanted to see me in his office and that he had the report. As she ushered me into his consulting room, he stood up and greeted me with a handshake. I obliged and forced a smile. He offered me a seat and proceeded to interview me:

"Mr. Aveh, how old are you?"

I told him my age.

"What about your wife?"

I told him my wife's age.

"I am told you are a Chartered Accountant, right?"

"Yes," I replied.

"That means you are well-educated and mature enough to understand what I am about to say."

I nodded in response. I nearly told him that I already knew everything, but I held back.

He continued, “You see, life is full of ups and downs. Every human being would face one difficulty or another as long as he lives. You and your wife are still young and could still make a couple of babies.”

Was this doctor being serious? Did I tell him I needed help planning my life? I almost told him off. How dare he?

“I have the laboratory results for your son, but I am afraid the results are not too good. His chances of survival are very slim. He has cancer of the blood, what we call leukaemia.” He looked straight into my eyes to see my reaction.

I sat quietly showing no emotion despite being rather annoyed. Is this why you have called me? You could have done this biopsy over a year ago but did? You almost killed my son and today you have called me here, acting like God and preaching to me about how to live my life. As much as I wanted to tell him all this, I didn't. To be fair to the doctor though, he wasn't the one who had attended to us all those months.

After a few minutes of silence, he asked if I had any questions on my mind. I didn't. I barely thanked him as he handed over the report and I left his office. In my anger, I started praying in 'tongues' refusing his conclusions on my son's life. “Elorm will not



die. You are just a mere mortal like me, how dare you pronounce death on my son. He will not die but live to declare the works of God.” I kept repeating this over and over till I got to Korle-Bu hospital. I decided not to show the results to anybody and I haven’t done so till date.

I read as much as I could on Elorm’s condition and found that chemotherapy is a primary treatment for cancer. I also discovered that in some cases, where the illness is advanced, a doctor may also prescribe radiotherapy as an additional treatment. What chemotherapy does is to introduce toxins to get rid of the bad cells in a patient’s blood stream. The toxic drugs are nonetheless unable to differentiate between good and bad cells therefore destroying both cells in the treatment process. When the ‘killing’ of the cells is complete, new good cells begin to grow and give relief to the patient. At least, that is the expectation.

During the process, a patient is known to suffer greatly. He or she is constantly nauseated, developing mouth sores, weakness all over the body, loss of appetite and sometimes a complete loss of hair. The chemotherapy drugs are so strong that even the doctors administering them are careful not to get contaminated. It is said that one such drug could render a doctor infertile if it comes into contact with their bodies. In most cases, patients who agree to chemotherapy treatment are told before the treatment begins that the drugs may impair their fertility. Even so, I have seen people who have had chemotherapy and later had children. I prayed that Elorm would respond well to the chemotherapy. I hoped that the spread of the bad cells in his body did not warrant radiotherapy.

Luckily, we didn't have to carry out radiotherapy at this stage.

### ***Understanding Chemotherapy***

*Chemotherapy is the use of medicines or drugs to treat a disease, such as cancer. Many times this treatment is just called "chemo". Surgery and radiation therapy remove, kill, or damage cancer cells in a certain area, but chemo can work throughout the whole body. Chemo can kill cancer cells that have metastasized or spread to parts of the body far away from the primary (original) tumor.*

*More than 100 chemo drugs are used in many combinations. A single chemo drug can be used to treat cancer, but often multiple drugs are used in a certain order or in certain combinations (called combination chemotherapy). Multiple drugs with different actions can work together to kill more cancer cells. This can also reduce the chance that the cancer may become resistant to any one chemo drug.*

### **FACT BOX**

I had become a regular customer at the pharmacy at Korle Bu where I went to buy the many drugs prescribed for Elorm on a daily basis. In no time, I forged a relationship with almost all the pharmacists and attendants. This earned me some preferential treatment which other customers complained about. I was certainly grateful that I didn't have to deal with the endless queues and delays that characterized their daily operations anymore. Sometimes, the situation got so chaotic that one could spend more than an hour without being attended to. I dreaded leaving Elorm alone for even

ten minutes. I could see the discomfort written all over his face whenever I told him I was going to buy drugs. Sometimes he would ask if I could not get someone else to make the trip for me. I soon got familiar with names of drugs that I didn't even know existed before then: asparaginase, etoposide, dexamethasone, vincristine, daunorubicin, methotrexate, mercaptopurine, septrin, acyclovir, cytarabine, prednisone, hydrocortisone and the many other drugs that Elorm had to take. By the third week of Elorm's treatment, we had spent so much on drugs and tests. This was beginning to have its toll on our finances, but thankfully, Elorm responded well to the chemotherapy treatment. He was discharged after the third week and we were instructed to come back for treatment every other day. This routine continued for four months. After the fourth month, the schedule changed to once every week. Later, it became once every two weeks and this was to continue for three years as he was a boy. I learned that if Elorm had been a girl, the treatment would have lasted for two and half years, barring any complications along the way, that is.

For every infant cancer patient and their parents, the execution of the lumbar puncture was a nightmare. This terrifying part of the treatment was not avoidable. Getting a lumbar puncture involves the injection of a drug known as vincristine into the spine. It also involves the extraction of spinal fluid for testing at the laboratory to determine the extent of progress or retrogression of a disease. The procedure requires some dexterity and expertise due to the small opening between the two lumbar vertebrae (bones) in the spine where the needle is penetrated to inject the drug and/or

extract fluid from the spine. As delicate as this procedure is, it is a regular feature in cancer treatments. Children in particular often need to be cajoled into the process. If all methods of coercion fail, the alternative is to sedate the child. This is simply because a patient must be fully compliant in positioning themselves to prepare for the execution of a lumbar puncture.

During Elorm's treatment, there was only one Paediatric oncology doctor qualified for this procedure. He was supported by a few paediatric doctors, most of whom were students-in-training. Therefore, he was under a lot of pressure and patients requiring a lumbar puncture had to be completely cooperative. If the patient was restless in any way, the doctor wasted no time on that patient. He just moved on to the next one. This was often the case in Elorm's lumbar puncture procedure. I got frustrated sometimes but it was clear to me that these doctors were doing their best under the circumstances. Despite such challenges, Elorm made tremendous progress according to the doctors and indeed his laboratory reports proved that he was getting better.

He was now back to being regular at school but he had strict instructions not to engage in certain types of games that would demand that he exert a lot of energy, especially football. Elorm was an energetic child and his love for football made this directive difficult for him to follow. His immune system had been compromised by the chemotherapy treatment; his doctors advised that we kept him safe from situations where he was likely to get an infection. This forced us to reduce our social interactions to the barest minimum and of course, we avoided insanitary

environments. Mina, my sister-in-law in London, supplied us with a substantial amount of food supplements and herb-based products to help build his immunity levels. Elorm's recovery was a delight and a relief. In appreciation of the efforts of the medical team at Korle-Bu, Elorm donated a television set to the amenity ward. We also went to church where I gave a big testimony about God's miraculous work. I recounted how life had seemed bleak and impossible but God had intervened to save my son. Many were those who were moved by our attestation, but not long after this, disaster struck again.

### ***ALL in Remission***

*There are normal levels of white and other blood cells after treatment. Physical examinations, blood counts, and bone marrow aspirates show no detectable leukemia. Remission is the absence of signs or symptoms of leukemia. However, it is very important to continue treatment, even when a child is in remission, to keep the leukemia from coming back.*

### ***Recurrent ALL***

*Recurrent ALL is leukemia that comes back after the child has had some period of remission. The leukemia may recur in the bone marrow, spinal fluid, testicles (for boys), or less commonly, in other areas of the body.*

*<http://www.cancer.net/cancer-types/leukemia-acute-lymphoblastic-all-childhood/treatment>*

After three years, Elorm was declared to be in remission. This meant his recovery was well underway. His drug intake reduced significantly. All he had to take now was septrin and one other tablet at a much lower dosage. Unfortunately, it didn't take long after this diagnosis for Elorm to begin to complain of headaches and fatigue. These symptoms persisted for a few days, so I phoned our doctor to inform her. She asked a few questions, which I answered to the best of my ability and then the phone went silent. I called out her name and asked if she was still on the line. She was. I could clearly discern from her silence that something had gone wrong. When she spoke again, her voice was subdued. She asked us to bring him to the hospital the following day, adding that we should prepare for a possible admission. This shook the ground on which I stood. What had gone wrong again? We arrived early in the morning at the hospital and waited for the doctor. She tried to force a smile when she saw us but it was obvious something was amiss. She ushered us into her office and asked to see me separately.

“It appears there has been a relapse. In simple language, the disease has recurred. What this means is that we will need to start treatment all over again. However, treatment for a relapsed cancer patient goes beyond the normal chemotherapy. Though we will begin with that procedure, we have to start thinking about the possibility of including radiotherapy. And possibly, a bone marrow transplant which can only be done in either London or South Africa.”

In a reassuring way, she added that she had already begun consultations with some hospitals in London and South Africa where we could go to for advanced treatment. The only difficulty in her opinion was how to fund it. Without hesitation, I said funding would not be a problem. The fact at that time was that our family purse was completely dry.

So we started treatment again. A week into the treatment, Elorm collapsed on the hospital bed immediately after receiving an ‘asparaginase’ injection. It took the combined efforts of two doctors to resuscitate him. That terrifying image remains etched in my mind.

After some discussions and arrangements, we concluded on making a trip to South Africa to seek further treatment. A few days before our departure, Mr. Boateng, my sister-in-law’s husband, who is also a pharmacist, came to visit us at the hospital. We told him about our impending trip for a bone marrow transplant. He asked if I had really thought about this. His question hit me like a thunderbolt. I could not give an answer. I had not asked any questions when the bone marrow transplant option was suggested to me by the doctor. I had not even researched for further information on it. But the question was, did we have a choice in this matter? It was clear that Elorm needed further tests done for his diagnosis and this could not be done locally. Also, his only chance to live was to have a transplant, especially after his relapse.

I went onto the internet and began researching on bone marrow transplants. What I read terrified me. I remembered the question of whether we had really thought through our decision. After two weeks, we were ready to travel to Cape Town, South Africa for advanced treatment. My uncertainty of what lay ahead kept haunting me.

***What are bone marrow and hematopoietic stem cells?***

*Bone marrow is the soft, sponge-like material found inside bones. It contains immature cells known as hematopoietic or blood-forming stem cells. (Hematopoietic stem cells are different from embryonic stem cells. Embryonic stem cells can develop into every type of cell in the body.) Hematopoietic stem cells divide to form more blood-forming stem cells, or they mature into one of three types of blood cells: white blood cells, which fight infection; red blood cells, which carry oxygen; and platelets, which help the blood to clot. Most hematopoietic stem cells are found in the bone marrow, but some cells, called peripheral blood stem cells (PBSCs), are found in the bloodstream. Blood in the umbilical cord also contains hematopoietic stem cells. Cells from any of these sources can be used in transplants.*

***What are bone marrow transplantation and peripheral blood?***

**FACT BOX**





# 2

## THE BIG SEARCH

We were able to augment our funds with the help of my in-laws and some friends to make this trip possible. Since it was imperative that my entire family travelled, this was no cheap feat. Each one of us, especially our two other children, needed to be present to determine if our tissue types were compatible with Elorm's. Research showed that, typically, in every family of five, two members were likely to have the same tissue type. The family members whose tissue type matched the patient's can then donate some of their stem cells or bone marrow to the patient. This meant that the patient's bone marrow, which had been infected by the disease, would be removed and replaced with the new bone marrow or stem cells from the donor. We were also told that in the absence of stem cells, cord blood could be used. If no family match was found, the alternative was to look for an unrelated person who had the same tissue type to donate at a cost. International blood banks exist where one's data can be used to search for the

most appropriate match. As it was explained to me, this was a long and painstaking process. The patient-donor ratio is just dreadful with millions of people on the database waiting for their match. The former option was therefore considered less complicated and safer. Since the donor was a relative, it minimized the likelihood of future complications. After the bone marrow or stem cell transplant, problems sometimes arise when the patient's blood system comes in conflict with the newly introduced blood system. This is described as 'graft versus host' disease. There were moments when I felt inundated with information. Yet, with so many factors to consider and a lot of uncertainty, we set off to Cape Town, South Africa. We hoped that at least one of us will be a perfect match and that the transplant will be carried out successfully.

We arrived in Cape Town and were taken to a guesthouse in Rondebosch by a driver called Rashaad. Rashaad became our first acquaintance. We arranged with him to pick us up the following day for our appointment with one Professor at Groote Schuur. Groote Schuur was University of Cape Town's Private Academic Hospital. For the purposes of this story, I will refer to the said Professor as N. Professor N was a specialist in Internal Medicine and a Clinical Haematologist. He focused on the physiology of the blood. As anxious as ever, we waited to see the Professor. Once he appeared, I started shivering. However, once he spoke, his words somehow managed to warm my heart and reassure me considerably. He explained the entire procedure to us detailing step by step the processes Elorm and his siblings will be taken through. He was a patient man, who listened to all the questions

we had and answered them accordingly. The first step in the process was for the nurses to take blood samples of the three children for tissue-typing. We prayed fervently that one of them, at least, would have a tissue type that matched. A few days later, we received the results of the tissue-typing test. The two siblings had the same tissue type but Elorm's was different. That evening, my wife and I could not blink an eye. We stayed awake the entire night brooding over the results. I felt as though the whole world was crumbling before me. Regardless of our new predicament, we had to keep fighting. It was important that I took quick decisions if my son was to survive.

The next day, I phoned my sister back home to organize all my nephews and nieces to donate blood samples for testing. I was desperate. This was quickly done by one of the reputable diagnostic centres in Accra but we faced some challenges in airlifting the samples. Eventually, we had to buy a ticket for Fiifi, my nephew, who managed to 'smuggle' them to South Africa. In all, we had about 13 samples but not a single match. I was disheartened. All that money spent in getting those samples and flying them over had gone to waste. At this point, we were left with no option but to look at the international database for a match. As we were informed, this was a lengthy process which would require that we stay in South Africa a while longer. By this time, we had already spent two weeks in Cape Town with no progress made. Elorm continued his chemotherapy treatment at the Red Cross Children's Hospital. Elorm made a new friend at the hospital. His name was Lumkile, an eight-year-old boy who had also been diagnosed with

ALL. For the most part of our admission at Red Cross Children's Hospital, Lumkile's bed was next to Elorm's and they got along pretty nicely. I was particularly fond of Lumkile and anything I bought for Elorm, he shared with him. It was revealed that Lumkile's twelve-year-old sister was a complete tissue type match. She however refused to be his donor despite all the attempts made and Lumkile died. This was indeed a most unfortunate occurrence.

The weather was quite unfriendly but we struggled to cope and our finances were dwindling by the day. We soon had to move to Chaplaincy House, a much cheaper accommodation. The Chaplaincy House came with a lot of inconvenience and challenges. There, we had to share a bathroom with the other occupants. The general surroundings was nothing to write home about. This wasn't the best living arrangement especially for Elorm whose immunity was low. Assessing our situation, I impressed upon my wife to return home with our two other children, Delasi and Esinam, while I stayed on with Elorm. It was hard to say goodbye to them. Tears filled Naa's eyes as we said farewell, and my little girl cried once she realized that we were to be separated. Our eldest was most unhappy about leaving his younger brother and playmate behind. Reluctantly, they returned to Ghana on a cold, windy and rainy Saturday morning. Minutes after they had left, I went into the bathroom and wept.

It was during this time that we got connected with CHOC (Childhood Haematology Oncology Clinics), an organization formed by parents whose children had been diagnosed with

cancer. This organization had homes in almost all the provinces in South Africa. These homes were managed by parents who by virtue of their experience knew all about childhood cancers. The homes accommodated parents and their children who had been diagnosed with cancer and were currently on treatment at the hospital. The organization aimed to ease the burden of such parents who had been referred from the hinterlands to the major treatment centres in the city. The most notable of these hospitals was Red Cross Children's Hospital in Cape Town, where Elorm was being treated.

The initial intent of these homes was to help South African citizens, but over time, this opportunity was extended to foreigners. We paid token amounts for lodging in comparison to the charges of a hotel or hostel. I met the then local chairman, Mr. Kenneth Dollman, who we connected with through the Cutlands, pioneers of CHOC in South Africa. Mr. Kenneth Dollman is currently the President of International Confederation of Childhood Cancer Parents Organization-ICCCPO headquartered in Netherlands. After he met with us and heard our story, he told me all about his organization and offered to make our stay comfortable. The following day, he came back to visit with his wife and son, Michael and we went sight-seeing. Elorm and Michael hit it off right away. The Dollmans were amazed at the conversation the two eight year-olds were engaged in. They were most surprised by how fluently Elorm spoke the English language. To them, it was rare in their setting for a black child of that age to express himself in that manner. In his usual way, Elorm asked Michael all the intelligent

questions about his school, family and other issues. Naturally, we bonded with the Dollmans and became friends. We made a few other friends as well in South Africa, including Petra and her twelve year old daughter Simone, who had also been diagnosed with ALL. As we drove into Cape Town along the lovely roads, the well-trimmed flowers, and the lush, green landscapes were sights to behold. During our trip, we seemed to be climbing an unending hill and I got a bit scared. When I asked where we were going, the reply was, "Table Mountain." We got to a very high point on the mountain where we alighted only to see so many tourists in a queue, waiting to board the cable bus to the caves and restaurants carved out of the hard rocks in the mountain. I did not wait for our host to ask us if we wanted to travel in the cable to the caves. Cape Town was hundreds of feet below us and I was visibly shaking. I told our hosts that I was not mentally prepared for this adventure. Strangely enough, Elorm was excited and ready to get on the cable bus. I convinced him to abandon the idea for now as I had already planned for us to visit Table Mountain on another day. We had already been booked for this trip by an organization called Reach for a Dream. Reach for a Dream is a voluntary organization whose mission is to encourage children to use their dreams to fight life-threatening illnesses and to inspire hope. From the mountain, we drove to the Waterfront. It was absolutely riveting to watch the many activities that went on there. I was particularly thrilled by the display of magical prowess by a group of people and by their songs and dances that seemed more of a strenuous exercise than a dance. We feasted in a restaurant nearby after which we were ready to go for a boat ride on the sea. Our boat ride took us

within close range of the famous Robben Island where President Nelson Mandela spent over two decades in prison. Instead of being happy about all the beautiful things I was witnessing, I felt like a drunken giant walking with the limbs of a mosquito. I could simply not focus on anything, because I was too preoccupied with my son's illness. Eventually, we returned to Chaplaincy House very tired and soon retired to bed. While I was not enthused by the promise of our new friends to take us sight-seeing in the coming days, Elorm received the news with great excitement. When the Dollmans reminded me of their offer a few days later, all I wanted was to be left alone to think about what lay ahead of me. I kept giving excuses till they realized I was simply not interested. The days that followed were full of expectations. I was hopeful that the hospital would find a blood match, meanwhile the chemotherapy treatment continued at Red Cross Children's Hospital. After almost a month of treatment, Professor A.D. informed us that Elorm may not need a transplant because he was fine, especially when there was no possibility of a match. He gave us a letter to be given to our doctor in Ghana detailing the way forward. We quickly prepared to travel back home. Rashaad, our friendly driver, took us to the airport and that same evening we landed in Accra.







# 3

## THE HEALING SCHOOL

In August 2006, I got a new job at the Institute of Professional Studies, now the University of Professional Studies. I took on a role as a lecturer in Accounting and Auditing. I had to leave both my previous jobs due to misunderstandings with my employers. They could not understand that I was balancing my work with my son's illness. Elorm's welfare was as important to me as my job. There were a few occasions where I had to stay away from work to be able to take him for treatment. I owned a large pineapple farm from which I exported produce to Europe. Due to my son's illness, I could not pay much attention to it. The farm manager took advantage of my absence and mismanaged affairs. In fact, he stole everything in the course of time, leaving me with a debt to settle at the bank. Despite these mishaps, Elorm was doing well. Back in school, he was one of the top pupils in his class in spite of his long absence. His intelligence earned him the nickname 'Prof'.

In a chat with Professor Joshua Alabi, the Pro-Rector, now the Vice Chancellor, of the Institute where I worked, we ended up talking about Elorm's health. He suggested that I take Elorm to Pastor Chris' Healing School in South Africa where Elorm's restoration was sure to be made complete. I bought into the idea as soon as I heard it because we were scared he would suffer from a second relapse. A few days later, we registered and left for South Africa, this time to Rustenburg.

Before our departure, the Rector of the Institute, Reverend J.J.M Martey, called me into his office and prayed for God's blessings and favour upon our lives as we embarked on this trip. Our doctor gave us a stock of the drugs Elorm was still taking but for some odd reason, we could not get the most essential of his drugs from any of the pharmacies in Accra. That being the case, we were given a prescription to buy them in South Africa, but even there, they had run out of stock. Then it occurred to me that perhaps God wanted to show his control once more, proving to us that He was still in the healing business and so we did not need the medicine. Convinced, I took a second look at the other drugs he had and put them all aside, except for one. I decided that we would concentrate instead on given him regular doses of the food supplements we had.

On our first day at the Healing School, I marveled at what I saw. As we went through the registration process, I was impressed by how well-organized the institution was. I knew then that I was at the right place and I was convinced that this time, God would

certainly hear our cry and end our turmoil. I was ready to experience God's presence and His awesome power like never before.

There were people from all over the world with various sicknesses - Blacks, Caucasians and, every other race you could think of at the Healing School. Even though there was a limit on the number of people admitted to each school session, there was still a multitude present each time. The Healing School had a routine everybody had to follow without fail. The major activities included intensive prayers, bible reading, fasting and singing with short breaks for lunch. We had prayer sermons by the elders and watched videos of past healing school sessions showing how people were miraculously healed.

There were also 'inner room sessions' where we were called into small rooms and prayed for individually by the elders. Praying in tongues was the preferred option and we were all encouraged to pray in this medium. It was amazing how Elorm coped with this intensive three-week healing process when some adults retired along the way. All the adults he interacted with were fascinated by him. He could now pray in 'tongues' at age eight. During this time, my son became my bosom friend. We talked about a wide range of issues from football to social matters. His depth of knowledge and appreciation of issues even at that tender age astounded me. During the second week, I heard my name over the P.A system. I was asked to report to the announcer immediately. My heart quickened and I concluded that they were taking us to see Pastor Chris, whom no one had seen yet. Finally, the leaders of the

Healing School had realized that my son needed special attention, I thought. Contrary to my expectations, it was Professor Joshua Alabi and the Registrar of my university who had come to visit us on their way back from a conference in Zambia. After feeling so alone on our journey, their visit restored my faith. It gave me an assurance that I was not alone. The Healing School regulations discouraged spending too much time with visitors, so I briefly updated my guests about our progress and they left. That same day I received a call from my wife, reporting that that thieves had come to ransack our home taking away many valuable property. Interestingly, Naa asked that I tell the pastors of the healing school to help me pray that the thieves return the stolen items. Both Naa and I had nothing else to hold on to but our faith in God.

The great day came at the end of the third week. Even though no one had seen him yet, we were told that Pastor Chris himself was going to be present for the actual healing sessions. We were split into groups with each person carrying a placard detailing the illness that brought them there. Regardless of what illness it was, one was expected to display it openly. It was during this time that I discovered that a fellow house-mate from Botswana, with whom we commuted daily to and from the Healing School, had HIV-AIDS. Indeed, it was that day that we each discovered what illness the next person suffered from. Long before, the man of God entered with many 'disciples' following and seemingly shielding him from the congregation, the auditorium was fully charged. Pastor Chris was immaculately dressed in an all-white suit and matching white shoes. The auditorium was set 'ablaze' with shouts and raised hands

as people surged forward in ecstasy and excitement. Everyone in the room was convinced that their ailments will not follow them after the session. This was the last stop of their sicknesses. This was the greatest hour in their lives. It simply reminded me of the triumphant entry of Jesus into Jerusalem and the multitude that thronged there to see him. It was a scene that was better seen than described.

The man of God went straight to business, touching and anointing people with oil and healing them. Almost everybody run into their inner circle shouting, "I am healed!" after the man of God had touched them. I saw people who hitherto could not walk unsupported throwing their clutches away, walking and praising God. I saw people who were visually impaired, now professing to see. Aside these visibly afflicted individuals, there were the majority of people amongst the congregation who suffered from diseases like HIV-AIDS, cancer and diabetes. These people, unlike the first group, didn't have any outward sign to indicate that they had been healed. Interestingly enough, some people from this latter group also jubilated. They shouted and proclaimed their healing. It was then that it dawned on me: How could I tell for certain that my son had been healed after receiving a touch from the man of God? I remembered one of the past experiences shared at the school. It was about a man with an infection of the neck. The stiffness in this man's neck wasn't cured on the premises of the church. It was at home that he received his healing because as we were told, he believed, deep down in his heart, that he was healed.

After receiving the touch from the man of God, my son shouted without any prompting from me, “I am healed. Thank you God!” My eight year-old had been watching what the others were doing. He had had enough torture from the hospitals; he had had enough toxins in his body and was declaring ‘enough is enough’. I wept.

During this trip, we stayed in a house run by a fairly old white couple. This was where we made our daily journey to and from the Healing School. It was ironic that during our three weeks stay with them, we discussed everything under the sun except the Healing School. “So, what do you think of your son now?” When our host asked this, on our way to the airport to catch our flight back to Ghana, I decided to seize the opportunity to preach to him about God. I started by telling him about how my son has been healed miraculously. I did not hesitate in telling him about the goodness of God and how God was still in the miracle-working business. I told him about how God was using some men to make the world a better place, and about the limitations and fallibility of medical doctors. A part of me was still incensed, how could doctors think they had the right to pronounce death on my son on not just one, but two occasions. I rambled on with no restraints; He listened as he drove along from Rustenburg to Johannesburg Oliver Tambo airport. When I was done, he wished us well and we flew back to Ghana.

When I think back, could it be that he knew something that I did not know? Because I remember he and his wife both complained about high blood pressure and how it had forced them to stop

drinking their favourite coffee. They lived close to the Healing School and in fact many people who had come to the Healing School had rented their rooms and were transported there on a daily basis by this couple. So, why hadn't this couple gone to the Healing School for their healing? Maybe they knew something I didn't know after all.

From the beginning of human civilization, people have always had the need to explain why things happen the way they do; people have always had a desperate yearning to understand what goes on in their societies, communities and environment. This desire to ascribe meaning to happenings is quite different in the realm of religion. In religion, it is not everything that we can explain. We cannot conveniently draw a line between cause and effect. This situation became increasingly clear in Elorm's battle with cancer. I needed to make meaning out of everything that was happening around me. There were many questions and very little answers. So despite being a believer, I sought to make sense of the world through the lens of social criticism, not religion. As a result, a part of me wanted to do what was humanly possible for my son, while God fulfilled the divine aspects of healing.

We returned to Ghana full of excitement and praises to God for the 'healing'. Many family friends came and prayed with us and we readily recommended a visit to the Healing School to many people for answers to their hidden problems. We went to Korle-Bu to visit our doctor and were told she had travelled. We met Dr. V. and I happily informed her that my son was well and was not

on the strict chemotherapy drugs anymore. She sized me up and asked, “Did Dr. R. ask you to stop the medication?” I replied in the negative and that was the end of the conversation.

When our doctor returned, she invited us over. We found out that Professor N whom she had been communicating with via email had managed to secure cord blood from the international bank for the transplant to be done. I paid very little attention to her and rather dwelt on the ‘miracle’ that had taken place in the ‘Healing School’. Sensing my disinterest, she hesitantly suggested that she would find something to communicate to Professor N.

A few weeks later what we feared most happened. Elorm’s headaches and tiredness recurred. How do I go back to Korle-Bu to tell the doctor that the Healing School did not help us? How would friends and relatives who heard about us take this? What would my colleague lecturers say about me? What about my church members? I felt completely ‘humiliated’ and emotionally shattered over the return of my son’s sickness. I was also concerned about what the public will perceive of me and my unreliable testimonies. Left with no alternative, we went to back to Prof. N to inform him that we would be coming for the transplant and he in turn sent us the following:

Actual cost of cord blood and transplant \$100,000. We needed to make provision for our travels, accommodation, feeding and other incidentals while in Cape Town. The details of the cord blood read as follows:



**HISTOCOMPATIBILITY TESTING FOR BONE MARROW TRANSPLANT**

Name:	Elorm Aveh	09ERIBB00100184
Relationship:	Patient	Cord Blood
Date of Birth (Age, Gender):	21/12/99 male	1988 female
ABO & RH:	B Rh Pos	A Rh Pos
HLA Typing:	A      03      68	68      2
	B      57      18	57      18
	C      02      07	-      -
HLA CLASS II:	DRBI   0701   1101	0701   1104
	DQBI   0202   0301	-      -

The explanation for all the above data is that the cord blood was 60% compatible! At this point, the assurance was that the cord blood was the safest option and the percentage compatibility did not really matter.

We could not raise the amount involved. Prof. Joshua Alabi and the University were yet instrumental in securing sponsorship through the government that covered the cost of the transplant and our airfares. We managed to raise some money ourselves through the benevolence of my in-laws and some sympathetic friends. On the

28th of April 2008, I was airborne with my son for the third time to South Africa. Even though, I knew what was ahead of us, I was very apprehensive.

### ***How is bone marrow obtained for transplantation?***

*The stem cells used in BMT come from the liquid center of the bone, called the marrow. In general, the procedure for obtaining bone marrow, which is called “harvesting,” is similar for all three types of BMTs (autologous, syngeneic, and allogeneic). The donor is given either general anesthesia, which puts the person to sleep during the procedure, or regional anesthesia, which causes loss of feeling below the waist. Needles are inserted through the skin over the pelvic (hip) bone or, in rare cases, the sternum (breastbone), and into the bone marrow to draw the marrow out of the bone. Harvesting the marrow takes about an hour.*

*The harvested bone marrow is then processed to remove blood and bone fragments. Harvested bone marrow can be combined with a preservative and frozen to keep the stem cells alive until they are needed. This technique is known as cryopreservation. Stem cells can be cryopreserved for many years.*

## **FACT BOX**

# 4

## THE TRANSPLANT

*'We are going; heaven knows where we are going. It will be rough we know, heaven knows that it will be muddy and rough'.*

This is the song that continuously played in my head along with the voice saying over and over again—‘Have you seriously thought about this?’ I should have adopted a wait and see attitude, maybe God would have intervened somehow. But the expected miracle had been too long in coming. I tried to assure myself that I had done what any responsible father would have done. The truth is that when you are in trouble, all manner of people suddenly become experts and offer their often unsolicited ‘professional advice’. My head was constantly pounding and I had developed frequent heart palpitations. I was also not eating well. How could I eat well when I was staring at death in the face? Nonetheless, I was determined to fight this battle. There was no way I was ever going to give up on Elorm’s health. Then I remembered a quote:

*“Ever so often we are blessed with peace and harmony in our lives and sweet sounds permeate our life. It is when the harsh noise of difficult times reverberates through every cell in your body that the cry for help to cope rises within us.”*

*-Irma Schutte*

Before we departed to South Africa, a friend called me and told me he would accompany us to an all-night miracle and wonders church service at the Baden Powell Hall. He spoke highly of the Prophet in charge and added that we should give a generous offering as that would attract the kind of miracle we are expecting. On the day, the three of us including Elorm went with great expectations and gave a good offering even though we were struggling financially. After the service, we met the Prophet and he prophesied into our lives. I was to read Psalm 40 with emphasis on verse 13 to 16 which reads:

“Be pleased, O Lord, to save me; O Lord, come quickly to help me. May all who seek to take my life be put to shame and confusion; may all who desire my ruin be turned back in disgrace. May those who say to me, “Aha! Aha!” be appalled at their own shame. But may all who seek you rejoice and be glad in you; may those who love your salvation always say, ‘The Lord be exalted!’”

The following day we were on our way to South Africa. We arrived in Cape Town at about 11:30 am and we were picked up by Mr. Christi Koorts who together with his wife Lubi, were the

managers of a home for parents and their children who had not been fully discharged to go home, which meant they needed to attend hospital at specified times.

This home located in Plumstead, was one of the seven of such homes in South Africa owned by CHOC (Childhood Haematology and Oncology Clinics). Mr. Koorts had been instructed to take us to Red Cross Children's Hospital where we were to begin the process leading to the bone marrow transplant. Our luggage was taken to CHOC House but we remained at the hospital. I began noticing a change in Elorm's behaviour. He was asking all manner of questions to which I gave very short answers. Despite how much he understood regarding his circumstance, I still felt the need to safeguard him from any thoughts that might still instill fear in him. Eventually, he asked: What is a transplant? I was dumbfounded. He may have overheard me or someone else discussing this matter. I tried to parry the question, but he insisted. I went round the topic in a winding manner in an attempt to confuse him. He was crisp in his response: "I don't understand what you are saying." I told him I will explain further to him later.

Within minutes of our arrival, Elorm was taken to the theatre for a HICKMAN LINE to be inserted. A HICKMAN LINE is a special kind of intravenous tube for the transfusion of blood and medication. Elorm's was inserted for the present procedure, and

it was meant to last for all other future transfusions. This way, the difficulties that are sometimes faced when trying to locate a vein and the regular and painful needle piercing of veins are avoided. This frightening operation involved an incision into Elorm's chest. After the incision, a plastic tube was inserted into the veins in his chest, leaving two tubes hanging outside his body. Usually, these tubes are covered by a special plaster to avoid contamination. The HICKMAN LINE was meant to last for as long as it remained infection-free. I went to the theatre with him to give him support but not without difficulty. He insisted on knowing what they were going to do with him. I told him I did not know. He paused for a minute and again asked me to ask the nurse who had come to take him. The nurse, who was all this while watching our interaction, smiled and said, "My dear, the doctor just wants to see your handsome face." While the nurse and I smiled, Elorm kept a straight face. When we got to the theatre, the atmosphere terrified Elorm to the point that he asked me to take him back, he said he didn't want to be there. Within a twinkle of an eye, an anaesthesiologist had managed to sedate him. I was asked to leave the room after Elorm was sedated.

The surgery lasted for about two hours, after which I was called to come and wheel him to the main ward. He was still sleeping due to the effect of the sedative. When he gained consciousness and saw the HICKMAN LINE, the questions started again. This time he accused me of not telling him the truth even though I was aware of what was going on. He insisted that the doctors should have told him what they were going to do. I needed to do

or say something sensible to end the debate. I congratulated him and told him he should know that his father would always seek what was in his best interest and that whatever it took to make him well again, I would do. I knew the journey ahead was going to be a tough one. Elorm was going to ask me to explain every move of mine, the doctors, and even the nurses. This was exactly what happened in the weeks and months that followed.

On hindsight, I realize that Elorm's level of maturity and understanding was such that if I had explained issues to him, we would have had better communication. Indeed, children are very perceptive and can sense when information which is meant to mislead is handed them. Being sensitively factual ensures one builds on trust as the opposite breeds mistrust for the adult passing on the information.

The following day we were discharged to go to CHOC House where we had a lovely room to ourselves and a beautiful environment. A cartoon channel on DSTV soon absorbed all his pain and fears. He was an ardent follower of all the cartoon shows and he could recite an entire programme after watching it just once. There were other families there too, each allocated different rooms. I brought a few traditional shirts and dresses from Ghana for the few friends I had made on our earlier visits. One of them was Rashaad Davids, the driver. I tried his number many times. I wanted to inform him that I was back in Cape Town and I had brought him something special from Ghana. When someone eventually answered my call, it was female voice.

I asked to speak to Rashaad. The person asked who I was and how I knew Rashaad. I told her how I had met Rashaad and informed her that I had brought him some presents from Ghana. She identified herself as his wife and told me that Rashaad had died a month earlier. In my shock, I screamed causing Elorm to ask what had gone wrong. I told him Rashaad was dead. Intuitively, Elorm asked me to tell the widow to come for the shirts. I looked at my son and wondered where that came from, then I asked Rashaad's widow if it would be possible to arrange a meeting so she could pick up Rashaad's present. She said yes and we agreed on a date. The meeting with Rashaad's widow was laden with a lot of painful emotions. I told her about her husband's generosity, and about how kind he had been to Elorm and me. Through it all, I couldn't help but ponder upon the triviality of life; one could be here today and gone the next day.

Elorm and I were often driven to the Red Cross Children's Hospital by the manager of CHOC House in a bus which had been made available for use of by housemates. One morning on our way to the hospital we saw a billboard which had the inscription: **Warning by the Surgeon General: "Cigarette smoking can be harmful to your health. Smokers die young"**. Elorm asked me who the Surgeon General was. I told him the title did not relate to a specific person. The following morning, I was in the kitchen busily preparing our breakfast when Elorm came quietly and asked me to follow him to our bedroom to see something. I was confused but I obeyed anyway. When we got into the bedroom he asked me to peep through a small opening by the curtain while asking me to keep quiet.



When I peeped, I saw the manager of the house puffing hard at his cigarette in a corner covered by the flowers and trees. He had been making a deliberate attempt to hide so I wondered how Elorm had been able to spot him. I knew the question that was to follow. "Does he know cigarette smoking can be harmful to his health?" he asked. I hesitated for a second, "It is a question of choice," I replied. I went on to give many examples dwelling especially on the bible which teaches us to do good but many people delight in evil doings which they would definitely account for on judgment day. Elorm still had other questions for me. "The Billboard we saw also said "Smokers die young" but this man is old and should have died long ago," he said. I stood watching him not knowing what to say. After a while he concluded, "It is not everything you see that you should believe." I considered disabusing his mind about his last statement but I just could not speak; I could only admire his depth of knowledge and articulation. From that day, it became a routine for us to spy on him every morning as he puffed his cigarette in his hideout. Life at the CHOC house was more comfortable than we had expected. Ours was the only family in the house that hailed from outside South Africa. For the next eight months we lived in this house and paid very little rent and we were well catered for. There was ready transportation to take us to and from the hospital. The CHOC bus also catered for our trips to the stores when we needed it. We cooked every meal we wanted and this to a large extent enabled us to settle in. Every evening, we received calls from home and we would take turns to speak to each person. Normally, Delasi, Elorm's elder brother would ask about the final scores from the English Premiership since we had DSTV. Elorm was

happy to talk about the games and the scores, often dwelling on how Manchester United fared, especially if they had won their match. Delasi is an Arsenal supporter, and I am a dye-in-the-wool Liverpool FC supporter. One day, Liverpool walloped Manchester United 4-1, and Elorm refused to eat because he thought I was teasing him. Not long after the match, we had a call from home and as usual his brother asked for the scores. Elorm told him all the scores and skillfully left out the 4-1 drubbing. It was rather funny. I later asked him why he left out the Manchester United and Liverpool game score, and he said it did not make a difference since his brother was neither a Manchester United supporter nor Liverpool FC supporter.

Elorm loved going out, so sometimes we would take walks into town. There were times when we had dinner at KFC or at Nando's. Other times we went shopping. One of such days while shopping, I bought him a "Ben 10" branded watch. Ben 10 was a popular cartoon programme shown on DSTV. On the show, Ben 10's watch is an amazing device capable of achieving many feats. Elorm was so excited by his new watch. We got home and he quickly assembled it but to his dismay it did not have any of the functionalities associated with it on television. He was disappointed and I had to explain to him that most of the things shown on television are fiction. "What is fiction?" he asked. I explained to him that 'fiction' meant 'not real'. Not long after this conversation, Ben 10 was showing on the television and he watched it with the children from the other families. He kept reiterating to the children, "This is fiction, this is fiction," to which the children asked, "What is

fiction?” From that day, any time they were watching any show, the children would ask, “Elorm, is this one also fiction?”

For three and half months we went up and down Red Cross Children’s Hospital. We were told they were preparing us for the transplant, until we received a programme which read:

Patient Name:	Elorm
Date of Birth:	21/12/99
Medical Aid:	Private
Diagnosis:	Acute Lymphoblastic Leukaemia in CR3 after CNS relapses
Transplant Type:	Allogeneic placental cord blood 4/6 matched transplant

#### PATIENT STEM CELL TRANSPLANT PROGRAMME

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DATE	DESCRIPTION
13 August	Visit to the Clinic
15 August	LE32 for planning (Dr. M.)
20 – 29 August	Cranial Radiotherapy 12 Gy in 8 sessions
02 September	Admit to F4 for prehydration
03 – 05 September	TBI 12 Gy
06 & 07 September	Cyclophosphamide 60 mg/kg x 2 days
07 & 08 September	ATG Fresenius 3mg/kg x 2 days
09 September	Infusion of the placental cord blood graft
27 October	Discharge from Unit

Prior to this notice, I hadn't thought of the possibility that the transplant could span such an extended period of time. When I received this programme, I wondered if we were going to stay in the hospital for the two and half months. I approached one of the young doctors to kindly explain the programme to me. After reading it, he forced a smile and said it is the normal procedure and that we could be coming out of the hospital earlier than schedule depending on Elorm's response to the transplant. He added that the period could also be longer if complications set in. "It is a fifty-fifty chance," he concluded without showing any emotion. The truth is we spent more than the number of days stated on the programme.

We were due to see Dr. M. on the 13th of August but we went on the 29th of July instead. Fortunately, Dr. M. had a fairly relaxed schedule at the time so she was able to start the stem cell transplant process that same day. When Dr. M. mentioned the word 'Process', Elorm cut in to ask what she meant by that. The Dr. took time to explain to Elorm that it simply meant they were going to measure the size of his head so they could mould a protective head covering or a mask for him. This mask would be used to protect some parts of his head as he starts his Radiotherapy sessions.

After this explanation from the doctor, I turned to look at my son and it was clear from the look on his face that I was going to have a tough time convincing him in subsequent operations. Thankfully, these measurements were carried out with little resistance from Elorm. We were then asked to go home and come back on the

19th of September. I was extremely grateful for this two-month break. All along, I had been praying for an opportunity to fly back to Ghana for a two-week break. I thought it would be best if I was home to update my close family relations about Elorm's health and to confer with them on what was to come. More so, I needed to ask them to bear us in prayers. It finally occurred to me that in my desire to make Elorm as comfortable as I could, I hadn't paused for a single day's rest. I thought home would be the perfect place to get this much needed rest. I wasn't the only one who desired to go back home, Elorm was itching to see his mother and siblings to tell them about all that had been happening to him. He couldn't wait to talk to his grandfather about Manchester United. I could tell that he had missed his friends too, especially, Miss Ntemah Okai.

When I look back to the days we spent in South Africa, I realize that Elorm had gained a perceptiveness that was beyond his age. With all the questions running amok in my head, Elorm remained strong in spite of his situation. When we boarded the plane in Johannesburg, something very remarkable happened.

As I was putting our hand luggage in the overhead compartment, Elorm started singing:

*Because He lives, I can face tomorrow,*

*Because He lives all fear is gone, and now I know, yes I know He holds the future,*

*Life is worth a living just because He lives.*

I was speechless as I sat down beside him. Many people turned to look at him but he paid them no mind and did not stop singing. This was one of the many songs we used to sing at the Healing School but neither of us had sung that song in a long time. If I ever felt my faith was not enough to get Elorm back to good health, he was telling me that he had his own faith and he could face tomorrow. I thought about my son's powerful song as we flew back to Accra for our two-month holiday.

When we arrived in Ghana, I discovered that coming home for that short time was a worthwhile decision after all. I had time to plan and strategize for the impending hospitalization and transplant. I needed to psyche myself to face what was ahead of me. On the third day after our arrival a pastor visited us. After prayers, he directed me to go and fetch sea water and put a few drops in Elorm's water for bathing. I went to the beach to fetch the water and I realized I could draw so much strength from just being alone at the beach. So on five occasions, I left home and spent some time at the beach, just watching the sea, waiting for the tides to help clear my head. I did not know exactly what I was searching for anytime I sneaked out of the house to the beach but there was a heaviness in my heart and many questions on my mind; questions I needed answers to, from where I did not know. I was hoping for some intervention, any intervention at all. Much to my surprise, I found myself gravitating towards a divine intervention. A part of me couldn't believe that my faith was still intact after all Elorm and I had been through. My mind told me to rule out any intervention from God, but I still found myself clinging on to

Him. One day as I sat there soliloquizing, I asked God why He would not send an angel to help me out. I needed answers, and all I heard was silence. Some days after this conversation with God, I visited the beach again and decided to read my bible. When I picked it up, I inadvertently opened the bible to Psalm 37 verse 3-7. I thought this was the doing of the Holy Spirit, and the long awaited answer from God. The verse reads:

*“Trust in the Lord and do good. Then you will live safely in the land and prosper. Take delight in the Lord and he will give you your heart’s desire. Commit everything you do to the Lord. Trust Him and He will help you.”*

As I headed towards home I was convinced I was going to see a miracle from somewhere, from where exactly, I could not tell. I got home and there was no miracle. My son was still the same. At that moment, my old doubts about my faith came flooding back. Did I really belong to Christ? Did He not say we should cast our cares upon him?

The days passed by hurriedly and very soon it was time to go back to Cape Town. We managed to take plantain, which the South Africans called big banana, kontomire and okro stew, kenkey, fried fish, gari and ‘shitor’ along with us. We arrived in South Africa on 7th September, two weeks before the transplant process was to begin. We visited the hospital the day before and met with Dr. M. who brought the ‘mask’ to see if it fitted Elorm. It did not fit exactly and needed a little adjustment which was subsequently done.

Before we went on admission, a twelve year-old girl, Sisiphiwe had just been discharged from the ward after a transplant. Her six year old brother was a complete match and he donated stem cells for the transplant. In a conversation with Sisiphiwe's mother, she recounted how she nearly aborted the boy because she was not ready for another pregnancy at that particular time. Her testimony was a classic case of the stone the builders rejected becoming the head cornerstone. Though our stories were somehow different, the sight of Sisiphiwe gave me much confidence to face what was ahead of us. She had a related donor of bone marrow but ours was an unrelated allogenic placental cord blood which was not even a complete match. It was 60% match! The odds were high.

We were ready to start Cranial Radiotherapy 12 Gy in 8 sessions. It involved putting Elorm in a still position inside a machine each morning and evening for four days while ultra-violet rays (radiation) were directed to certain parts of his head with the intention of killing any bad cells that may have lodged in his head. Each session lasted fifteen minutes and I could watch him from the computer screen in the reception. Radiotherapy has many side effects, for instance, it may reduce a patient's mental faculties in the future. Additionally, it may cause infertility in both men and women. After every session of radiotherapy, the doctors commended Elorm for his comportment. According to them, even some adults hadn't been as comported as Elorm had been.

After the last of the Radiotherapy sessions, we were admitted into F4 ward for pre-hydration. Pre-hydration is a process which



involves the administration of a heavy dose of infusions. In Elorm's case it continued for five days. All this was to prepare him for the actual cord blood transplant. These were very difficult moments. As it normally happens for patients in pre-hydration, Elorm became weak and nauseated and he threw up at the sight of food. I was given a bed right beside him during our stay in F4 ward. The hospital also provided me with specialized clothing, just like the kind surgeons wore in operating theatres. In case I had to step out, which I seldom did, I had to change into a new set of sterilized hospital clothing. This was to avoid contamination which could be transferred to Elorm. Only few nurses were allowed into our room. We were fed three times a day in this solitary confinement and the food was very good.

As I had no way of going on my regular morning walks, I paced up and down the corners of the room, obeying the commands of my son, "I want to poo poo, I want to brush my teeth, please lower my bed, I want to play games on your computer, I am cold, please give me another blanket." Our confinement in the F4 Laminar 1 room was a voluntary imprisonment which I found most foreboding. There was no beginning and no end. There was only one's own mind, and even that began to play tricks on a person. Was that a dream or did it really happen? One begins to question everything. Did I make the right decision? Was this journey worth it? In solitude, there is no distraction from these haunting questions. However, even in this predicament, I discovered that the human body has an enormous capacity for adjusting to trying circumstances. I learned that even in the midst of trial, it

was possible to bear the unbearable as long as one was willing to fortify his spirit by keeping his eye on the goal. Strong convictions are the secret of survival in these circumstances. I remembered a quote from ‘Desiderata’: “Nurture strength of spirit to shield you in sudden misfortune. But do not distress yourself with dark imaginings. Many fears are born of fatigue and loneliness.” With these in mind I did my best to stay strong.

On the morning of September 19th, a young lady entered our ward; she looked around before examining Elorm quite thoroughly. She checked every part of his body without asking many questions. Then, she went out briefly and came back; still not communicating which I found a bit unusual. I tried to start a conversation but I only received a terse response, “We are getting him ready for the cord blood.” My heart nearly missed a beat. The day had finally arrived and I felt a mixture of uncertainty and sadness. Elorm was apprehensive; he did not want me to leave him for even a second. He would not allow me to even visit the loo in the same room. For a boy of his age, it was understandable. He had been through so much torture and still there was no end in sight. What was it this time? The atmosphere had been made tense by the body language of this lady. She would not communicate, which was a sharp contrast in comparison with Dr. M. and all the other nurses we had encountered so far. She spent some minutes in the corridor mixing something. I wanted to go over and see for myself what it was, but Elorm would not allow me.

At about 9.am, Professor N. appeared in the company of two other

nurses and in his hands were two sachets of something that looked like blood. He greeted and asked how we were doing. All eyes were on him and Elorm watched every move of his. He realized he had to do something to bring down the tension in the room. He forced a smile and told us it was just a continuation of the process. In a swift move, the cord blood was set up and connected to his HICKMAN line and it began to flow. Not long after that, Elorm requested to use the bathroom. I brought him the chamber pot and his excrement was strange, green and watery. This was to be the case for the remaining days of his life. Any time, we had the room to ourselves, without the presence of the nurses who were constantly monitoring Elorm, I spent time praying. I was not alone; my wife, my sister-in-law and many other people were fasting and praying on this particular day as well that all will go according to plan.

At exactly 1pm the flow of the cord blood transfer ended. I sat and pondered over the meaning of life. I began to wonder if life could ever be perfectly understood by any being. I wondered how an eight year old boy could tolerate such tough treatment on such toxic and poisonous medications. As I had already mentioned before, one of the people I got acquainted with over a year ago was a lady from Port Elizabeth called Petra. I met her at the Red Cross Hospital with her daughter, Simone. Simone was also suffering from leukaemia and Petra and I became friends. On our return to Cape Town, we met again and as usual we compared notes on the progress of our children as advised by one of the doctors. At 2pm on the day of the cord blood transplant, I had a call, strangely from

Petra. I was excited and anxious to tell her about our successful transplant and about the notes I had put down to share with them since they were also due for a transplant. She listened and after I had finished, she said, "Sorry, Simone is dead!" I stiffened at her statement, I was dumbfounded. I showed no emotion that would cause Elorm to start asking questions I didn't have answers to. How does a father explain to his son that another child had died? What explanation could I give to Elorm for Simone's death? After a while, I took a pen and wrote a eulogy to her memory which I titled 'A girl called Simone':

My girl Simone you have given up too early or can I say God wants you early.

Sad to hear of your passing away

You were such a nice and respectful girl

I remember you always brought Elorm candies and little presents

I also remember the comment you passed about how well Elorm was always dressed

Elorm was always the first to draw my attention of your entry into the hospital

How do I break this sad news to Elorm?

I salute you for the good fight

Walk into your heavenly rest, where there is no sickness, pain, sorrow and death

Your name will forever be etched in my mind

Your memory would never fade  
Oh Lord, let her live in the glory of your grace  
Fare thee well, my dear daughter, till we meet again.

At this point a pattern was beginning to emerge as all the beautiful children diagnosed with cancer were dying one after the other, but I refused to see it. I was different, my child was different, and his story was going to be different.

I dreaded the mornings that followed immediately after the transplant. There was the daily injection of a drug called Neupogen which was administered on Elorm's stomach. This was a struggle for me as I could not stand the sight of the needle being pushed into my son's stomach, but I was expected to help the nurses calm Elorm down for the injection.

On the 21st of September, I had to keep wake because Elorm was running a high temperature of 38.7. So, I kept the lights on and read the bible. I was just repeating Psalm 23 over and again: *The Lord is my Shepherd*. Elorm was going to come out victorious, I prayed. The night nurse entered our room and asked if I was not going to sleep. I only smiled. She left and came back a few minutes later while I was still praying, she went to our bathroom and as she was leaving the room switched off the light and closed the door after her. I sat glued to my seat in disbelief asking what this could mean. Was it a show of power or was she simply an agent of the devil? I sat still and watched through the glass window trying to decipher what her next move might be. A few minutes later, she

came and peeped through the glass panel and our eyes met. She stood there for a while and then left. It was also during this time that I realized my blood pressure was swinging like a pendulum. The doctor and the nurses asked me to go to CHOC house and take a rest or go and take a walk in the park and admire the beauty of nature. I flatly refused.

On the 23rd of September, Elorm started urinating pure blood. I could tell from Professor N's initial reaction that he was worried by this development. Elorm's blood pressure had shot up. He was also having difficulties breathing, so, he had to be put on a ventilator. During this time, Elorm would only sleep on my lap on the hospital bed. Much to everyone's relief, the fourth time he urinated that day, it appeared normal.

Every morning, the nurses came and drew blood for laboratory tests. After a transplant, the cells are expected to start forming and growing and this was the reason for the daily blood test. Elorm's cord blood procedure had slowed down his cells growth. I struck some acquaintance with two nurses and resorted to bribing them to smuggle the detailed lab report to me as soon as it was ready. The basic laboratory report consisted of White blood cells (WBC), Red Blood Cells (RBC), Platelets, Haemoglobin (HBG) and Weight (Wt). After transplants, signs of recovery are indicated by the white blood. .

On the 27th of September, as usual, the nurse came running and smiling with the smuggled report and asked me to take a look and for the first time I noticed a growth in the white blood cells. This was the report:

WBC	0.1
RBC	3.07
Platelets	157
HBG	9.1
Wt	40

As usual, I thanked her with another bribe and just as she left the room, Professor N. entered with smiles saying, “the white blood cells are coming up; a very good sign. The healing process would be much faster.” “Thank God,” I exclaimed even though I had already seen the results. My excitement was short-lived, the WBC refused to grow as expected and for days it stayed at 0.1. On a few occasions it even went down to 0.00. Elorm was running high temperatures and vomiting intermittently. On the 25th of September, Professor N. informed me that they had detected a bug in the blood sample which was drawn in the morning and that if his temperature kept going up they would have to change the HICKMAN LINE. As they put it, the line had been colonized. By this time, Elorm had grown so weak and was mostly on morphine. That evening, Elorm called me and said, “Daddy come, I am very tired. I want to sleep on your lap.”

On the 29th of September, one of the senior nurses came to show me an x-ray of Elorm’s chest. The x-ray revealed that Elorm’s lungs couldn’t process enough oxygen. According to the nurse, this result could be an indication of a malfunctioning liver. I had observed that any time Elorm was given Vancomycin his condition got

worse and so I reported this to Professor N. and he agreed that they should stop administering it to him. A physiotherapist was assigned to massage Elorm's chest. After three days of the chest massage we were told his chest was looking much better. But the problems would not stop. We were confronted with removing the HICKMAN LINE and putting in a new one, this time on the right side of his chest. However, after the doctors had conferred they decided to put a temporary one in his groin. The new HICKMAN LINE in Elorm's groin made movement very difficult for him. He also complained about severe pain in his legs. Just three days after the doctors fitted Elorm with a new HICKMAN LINE, they informed us that they had to replace it with yet another one as the second HICKMAN LINE had also been infected. It took a lot of convincing for me to make sense of everything they were saying. Even though I had heard them, I didn't want Elorm to be put through another ordeal of fitting the HICKMAN LINE, as if the pain we were experiencing wasn't enough already. I wanted my son up and running around again so, eventually, I agreed to the procedure and we were wheeled into the surgical theatre. Although sedated before the operation, Elorm wasn't completely knocked out and kept calling for me: "Daddy, Daddy come," he said. I sat in the corridor outside the theatre and wept. When he came back from the theatre he was bleeding from his mouth and also from his chest where the line had been inserted. As usual, I asked questions every step of the way so we were fairly accustomed to the routine of Elorm's health care. One day, as a nurse was hanging up his platelets, Elorm quickly asked, "Where is the Phenergan?" The Phenergan was to be given before the platelets and the nurse



apologized for this. Even in his condition, his own attentiveness to his treatment was outstanding.

We were later transferred back to the Red Cross Children's Hospital to continue with recuperation. He had started shivering again and upon examination, the doctor asked that they stop the neupogen (stomach injection) and indeed his symptoms ceased after that. The second day a strange thing occurred. After we had prayed and were about to sleep, the nurse on duty came to examine him. Without asking any questions, she pulled the plaster covering the line on his neck and blood started oozing out. She carelessly put the plaster back. The plaster didn't stick properly, yet she left the room without a word. Since Elorm was still bleeding, I thought she had gone to get something to stop the blood. After a few minutes, I stormed out in anger only to find her sleeping in a couch. I remembered the encounter I had with that other nurse during the transplant. Could she be the same person appearing in a different form, with a different *modus operandi* aiming to harm my son? I had heard stories of hospital staff with sinister spirits that fed off the blood of innocent patients. Could she be one of them? I felt some anger welling up within me, my first reaction was to toss her over in the couch and give her a real beating but instead I shouted, "What the hell do you think you have done? Would you do the same to your child? Come and see what you have done to the boy? Do you know who I am?" I wonder what the last statement was meant to achieve. At that moment, I didn't care that that statement was the anthem of men of straw, I didn't care that I was just an ordinary Ghanaian in a foreign land because

the facilities in my country were woefully inadequate for the kind of treatment my son needed. I quickly phoned the head doctor and told him what had happened. It was late in the night but the doctor came over from home in the company of another doctor. They managed to stop the bleeding and I later saw that they were giving the nurse a dress down. She never attempted to come near us until our last day in the hospital where I deliberately gave her some of the gifts I had bought for almost all the nurses and doctors in the G1 ward. She smiled and collected the gift as if nothing had happened. I said to myself, "You agent of the devil, I have defeated you."

On one of the occasions that officials of Reach for a Dream came to visit the children at the hospital, they talked about their fun tours for the children and their families. As they interacted with the children, they shared gifts. Kids twelve years and below, received PlayStation game consoles, while the older ones received laptops. When Elorm was asked what he wanted, he said he wanted a laptop but he was told that he would get a PlayStation instead. He then told them he already had one and that if they insisted on giving him the console, he will give it out to someone else because he did not want to have two. The officials called me aside and told me what had transpired between them. They marvelled at an eight year-old boy who knew what he wanted and insisted on it. They actually asked if I had coached him to say that. They also wanted to know if he had schooled in England or in any other place outside West Africa. I answered in the negative to both questions. They were simply astounded by his confidence, but that was Elorm for

you. Reach for a Dream got Elorm the laptop he had requested, and even added a printer. They also booked us for a trip to Robben Island for whichever date we may find convenient. With his own laptop now, I went to Cavendish and bought him twelve DVDs which occupied him and appeared to ease his pains. We made progress, albeit slowly.

We had spent more time at the hospital than planned. One morning when our doctor came for his routine check, he indicated that if Elorm's progress continued at a steady rate, they would discharge us to go to CHOC House. From the CHOC house, we would report occasionally to the hospital for the necessary monitoring. That was good news but he also added that in view of Elorm's peculiar circumstance, we might have to stay in Cape Town for six more months so they could review his progress. 'What will happen to my job?' I mused. Two days later we were discharged from the ward. What a temporary relief!



Happy Dad with Elorm



Elorm



Elorm at the “Healing School”





Family picture



A day out sight-seeing in SA.



Elorm at the Red Cross Hospital





Elorm & Ntemah



Elorm wrapped in Specially Quilted Gift



Elorm at the Waterfront



Elorm Trying His Hands at Boxing



# 5

## THE PAIN AND SORROW

We returned to the CHOC House full of gratitude. I phoned my family back home and informed them about our trip being extended for six more months so the doctors could monitor Elorm's progress. My wife and I agreed that we needed to plan towards this taking into account my job. What I was certain about was that I would give up everything, including my job, to ensure my son gets well. I had often communicated my position to Elorm anytime we had our conversations. He was comforted knowing that I would be there for him no matter what. In his eyes, there was nothing he couldn't face as long as I was by his side. Day by day the bond between Elorm and I grew thicker and stronger. We talked about a wide range of issues, some of which I felt went beyond his comprehension. It was during one of such conversations that I asked him how he planned to catch up with his classmates when we returned to Ghana. He quickly reminded me that I had promised taking him to school in London. "Yes, I will, but until then you

will need to join your friends while I sort that out. You know we have been away for some time and I have to get my finances in shape before you can attend school in London,” I responded. He thought for a while and said he will collect Ntemah’s books and copy them and he will be fine in no time. “Wow, that’s the Prof,” I exclaimed and showered more praises on him. I wanted my little boy to feel good. “Remember, Daddy will do anything for you. I love you and you know Mummy loves you too.”

Elorm and I had regular morning devotions as we used to do back in Ghana, a ritual that was reinforced by the Healing School. Our morning devotions were characterized by singing and speaking in ‘tongues’. We had done this consistently over the years, even when we were ‘caged’ in the hospital ward, but of course then we prayed quietly so not to disturb the other patients. Now, I noticed Elorm was not as excited as he used to be during prayers. I tried to find out why but he would not talk about it. This situation went on till it got to a point that he would just sit down and watch me as I prayed. Then one day he asked why we prayed in ‘tongues’. I struggled to answer this question. Then, I took my bible and referred him to Ephesians Chapter 6 verses 12 to 18, stressing on Chapter 18 which reads: ‘Praying always with all prayer and supplication in the Spirit, watching thereunto with all perseverance and supplication for all saints.’ I went on to explain what praying in the spirit means. He sat and listened attentively but did not utter a word.

We were introduced to the Baatjes family by the Koorts as their stand-ins whenever they decided to take their short rest days which were normally over the weekends. The Baatjes were members of a prayer group and they extended an invitation to me so we could go and pray together. One day after convincing Elorm that I needed to go and pray for our own good, I honoured the invitation of the Baatjes. The prayer session didn't last for more than an hour. I returned to find Elorm watching television. The managers of house seemed unhappy that I left Elorm all by himself, and they actually gave me a severe reprimand. I found their reaction rather strange, so I asked Elorm if anything had happened in my absence and he said nothing had. To date, I cannot tell exactly what got them so judgmental but perhaps it is that thing they say back home in Ghana, that when you are in need, you are at the mercy of everybody.

One afternoon, the other housemates in the CHOC House decided to go shopping at the nearest supermarket. They tried convincing me to go with them but I refused. I was not prepared to pay for their shopping; an incident that had occurred a number of times before. They then invited Elorm to come along and he was happy to go. I tried to convince him to stay with me and promised to take him another time but he would not listen. He wanted to go and get some toys which I had promised to buy for him. I wanted to please him so I reluctantly gave him some money to go and buy whatever he wanted. I thought going out will be good for

him after all the doctor had advised that he should be active. This decision to allow him to go turned out to be a rather poor one; one that haunts me to date.

After waiting for over an hour for them to return, I got worried and decided to go after them. Just as I got outside, I saw them on their way back, with Elorm trudging along far behind the group. I was told that he had delayed them because he kept stopping at short distances to rest. I managed to bring him home and not long after settling down, Elorm asked to use the bathroom. When I went to check on him, I realised his urine was heavy with clots of blood which he was forcing out with a lot of pain. This continued every thirty minutes and I got very frightened. I quickly asked the managers of the house to take us to the hospital. This began another bout of our journey down the hills of extreme anguish, pain and sorrow.

His condition began to deteriorate rapidly after this episode and the doctors were obviously worried. The bloody urine did not stop and required a catheter to aid his urination. He developed an abscess on his finger which eventually had to be opened up in the theatre. He refused food and was only consumed liquids. He also started developing sores in his mouth coupled with excessive mucous. His tongue and cheeks got inflamed and therefore he could not brush his teeth. The doctors decided to feed him through his nose with a tube. This continued for some time. It was clear the doctors had come to their wits' end and they decided to treat his case as palliative. In other words, he had reached a stage where

they would have to manage him till he passes away. The bills were also mounting and we needed to act quickly. I made a few calls to some people I knew asking if they could help me financially to enable me send Elorm to UK for further treatment. How could I give up when God hadn't given up on us? All my attempts yielded no positive response. One day, I received a call from Mrs. J. Q. who told me that she had been assured by her pastor that everything would be fine. Upon her pastor's instruction, I was to write this bible quotation and put it under Elorm's pillow:

*"For the word of God is quick and powerful and sharper than any two two-edged sword piercing even to the dividing asunder of soul and spirit and of the joints and marrows and is a discernor of the thoughts and intents of the heart." -Heb. 4:12*

I obeyed and acted accordingly.

Elorm celebrated his ninth birthday in the hospital writhing in pain. On that day, I asked him what he wanted so I could buy it for him. He stared at me for a while and managed to say: '*Nothing*'. He got more than his '*nothing*'. A social worker named Shamimah surprised us that day with a birthday cake decorated with the Manchester United logo. Elorm was so excited but he couldn't even take a bite because of the pain he was going through.

On the 24th of December, there was a fire service rescue operation simulation in the hospital. It started from the top floor accompanied by a brass band, masqueraders and a gift-bearing Santa Claus. Only a few nurses were on duty and the few patients who could walk all trooped out of the ward to witness the spectacle. We could see what was going on outside through our window. Elorm could not walk but he insisted I take him to see 'Father Christmas'. I told him that was not a good idea but he was quite adamant about it. I refused to take him all the same and he burst out into tears. I got angry and yelled at him to stop misbehaving. This worsened matters as he began to wail. For a brief moment, I lost patience with my little boy and upset him even further. Later, I went to get a wheelchair and wheeled him outside. We got there just in time for him to catch Santa's eye. Santa stopped and gave him a hand. He then brought out assortment of presents hidden in various parts of his costume. The next day, Santa turned up at our ward again, bearing many more gifts for Elorm.

I had decided not to furnish my wife, Naa, with all the details concerning Elorm's deteriorating health. I didn't want to put her and the other kids through the agony we were experiencing in South Africa. Instead, I impressed upon Naa to come over to Cape Town. She arrived on 2nd January, 2009 and came straight to the hospital. I had already told Elorm his mum was coming over and when she finally arrived, Elorm burst out into uncontrollable tears as if to say; where have you been all this time while I underwent torture upon torture? We all burst out crying.



The days that followed were very difficult days for us. I was experiencing chronic headaches, and I realized I needed to take it easy. My wife and I decided to alternate our hospital sleep-overs. Naa's arrival had been a refreshing change after all; she helped in planning the way forward as well as helping me regain my composure.

I told Naa the doctors had given up on us but she did not believe me, so I told her to check their body language as they made their morning ward rounds. She could not confirm my fears because she had only been around for a few days. I had been there long enough to pick up on their tiny little gestures of despair, their subtle gazes that said we were waging a lost battle. For about a week, all the doctors ever did was repeat the same old things, which did not change anything. Elorm was deteriorating by the day. One morning I approached the senior doctor and asked him if there was anything different they could try. His response confirmed my worst fears; they were treating Elorm as a palliative case. He didn't say those exact words however, but it was clear enough for me to understand. I suggested that he release us to go back to Ghana to see if there were other options open to us. He readily began the release process. We bought a three month consignment of Elorm's medication and others necessities like catheters. Ready to go back home, we booked our flight.

At the CHOC House, there was a big book full of testimonials for guests to write about their experiences or to share any comments they had when leaving the house. So on the morning of our departure I wrote:

“What do you say when words are not enough? This has been a journey into the unknown, though our faith and confidence were deeply anchored on the Lord. It was a dark, long and slippery alley but it was time to confirm our seats and positions of who we truly are and where we belong. For us it was the building blocks of faith and communion. I will forever bless HIS name. God is good all the time. I will forever refuse to see the darker side of the world. CHOC House accommodated and fed us. Lubi and Christi were the main architects in this regard. A wonderful couple one would be proud to emulate. The sun will rise with a ‘thank you’ and it will set with a ‘thank you’ for the sacrifices you made. We will miss you and when our stories come to be written your names would definitely find space.”

As I got up, I saw the couple standing behind me. Naa and I took turns to embrace them, and they embraced Elorm, who was sitting in a wheel chair. It was an emotional departure; we all burst into tears with Elorm looking on, unable to utter a word due to his swollen tongue and cheeks. He just sat still in his wheel chair, a HICKMAN LINE underneath his shirt and a catheter strapped around his leg underneath his trouser.

Elorm had come to Cape Town walking on his own without any support. Elorm came to Cape Town a free boy, but he was now carrying a HICKMAN LINE on his chest and a catheter to help him pass urine. Elorm came to Cape Town talking and communicating intelligently with me, but now he could only do so with a lot of effort. When we got to the airport there were some of the nurses of Red Cross waiting to bid us farewell. The scene at the airport was solemn and we were all drawn to tears.

We flew from Cape Town to Johannesburg only to hear our names by the airport announcer that we should proceed quickly to board the Accra bound plane. Apparently, we had delayed the flight. Here we were with Elorm in a wheel chair so we could not run. What was even worse was the fact that the distance was a really long one and as we struggled to get to the plane, the announcer kept calling out our names. When we eventually got to the plane, they did not have any means of lifting Elorm unto the plane. While panting for breath, I carried Elorm in my arms unto the plane, making sure not to disengage the Hickman line and the catheter. I did not know where the strength came from but for me it still remains a miracle upon reflection.

We arrived in Ghana and were met at the airport by family members and Ntemah's family. I saw Elorm's face brighten up on seeing family members and Ntemah and that gave me some comfort. I could clearly see question marks on their faces as they could not communicate with Elorm who was sitting in a wheel chair.

Naa took him to Korle-Bu the following day and I stayed behind to plan another trip preferably to the UK. I was not prepared to give up. Quoting from Nelson Mandela's book, *Long Walk to Freedom*:

*"I am fundamentally an optimist. Whether that comes from nature or nurture, I cannot say. Part of being optimistic is keeping one's head pointed towards the sun, one's feet moving forward. There were many dark moments when my faith in humanity was sorely tested, but I would not and could not give myself up to despair. That way lay defeat and death".*

# 6

## THE EXODUS

When we arrived in Accra from Cape Town, I was worn out. A hot shower and a nap would have done me a lot of good, but there was no time to relax. It was 8pm the next evening when my phone rang. It was my sister on the other end of the line. She was at the Korle-Bu Teaching Hospital with my wife and my sister-in-law. Her tone was unusually subdued and I could hear someone in the background praying in ‘tongues’ and clearly sobbing.

“The doctor would like to see you as soon as possible,” she managed to say.

My heart nearly missed a beat.

What could be happening that three adults could not handle? Is he gone? No, this cannot happen to me. We have come too far for this to happen. I started repeating to myself the words: *My son cannot die! My son cannot die!* So many thoughts started running through my mind.

In my confused state, I jumped into my car and started driving towards Korle-Bu Hospital. Strangely, the traffic was heavy especially for that time of the night. Perhaps things had changed while I was away, I mused. I struggled to keep awake during that drive, yawning heavily and dozing off behind the wheel. Anytime the traffic started easing, I was awoken by the loud honk of the vehicle behind me. I tried not to sleep but I was helpless even with the gum I was chewing. I was completely drained - body and soul.

It was past 10pm and pitch dark when I got to James Town. I decided to use the road that run alongside the beach to the hospital. It was the most straightforward route. I almost run into a blockade as I couldn't see even a metre ahead of me in the darkness. The road had been blocked because of ongoing construction work. In my confusion, I tried to reverse but that was an uphill task as both sides of the road had deep trenches. I wanted to get down and see how I could manouevre my way out of the entanglement I found myself in. I was slightly apprehensive because I could not see a thing around me. I sat in my parked car for a while, pondering my next move. Suddenly, there was a hard knock on my car from the passenger side and the chills that run through me felt like death. I froze instantly thinking something sinister was about to befall me. I rubbed my eyes to make sure I was seeing well but the fog from the sea breeze was not helping the situation. After a second of heavy staring though, I was quite certain of what I could see; a human being, an old man with white loin cloth strapped from one shoulder to barely the knee and holding what looked

like a walking stick. He looked as though he was beckoning me to get down. I ignored him and checked to see if my car doors were firmly locked. After a few long minutes, he got in front of the car and removed one of the barricades and signalled me to use that opening to reverse or so I thought. Who was this and what was he up to? An inner voice told me to follow his instructions and I did, after all, I was between the devil and deep blue sea. As I moved the car forward, I saw him raising his hand signalling me to stop. I obeyed. He moved to the back and asked me to reverse. I obeyed. This back and forth motion continued for a while, until I was able to reverse fully. I was now confronted with the man standing directly in front of the car. I attempted lowering the side glass to give him some money or just to say thank him. Upon second thought, I sat still watching his next move with the car doors still firmly locked. I could clearly see him now in the shadows of my blazing headlights. He looked very frail with unkempt grey hair and a beard. He was barefooted. He moved to one side and signalled me to pass, smiling to reveal an empty gum save for two or three giant-looking teeth. I drove past him and stopped a few metres away. I was beginning to feel guilty for not even saying a word to him. Impulsively, I got down with some money in my hand which I was going to throw at him and quickly jump into the car and drive off, but he was gone!

I drove in silence asking myself repeatedly: Was he a human being, a ghost or an angel? I did not believe what I was going through and before I realized I was climbing the stairs to the third floor of the children's block. Now, I could clearly hear the 'tongue' speaking

and the voice was a very familiar one. It was Naa in the corridor leading to the ward. She did not stop even when she saw me and I also did not attempt to interrupt her. She had been asked by the doctors to stay away from the ward, I was later told. I was very confused but I headed straight to the ward where I saw two doctors desperately pumping oxygen to revive Elorm. My sister-in law, Mabel stood a few metres away watching in anxiety and murmuring to herself. The doctors upon seeing me heaved a big sigh of relief and seemed to have stopped what they were doing. Elorm's eyes were opened but he hardly moved. I saw him smile and a few seconds later his eyes closed. He had given up; he was no more with the living. The 'Professor' died at 11:27pm. I quickly lifted him up and embraced him tenderly, kissing his forehead as his mother always did before he went to sleep. I put him back on the bed and turned to the doctors, one of them had been with us all along this tortuous journey.

"He was calling your name and I think he was satisfied seeing you before finally closing his eyes."

"Maybe, he wanted to say thank you and good-bye," the other doctor chipped in. I turned round to look at the motionless body on the bed. His HICKMAN LINE was still stuck to his chest and his catheter down below. There was complete silence in the hospital ward for a while as none of us spoke.

Staring at his lifeless body, I had a vivid recollection of a dream I had the night before. In the dream I saw the 'Prof.' in his favourite



Manchester United jersey busily playing football alone in a desolate place and yet he looked so happy. Then out of nowhere many children of his age rushed and carried him shoulder high. I shouted at them to let him down because he was unwell but they would not listen. I was angry and desperate, so I rushed to rescue him only to realize that it was a dream. I wondered what this dream meant. I did not give it much thought then because I was too tired to think. Was it a revelation of what happening now? What about the old man who helped me and vanished into thin air? Was he an angel? No, God did not hear my prayers so why would He send an angel? I found myself questioning the existence of God. What about the generous offerings and tithes I had given at church? I thought those were meant for God to rebuke the devourer for my sake as the bible teaches us in Malachi 3: 10-12. Indeed, ever since he was diagnosed with the disease, all my offerings and tithes had been accompanied by a petition to God to heal my son. Why did He not hear me? Why should a child suffer so much and eventually die? Why me? Our society is able to accept infirmity in old people but it goes against all our dreams, hopes and wishes when a child becomes ill; why my child? Why? Why? Why? I was desperate for answers but they were not forthcoming. Then my thoughts shifted to the beginning of our journey.

Elorm had shown remarkable bravery and exceptional tenacity from the age of four when he was diagnosed with Acute Lymphoblastic Leukaemia (ALL) till he passed away at nine years, thirty seven days. He was an exceptionally intelligent boy, full of

wits and bravery. Even at that tender age, he was not afraid to speak his mind, a trait that runs through the family. He was a deep thinker by all standards. He understood the degree of his ailment and the only way he could live life fully was to boldly face all those numerous surgeries – an endeavour frightening to even adults like me. As I looked at the doctors for the next step, I tried very hard to suppress my tears, but I was unsuccessful. My tears flowed freely as I was joined by Naa and my sister-in-law Mabel. This had indeed been a long and painful journey ‘home’ to his maker. Why should a young boy of his age who has committed no sin suffer so much? Did he have to go through all that and eventually die? This is certainly a path no child should ever walk. According to his doctors, he suffered from Acute Lymphoblastic Leukaemia (ALL) but he died of Hemorrhagic Cystitis.

In Plato’s allegory of the metals, the philosopher classified men into groups of gold, silver and lead. Elorm was pure gold; there was gold in his intellectual brilliance, gold in his capacity to endure, gold in his smile and humanity.

I have lost a son, a bosom friend and a companion.

Indeed the nation and the world has lost one of its future leaders.

# 7

## WHO KILLED THE PROF?

After Elorm's death, I began asking myself questions about God, my actions and inactions, human existence and the meaning of life. As I kept asking about the reality of God, I saw this quotation:

*To have God in our lives does not mean sailing on a boat with no storms. It means having a boat that no storm can sink.*

But this is a child God should have saved, I insisted. A few minutes later, I saw a magazine with this poem:

### *And God said No!*

*I asked God to take away my pride. And God said, "No". He said it was not for Him to take away, but for me to give it up.*

*I asked God to make my handicapped child whole. And God said, "No". He said, his spirit is whole, his body is only temporary.*

*I asked God to grant me patience. And God said, "No". He said that patience is a by-product of tribulation, it is not granted, it is earned.*

*I asked God to spare me pain. And God said, "No". He said suffering draws you apart from worldly cares and brings you closer to me.*

*I asked God to make my spirit grow. And God said, "No". He said I must grow on my own, but He will prune me to make me fruitful.*

*I asked God to give me a child. And God said, "No". He has already given me HIS son.*

*I asked God if loved me. And God said, "Yes". He gave me His only SON who died for me, so I would be in heaven someday because I believed.*

*I asked God to help me love others as much as He loves me. And God said, "Ah, finally you have the idea."*

I stood still pondering over this but that did not stop me from asking the question, "Can a "No" also be an answer from God?"

2nd Chronicles 7:14 says,

*'If my people, who are called by my name, will humble themselves and pray and seek my face and turn from their wicked ways, then will I hear from Heaven and will forgive their sin and will heal their land'.*

As believers we have been taught that the land could mean our bodies. Why did God not heal his body after all that he went through? Why did the doctors in Tema tell me it was viral when it was not? Why did

I not agree to take him to Korle-Bu Teaching Hospital and instead chose the more convenient option of 37 Military Hospital? Why were the doctors at 37 Military Hospital of all places not able to make the right diagnosis but kept us going there for months till the disease got to an advanced stage? What about those who gave him the Diploma Certificate? Why did they not see anything? Why did I not seriously consider the thoughts of Mr. S.B when he asked, “Have you seriously thought through the transplant?” Why did the Professor administer a cord blood that was not a perfect match? Why did I not ask the Professor to keep searching for a better match? Did those nurses whom I described as sinister in the wards have something to do with this? The bigger question which keeps haunting daily is “Why did I allow him to go to the shopping centre in the company of strangers? Did they force him to overwork himself, hence the bleeding? Why should this happen to me? Did I live up to my responsibilities as a father or could I have done better? What about the Healing School? Was it beneficial at all or even real? What about the many pastors and prophets who told us everything was going to be okay? Did we do something wrong for the disease to relapse when he went into remission? Maybe I should have taken him to the UK to continue treatment the first time he got into remission. Why? Why? Why?

On his tomb are his two favourite hymns and the inscription:

**'Professor' Elorm Kobla Aveh**

21/12/1999 – 27/2/2009

My hope is built on nothing less  
Than Jesus' blood and righteousness  
No merit of my own I claim  
But wholly lean on Jesus name.

Chorus: On Christ, the solid rock I stand;  
All other ground is sinking sand.  
All other ground is sinking sand.

**Catholic Hymn 376**

Take my life and let it be  
Consecrated, Lord to thee;  
Take my moments and my days,  
Let them flow in ceaseless praise.

Months after Elorm's death, I could not help but ask God some serious questions and my faith in God began to wane until I read this piece:

"Everything that happens to you is directed by God. Sometimes we do not understand Him; yet His choices are the best for our lives. If God were to reveal the acts 'behind the scenes' to us, we would be screaming our heads off asking Him to stop. Marilyn Monroe said,

‘I believe that everything happens for a reason. People change so that you can learn to let go, things go wrong so that you appreciate them when they are right; you believe lies so you eventually learn to trust no one but yourself and sometimes, good things fall apart so better things can fall together’.

A survivor of the 9/11 attack, Lauren Manning says she is alive because she was late for a meeting on that fateful day. If everything had gone right she would have been on the 105th floor by the time the plane hit it. But because she was late, a fireball raced down the elevator shaft in which she was riding and shot her back out. She suffered more than 80% burns, but she is now well and thankful to God that she can walk with her 5-year-old son in the park and even run after him.

For every disappointment, my brethren, know that God has another appointment for you so never despair.





# 8

## WHAT EVERY PARENT SHOULD KNOW ABOUT CANCER

Courtesy the South African Childhood Cancer Study Group, the St. **SILUAN**, the following are early warning signs of cancer in children:

- |                      |   |  |
|----------------------|---|--|
| <b>S-Seek</b>        | : | Seek medical help early for persistent symptoms.   |
| <b>I-Eye</b>         | : | White spots in the eye, new squint, blindness, bulging eyeball.                              |
| <b>L-Lump</b>        | : | Lump in the abdomen and pelvis, head and neck, limb, testes and glands etc.                  |
| <b>U-Unexplained</b> | : | Unexplained fever, loss of weight and appetite, pallor, fatigue, easy bruising and bleeding. |

**A-Aching** : Aching bones, joints, backaches and easy fractures.

**N-Neurological:** Change in behavior, balance, gait and developmental milestones, headache and enlarged head.

The above listed symptoms are not exhaustive but these are the signs that parents can look out for.

# 9

## NUTRITIONAL REQUIREMENTS FOR A CHILD WITH CANCER

**(By the Children's Hospital of Pittsburgh)**

The importance of good nutrition:

Good nutrition is very important for children being treated for cancer. Children with cancer often have poor appetites due to one or more of the following:

- The hospital environment
- Side effects of chemotherapy and or radiation
- Depression
- Changes in the cells of the mouth which may alter the way food tastes
- Side effects from medications
- Inadequate absorption of calories, vomiting and diarrhoea

Poor nutrition contributes to poor growth. If a child with cancer maintains adequate nutrition, then he/she may be more likely to:

- Better tolerate chemotherapy or radiation and with fewer side effects
- Heal
- Grow and develop
- Maximize quality of life.

### **Special diets for children with cancer:**

Children with cancer often have increased calorie and protein needs. Protein is needed for growth and to help the body repair itself. Getting enough calories can help the body grow, heal and prevent weight loss. If your child is having trouble eating enough calories and protein, your child's physician or dietician may suggest serving high-calorie and high-protein foods (i.e. eggs, milk, peanut butter and cheese).

Sometimes, even when high-calorie and high-protein foods are offered, children with cancer have trouble eating enough. Tube feedings may be necessary to help provide your child with adequate nutrition or to prevent malnutrition. This involves placing a small tube (called a nasogastric or NG tube) through the nose, down the oesophagus and into the stomach. A high-calorie formula or supplement can be given to your child through this tube to help promote appropriate growth and development.

Children undergoing treatment for cancer sometimes need total parental nutrition (TPN) to help meet their nutritional needs. TPN is a special mixture of glucose protein, fat, vitamins and minerals that are given through an IV into the veins. Many people call this “intravenous feedings”. TPN provides the nutrients your child may need when he/she cannot eat or absorb the nutrients from foods. The TPN solution is usually infused continuously over several hours of the day.

### **Managing treatment side effects and maintaining proper nutrition:**

Your child’s cancer treatment (chemotherapy, radiation and surgery) may cause side effects that make it difficult to eat enough food. The following are some of the side effects and ideas on how to manage them:

#### ***Poor appetite:***

- Try smaller, more frequent meals and snacks.
- Try changing the time, place and surrounding of meals.
- Let your child help with shopping and preparing meals.
- Offer high-calorie, high-protein meals and snacks.
- Avoid forcing your child to eat--this may make your child’s appetite worse.
- Make meal time a happy time.

### ***Mouth Sores:***

- Use soft foods that are easy to chew.
- Avoid foods that may cause irritation to the mouth including the following: citrus fruits (i.e., orange, tangerine, and grapefruit), spicy or salty foods, rough, course or dry foods (i.e. raw vegetables, crackers, toast).
- Cut foods into small pieces.
- Serve foods cold or at room temperature-hot foods may irritate the mouth and throat.
- Use a blender to make foods softer and easier to chew.
- Add sauces or gravies to food to make them easier to swallow.

### ***Taste changes:***

- Offer salty or seasoned foods.
- Use flavourful seasoning on foods
- Try serving foods at different temperatures.
- Offer foods that look and smell good.
- Keep your child's mouth clean by rinsing and brushing.

### ***Dry Mouth:***

- Try sweet or sour foods and drinks such as lemonade.
- Offer hard candy, popsicles or chewing gum.
- Offer softer foods that may be easier to swallow.
- Keep your child's lips moist with lip balm.

- Offer small, frequent sips of water.
- Offer foods that have more liquid in them.

### *Nausea and vomiting*

- Try easy-to-digest food such as clear liquids, gelatine, toast, rice, dry cereals and crackers.
- Avoid foods that are fried, greasy, very sweet, spicy, hot or strong-flavoured.
- Offer small, frequent meals.
- Offer sips of water, juices, sports drinks or other beverages throughout the day.

### *Diarrhoea*

- Try to avoid high-fibre foods including the following: nuts and seeds, whole grains, dried beans and peas, raw fruits and vegetables.
- Try to limit greasy, fatty or fried foods
- Limit gassy foods, including the following: beans, cauliflower, broccoli, cabbage, onions.
- Offer small, frequent meals and liquids throughout the day.
- Limit milk and milk products if lactose intolerance is a problem
- Drink plenty of liquids throughout the day.

### ***Constipation:***

- Include high-fibre foods, including the following: whole grain breads and cereals, raw fruits and vegetables, raisins and prunes
- Drink plenty of fluids; hot drinks are sometimes helpful.
- Keep the skin on vegetables when cooking them.

### ***Tooth decay:***

- Use a soft tooth brush and take your child to the dentist regularly.
- Encourage rinsing the mouth with warm water when gums and mouth are sore.
- Encourage brushing of teeth after eating meals and sweets.
- Limit foods that stick to the teeth such as caramels, taffy, gummy candy or chewy candy bars.
- The treatment of cancer can be difficult for anyone of any age. Supportive care (treatment of the side effects or symptoms of the disease) from the various members of the healthcare team, including dieticians and child life therapists, can make the nutritional aspects of treatment less difficult.
- Every child is different and every child tolerates treatment differently. Your child's physician and healthcare team will discuss the best method of promoting a healthy nutritional status during your child's treatment.



**Below is one of the speeches I delivered at the International Press Centre on World Child Cancer Day which falls on 15th February every year.**

Good morning Mr. Chairman, ladies and gentlemen of the Press. As we speak to you now, many children are dying of cancer. Many families are being torn apart as a result of the devastation brought about by the news of a diagnosis. For these families and even most of us here, cancer means nothing but death. The good news is that cancer is curable if detected early and the treatment protocols are duly followed. The bad news is that the cost of treatment is prohibitive and only few people can afford. We all know the low levels of income in this country. The result is that many families abandon treatment and allow fate to take its course. This is an unacceptable situation as it amounts to injustice and discrimination. Many potential future leaders die needlessly. Let us remember that these children and their families do not bring the suffering of cancer like malaria or other diseases upon themselves. It could happen to any of us here. This situation is compounded by the fact that the National Health Insurance Scheme (NHIS) does not cover the very essential drugs, and even with those covered by the scheme, the pharmacies in Korle-Bu Hospital do not accept the NHIS. Therefore, parents are still forced to look for money to buy all drugs. We are therefore appealing to the government to immediately look into this as a matter of utmost urgency.

Currently, the children with cancer occupy two side wards in the main ward at the children's block of the Korle-Bu Teaching

Hospital. The ideal thing as pertains in other countries is for them to have a separate ward due to their low immunity levels brought about by the chemotherapy and radiation treatment. The parents are forced to “perch” there as well which is most unfortunate. We are using this platform to appeal strongly to corporate Ghana and the world to join forces with GHAPACC to put up a hostel at Korle-Bu where parents who come from outside the capital and do not have relatives in Accra could sleep while they take care of their children at the ward. Fortunately, the management of Korle-Bu have agreed in principle to give us land for this purpose.

The International Society of Paediatric Oncology (SIOP) and the International Confederation of Childhood Cancer Parent Organizations (ICCCPO) joined forces at the First United Nations High-Level Meeting in New York last week on the Prevention and Control of Non-Communicable Diseases highlighted the urgent need to address the fight against cancers of children and young adults worldwide. The two organizations represent over 1500 paediatric oncology medical professionals and 138 parent support organizations, like the Ghana Parents’ Association of Childhood Cancers (GHAPACC), from countries all over the world accounting for over 84% of the global population.

Parents of children with cancer are demanding our government to take on board fully, the treatment of childhood cancer. This would engender a message of hope for children with cancer and their families. We are seeking political commitment and swift action from our government to address the challenges and struggles that

children with cancer and their families are confronted with each and every day. The time to act is now to save our future leaders! Complacency on the part of decision-makers will only exacerbate the situation, especially in low and middle-income families. Cancer in children is but a fraction of the global cancer burden, but for children with cancer and their families, it is the difference between life and death, hope and despair.

Each year 175,000 children worldwide are newly diagnosed with cancer, of which an estimated 90,000 will die from the disease. At the end of today, some 250 children around the world will lose their lives to cancer. These numbers are staggering given the fact that 70% of all childhood cancers are curable. Cancer is the second leading cause of death among children in developed countries. While eighty percent (80%) of children with cancer survive in wealthier countries. The reality is vastly different for those who live in resource-challenged settings where 80% of all children with cancer do not live and where knowledge about childhood cancer remains limited. Childhood cancer is often detected too late for effective treatment and is often compounded by very limited access to appropriate treatment and care, resulting in approximately eighty percent (80%) of them dying.

Ladies and Gentlemen of the Press, this is the reason for calling you here today. We know of the influence of the press and the role you can play in our struggle. Please join hands with us in this fight for a better Ghana for our children who through no fault of theirs suffer this disease called cancer. Most of us parents here, who have

lost our children through cancer or have been cured, have a stake in helping better the lot of mankind and to put our experience at the disposal of our unfortunate brothers and sisters whose children are still undergoing treatment. Posterity would not forgive us if we fail to attract the needed response from government and the world around us immediately. The Chinese have a saying that “many little things, done by many little people, at many little places can change the face of the world”

Thank you for coming.

## **CHILDHOOD CANCER CAN BE BEATEN**

**(Published by Daily Graphic and Ghanaian Times)**

Today, the 15th of February is International Childhood Cancer Day – a day in which the strength, courage and resilience of children with cancer and their families are celebrated.

The International Society of Paediatric Oncology (SIOP) and the International Confederation of Childhood Cancer Parent Organizations (ICCCPO), with Ghana Parents' Association for Childhood Cancers (GHAPACC), will be reaching out to communities, schools, hospitals and the public in general. Parents will be working alongside paediatric oncologists, paediatricians, nurses, public health advocates and others in disseminating vital and life-saving information to raise awareness about childhood cancer.

GHAPACC, SIOP and ICCCPPO are calling on governments worldwide including the government of Ghana to commit in winning the fight against childhood cancer. These include the access to affordable “best standard of care”, including programs for early detection and the adaptation of treatment regimens from resource-rich settings into developing countries. SIOP and ICCCPPO represent over 1500 paediatric oncologists and 158 parent support organizations, representing nearly 85% of the world’s population.

The field of paediatric oncology has matured significantly since systematic therapy for childhood cancer became available in the 1950s. In the industrialized world, five year survival has improved continuously from less than 20% in the 1960s to 80% at the turn of this century, with the expectation that most children with cancer will now be cured. The challenge remains in resource-poor settings, notably in low and middle-income countries such as Ghana where the majority of children with cancer live. Children with cancer continue to lose their battles in these countries due to the fact that programs for early detection, treatment and management are simply not available. Despite the fact that simple deliverables such as early warning signs have already been proven in wealthier countries, it has been observed that by adapting treatment regimens, the gap in cure rates would close. Cure rates for children with acute lymphoblastic leukaemia (ALL), for example, are 80-85% in high-income countries while much lower in resource-poor countries.

Case studies in Brazil, the Dominican Republic and Guatemala have clearly demonstrated that by adapting ALL protocols in North America and Western Europe, child survival rates significantly improved. Moreover, public education and awareness campaigns have successfully increased the rate of early diagnosis, even in low-and middle-income countries. Children and young people can be spared from some of the effects of the most intensive treatments if their cancers are diagnosed early enough and treatment begun early enough. In Honduras, for example, an inexpensive national awareness campaign was associated with the decrease in retinoblastoma that had spread beyond the eye from 73% to 35%.

SIOP President Gabriele Calaminus, a paediatric oncologist herself, explains that “the evidence is there. What are we waiting for? Thousands of lives can be saved if we act now! But, governments themselves must take the responsibility for their own people. The Alma-Ata Declaration has documented the need for “Health for All” more than 30 years ago stating that all people must have access to health services. The fact is, in 2013, this remains a target and not the reality”.

Kenneth Dolman, the president of ICCCPPO and a parent of a childhood cancer survivor notes, “I have had a personal experience where a child was initially misdiagnosed through a lack of knowledge. ICCCPPO members and partners are committed to supporting any project in the world that will lead to the early diagnosis of childhood cancer and already enjoy the support of

many forward-thinking governments. It just makes economic sense for governments to support such awareness and early detection projects and not only save on the extra costs of treating a patient with late stage cancer, but also to spare the heart-ache and suffering of its citizens.”

Both organizations are hopeful and optimistic that with the support of sister health NGOs and international health agencies such as the World Health Organization, the fight against childhood cancer, especially in regions where the needs are greatest, is at a major turning point for the better.

Childhood cancer experts will be meeting in Hong Kong on 25-28 September during the 45th SIOP World Congress, to follow-up on implementation plans.

## **GHAPACC**

The Ghana Parents’ Association for Childhood Cancers (GHAPACC) is an affiliate of ICCCPPO and was formed in 2009 by parents whose children have been affected by one form of cancer or the other. Other members include doctors, nurses and other well-meaning Ghanaians who have pledged their time and resources to see to the alleviation of suffering of children diagnosed with cancer. Since its formation, GHAPACC apart from its advocacy role, has organized a series of activities designed to raise public awareness about the early warning signs of cancer. Posters illustrating these signs have been developed together with the Ghana Health Service with funds provided by Africa Oxford

Cancer Foundation and World Child Cancer. It is known that early detection and treatment are key to survival. Recently, GHAPACC in conjunction with the oncology doctors at Korle-Bu interacted with the management and children of Queensland International School. The school later donated equipment worth over 30,000 Ghana Cedis to the oncology unit of Korle-Bu Hospital. This was realized through a sponsored walk by the school children. Through GHAPACC, other organizations that have contributed to helping the ward include Graphic Communications Group, Kasapreko Distilleries, and Multichoice, MaaSherawali (India Women's Association in Ghana), other spirited individuals and organizations. We are grateful to all others such as International Central Gospel Church who on their own accord have contributed immensely to the childhood cancer unit. GHAPACC and the oncology doctors at Korle-Bu children's block are planning a nationwide education/sensitization programme with the schools as primary focus.

Another area of concern is accommodation difficulties that parents face when they are referred from all over the country to Korle-Bu. GHAPACC with the support of management of Korle-Bu plan to build a hostel near the hospital. Corporate bodies, churches and the general public are being called upon to support this noble cause. Countries like South Africa and others have similar facilities to temporarily house parents whose children are on admission at the hospital.



## GOOD NEWS

The Daily Graphic on Wednesday February 6th (page 32), carried a news item to effect that the Government of Ghana was going to include the treatment of Cancer on NHIS. This is welcome news. This is what GHAPACC had been advocating all these years. We feel a sense of achievement. We are happy, parents will be very happy and the children will forever be grateful to our policy makers. They will not die needlessly. They hope to see tomorrow and have the chance to be called future leaders like other children. The truth is that cancer treatment can be very expensive and only few families can bear the cost. Most parents abandon treatment of their children for lack of funds. They are forced to come back to the hospital when the situation becomes very difficult to treat. Can we blame them? Thank you Government of Ghana! We pray this happens very soon.

Let us look out for these early warning signs, it may be cancer:

**S - Seek:** Medical help early for persistent symptoms

**I - Eye:** White spots in the eye, new squint, blindness, bulging eyeball

**L - Lump:** Abdomen and pelvis, head and neck, limb, testes, any part of the body.

**U - Unexplained:** Fever, loss of weight and appetite, pallor, fatigue, easy bruising and bleeding

**A - Aching:** Pains in bones, joints, back and easy fractures

**N - Neurological:** Change in behaviour, balance, gait and developmental milestones, persistent headache, enlarged head.

Remember, **CHILDHOOD CANCER CAN BE CURED.  
EARLY DETECTION IS IMPORTANT.**

This article is dedicated to the souls of all children who have died through cancer.

# 10

## TODAY IS WORLD CHILDHOOD CANCER DAY

(Published by the Daily Graphic)

Today the 15th of February is World Childhood Cancer Day. This is a day set aside to remind the world of the plight of children affected by cancer. The International Confederation of Childhood Cancer Parent Organisations (ICCCPO), World Child Cancer and the Union for International Cancer Control (UICC) have issued a joint statement to coincide with International Childhood Cancer Day highlighting the fact that these organizations are joining forces in the fight against a lack of awareness on childhood cancer.

Although cancer in children is a small fraction of the global cancer burden, most of them can be cured if prompt and essential treatment is available. Approximately 80% of the cancer deaths occur in resource-constrained settings as appropriate and affordable

treatment is not available or while strides have been made in the treatment of childhood cancer and subsequent improvements in survival rates, it is unfortunate that this has not reached the majority of children diagnosed with cancer annually.

“To improve upon this situation, ICCCP, World Child Cancer and UICC are developing international medical partnerships to improve diagnosis and treatment. Through the sharing of vital expertise and skills and the utilisation of valuable support from doctors in resource-rich countries, these combined efforts are already saving lives and reducing suffering,” says Julie Torode, deputy CEO, UICC. In the developed world children on average have a 75% chance of surviving cancer, however the situation in low- and middle-income countries, which accounts for 80% of the global incidence of childhood cancer, is very different, with only 20% of those that do receive treatment surviving as appropriate treatment is not available or affordable.

“The majority of children in the world who suffer from childhood cancer will die undiagnosed. This is largely due to the lack of awareness that some cancers are curable, poor access to information, late or no detection and lack of effective treatment,” says Benson Pau chairperson of ICCCP.

“This year ICCCP, UICC through the “My Child Matters” initiative and World Child Cancer will be supporting more than 40 projects in resource-constrained countries that will concentrate on the training of medical staff, the provision of infrastructure

and the support of the ill child and their family,” says Gordon Morrison, chairman of World Child Cancer.

Today, organisations from across the globe will be participating in International Childhood Cancer Day, to raise awareness of the plight of children living with cancer and the imbalances that exist between the quality of care provided to children with cancer in the developed world as compared to those in developing countries.

### **NHIA EXPLAINS**

It is one of the saddest experiences to witness children and their parents in countries such as Ghana unable and unmotivated to fight the battle any longer, just waiting in despair for the inevitable to happen, knowing that with funding from those able to help, the outcome could be so different. A visit to the Korle-Bu Teaching Hospital Children’s Block will tell you the story better; faces of parents portraying nothing but hopelessness and dejection. Their children diagnosed with cancer in the ward are crying for help from government and society. They seem to be asking if they are also part of the so-called future leaders. Why have they been neglected with all kinds of unacceptable explanations? The February 2nd edition of Daily Graphic, page 49 carried a kind of explanation by the Deputy Director of Strategy and Corporate Affairs and the Public Relations Manager of the National Health Insurance Authority (NHIA). I will not attempt to reply except to remind them about what humanity stands for and the fact that anyone can become a victim tomorrow. How many children are we talking about and what are the amounts involved which they claim

will collapse the scheme? Again are we saying that those children who through no fault of theirs find themselves affected by cancer should die because Ghana cannot take care of them? Let me also remind all those who think we cannot do anything for these unfortunate children that some countries that do not even have the kind of resources we have are taking care of their future leaders in this regard. The approach therefore is for us to find innovative ways of funding childhood cancer and not to throw our hands in the air in despair.

## **SIOP AFRICA**

From the 21st to the 23rd of March, the International Society for Paediatric Oncology (SIOP) Africa will be holding a conference in Cape Town, South Africa under the theme “Celebrating African Excellence”. This is a conference held every two years which brings parent groups, support groups, childhood cancer survivors, nurses and the medical experts together to brainstorm on how to improve cancer care and other related concerns. The world is moving forward and we must also do same. The Ghana Parents Association for Childhood Cancer is at the forefront in awareness creation and advocacy. It will be appropriate to bring to the attention of the Government of Ghana the need to train more oncology doctors and nurses, not to mention the urgent need to improve the facilities at the oncology ward.

On this occasion, I would like to thank organizations like Graphic Corporation, International Central Gospel Church, MultiChoice, Kasapreko and other individuals who have in the past contributed

and are still contributing to the cost of treatment for these children. Let us look out for these early warning signs, which may be cancer:

- S-Seek** : Medical help early for persistent symptoms
- I-Eye** : White spots in the eye, new squint, blindness, bulging eyeball
- L-Lump** : Abdomen and pelvis, head and neck, limb, testes, glands
- U-Unexplained:** Fever, loss of weight and appetite, pallor, fatigue, easy bruising and bleeding
- A-Aching** : Bones, joints, back and easy fractures
- N-Neurological:** Change in behaviour, balance, gait and developmental milestone, headache, enlarged head.

This article is dedicated to the souls of all departed children who have died through cancer.

