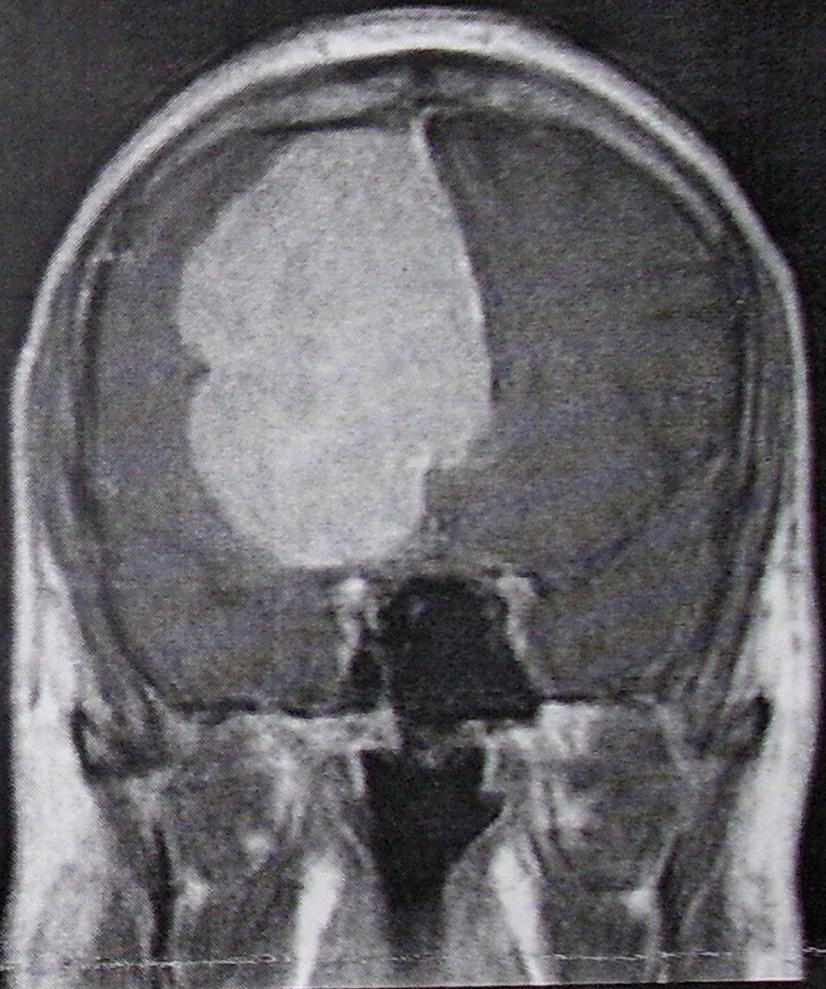


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Michael G. Simon

Objects for Deployment

Michael G. Simon

Objects for Deployment

veteransbookproject.com

Preface

This book reflects on my experience. I want to share it to help others better understand what a brain injury is, and how it can often be a hidden injury.

It includes my two experiences within the VA medical system - one that was totally demeaning, and one that was very productive. In fact, it is the latter experience that has given me the ability to live a productive life again. It has also given me the opportunity to tell my story through The Veterans Book Project.

I feel that veterans deserve the best care and that the VA is a good system. I have met some of the best people here. I feel that the Polytrauma Rehabilitation model of care reflects the very best that the VA has to offer.

THE HIDDEN INJURY

Introduction

On August 27th, 2008, my life changed forever. It had been progressively falling apart. I lost a lucrative sales job in the civilian workforce with a respected technology company. My military career with the Minnesota Army National Guard was in a complete downward spiral. And my stepsister, Sarah, had unexpectedly passed away. My family and friends did not understand me. Last, but not least, my wife was going to leave me. Things couldn't get worse. Or so I thought.

I had been locked up three times at the psychiatric ward of the Minneapolis VA Medical Center after being diagnosed with bipolar and attention deficit disorder by a VA psychiatrist. He prescribed lithium and Ritalin. But these didn't help my anxiety, stress and fear. My behavior was still erratic and impulsive. My life got worse before it got better.

The real cause was finally discovered when a different doctor ordered more specific tests: I had a nine-by-twelve centimeter frontal lobe brain tumor. The hidden injury.

Chapter 1: Growing Up, Education, Career and Joining the Guard

I grew up in Columbia, Missouri and went to college at Gustavus Adolphus College in Saint Peter, Minnesota. After working a series of sales jobs and getting my MBA, I enlisted in the National Guard in February 2003. After Basic Training and Advanced Individual Training (AIT), I became a 31C, otherwise known as a radio operator and maintainer.

By August 2005, I was balancing my Guard duties with a civilian sales job and talking with my girlfriend, Marno, about getting married. A call came through from the National Guard office. I was told that I had been reassigned to G Company 134 BSB out of Saint Peter, Minnesota as part of the 1st Brigade of the 34th Infantry Division. I was told not to contact any newspapers or other media outlets. In other words, I was getting deployed. I, along with twenty-five hundred other guardsmen in Minnesota, and fifteen hundred from other states, were getting pulled out of our lives for eighteen months. We had six months of training and a year of deployment somewhere in Iraq. I had less than thirty days to get my affairs in order.



Chapter 2: Deployment

This was stressful on my relationships with Marno and my family. I was in denial for the first couple of days before I accepted it as reality. Shortly thereafter, during a quick trip home to Missouri, I proposed to Marno. We were eventually married on New Year's Eve 2005, mid-way through my six-month training at Camp Shelby in Biloxi, Mississippi.

I served with the Golf Company out of Saint Peter, Minnesota. While deployed, I worked a variety of jobs, including in the Armament and Communications Shop, on the Sanitation Security Team – where we provided security for the sanitation, pump and garbage trucks going to and from dump sites – and in the Base Defense Operations Center, my favorite post, where I was a radio telephone operator.

The tumor was in my head for a while. Its eventual rapid growth can be attributed to two things: my prolonged exposure to uranium via ammunition, which I handled on a fairly frequent basis, and stress of the combat environment. I have heard through the grapevine that I am not the only service member who has suffered from this. This is quite similar to the service members who were exposed to Agent Orange in Vietnam.

Originally, I was scheduled to be deployed for 18 months, however at month sixteen, Bush's plan for a troop surge in Iraq was rolled out, and we were extended by four months. This didn't come as a complete surprise. There had been rumor of a possible extension before the decision was official. On July 21st, 2007, twenty-two months later, I got off the bus in Saint Peter, Minnesota, and saw my family again. I was home.





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Chapter 3: After Deployment

My wife noticed a change in my behavior within the first few weeks after I got home. My first major blowup came on our belated honeymoon to Spain. We were outside the Guggenheim Museum, and I had slipped and dropped my camera. The display screen cracked and I got angry. I threw it to the ground. The outburst embarrassed me and scared Marno. She told me that I needed to see someone about my anger issues once we got home. On the return trip, I got agitated because my suitcase wasn't showing up. I was convinced that Customs was tearing through my stuff like they had on the way to Spain. We decided to go to counseling. I began going to anger management classes. But, my behavior got worse before it got better. I fell deeper into panic mode. I, like many veterans, chalked my emotions up to PTSD, and other built-up stress from the deployment. But, in hindsight, my overreacting and lack of coping skills were caused, or at least exacerbated by, the tumor.

Up until now, I hadn't had any headaches or physical symptoms from the growth of the tumor. But, one day, I had a massive headache. I came home from a drill with the National Guard and could not move.



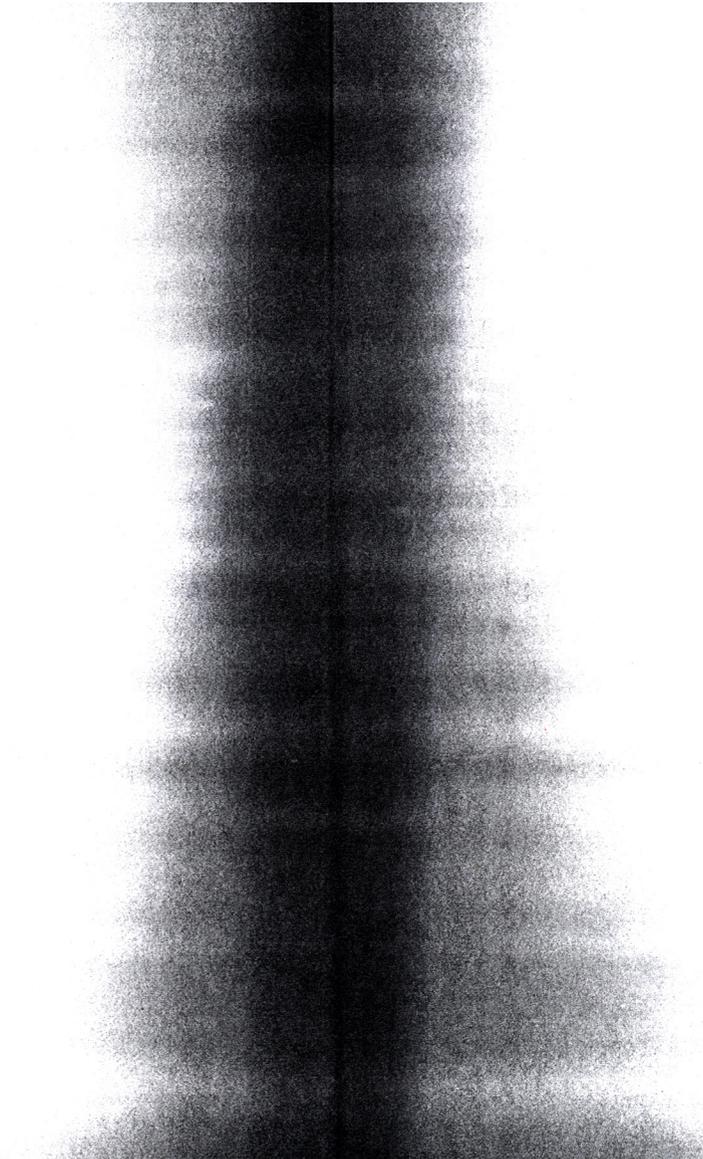


Chapter 4: Misdiagnosis

Marno and I were growing more distant. We weren't spending much time together. In the evenings after work I would go to the basement and spend the night on the computer. In May 2008, my therapist suggested that I see a medical doctor and begin medication for my anxiety and stress. I couldn't get in to see a physician on my private insurance, so I booked an appointment with a VA psychiatrist. He told me my attitude was bad, that I was destroying my marriage, and that I was messing up my military career. He interviewed me about my alcohol consumption (which had never been problematic) and noted that I was an alcoholic in my charts.

He was demeaning. Our meeting was the most degrading experience of my life – worse than a bad sales call. Before our meeting, I had felt like things were quickly falling apart, and during our meeting, I felt like it was my fault why they were. After our meeting – which lasted no longer than an hour and involved no in-depth testing – he determined I was bipolar and had attention deficit disorder (an extremely unlikely diagnosis for a man of my age). He prescribed lithium and Ritalin – a dangerous combination when taken together.

This misdiagnosis was huge. Needless to say, my behavior and cognitive abilities continued to deteriorate as I began treatment for the wrong issues. Things started to fall like dominoes. My relationships suffered, and I was put on a job-improvement plan at work. I could no longer solve conceptual problems or deal with customers, which was a problem in my role as a sales consultant. I was constantly picking fights with my wife and couldn't keep things organized and neat. My behavior was erratic, impulsive and completely out of character.



Chapter 5: Runaway Freight Train

At the end of June 2008, in the span of three days, Marno had a miscarriage, I lost my job and my stepsister, Sarah, began to lose her battle with stomach cancer. I had no sensitivity to any of these events. I couldn't cope. Instead of being there for my wife and family, I went out drinking with an old buddy. We ended up at a local gentlemen's club. Shortly after, I committed myself to the psychiatric ward of the VA hospital. I was considering ending my life. The worst part was, this all happened on my wife's birthday.

After I was released from the hospital, Marno and I traveled to the island of Turks and Caicos. We had been planning this trip for a very long time as it was in celebration of my cousin Angie's wedding. Unfortunately, it could not have come at a worse time. I continued taking my medications, but neither was addressing the true root of my problems: the growing tumor in my brain. As a result, my behavior and demeanor had not improved. Marno and I generally travel well together, but not this time. It should have been a joyous time for my cousin and everyone else, but I managed to make it miserable. I was up and down all weekend.

When a friend heard that I lost my job, he suggested I become a firefighter. One of my old girlfriends was a firefighter. Out of stupidity and desperation, I contacted her. We had talked twice while I was hospitalized, and even traded voicemail on the way to Turks and Caicos. While on the trip, I told Marno about this. Big mistake. The last night of the trip, we got in a huge fight. She was upset, and I got angry. I threatened her, which is hard for me to admit because I would never, ever hurt her. She made up her mind that we needed to separate after we got home again. We just couldn't make things work anymore. The trip home was terrible. By the time we touched down at home, we'd both decided our marriage was over. I did not know what to do. In a very short span of time, I was losing everything.

Would this have happened if I had been properly diagnosed the first time?

I want to take a brief moment to educate folks on the frontal lobe. If there is damage there, such as what can occur when a tumor is present, behavior and personality are immediately affected. According to the Centre for Neuro Skills, "The frontal lobe is considered to be the emotional control center, or home, to our personality. There is no other part of the brain where lesions can cause such a wide variety of symptoms (Kolb and Wishaw, 1990). The frontal lobes are involved in motor function, problem solving, spontaneity, memory, language, initiation, judgment, impulse control, social and sexual behavior ("Frontal Lobes")." Given this, it is easier to explain how and why I suddenly became such a jerk. Literally, I was not thinking straight.

On the advice of my mental health practitioners, I began the psychiatric partial hospitalization (PPH) program at the VA on July 24th, 2008. Through this program, I was supposed to get introduced to vocational rehabilitation, new coping skills for my "mental illness" and a fresh outlook on life. This did not happen and things got worse. At the end of the program, I was referred to treatment for alcoholism. As I stated before, I am not an alcoholic and have never had a problem with alcohol. By the third meeting with the psychiatrist, I was told I risked getting kicked out of the program. He said I had made no progress and that I had some real problems. He took me off of lithium and put me on Trazadone and Abilify, two psychotropic medications. Two weeks later, I graduated from PPH, but I was not any better off.

As time wore on, my symptoms became more heightened. I was emotionally detached; I couldn't speak or communicate coherently. I was disorganized, messy and making poor decisions. I ate fast food three-to-four times a day and smoked like a chimney. (Prior to this period in my life, I was not a smoker.) Marno noticed that I had stopped eating with silverware.

Chapter 6: Shocking Discovery

A breakthrough came in late August. My doctors asked if I would be willing to undergo a neuro-psychological test and an MRI. The next day, I took the neuro-psych test, which normally takes three-to-four hours, broken into sections. This test deals with a lot of short-term memory issues. I got so frustrated with things that I nearly threw a pencil at the test administrator. By the end of it, I had a headache and could not stand to listen anymore. That same night, I had the MRI.

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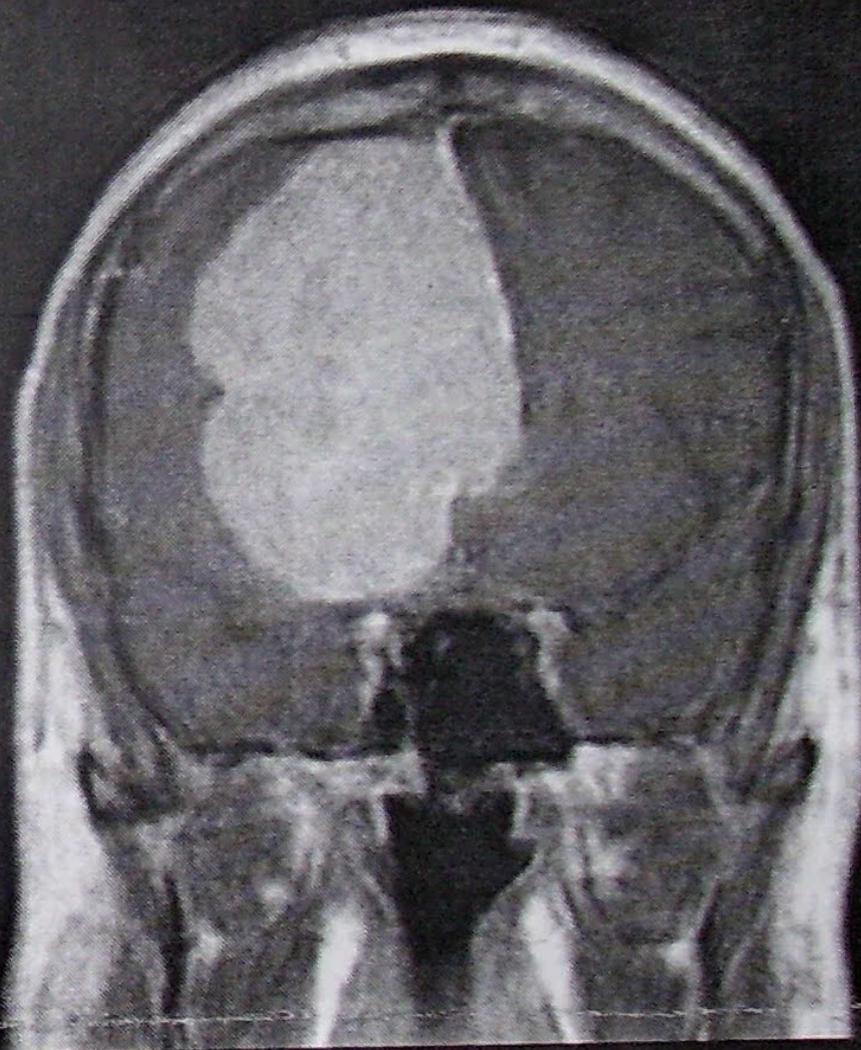
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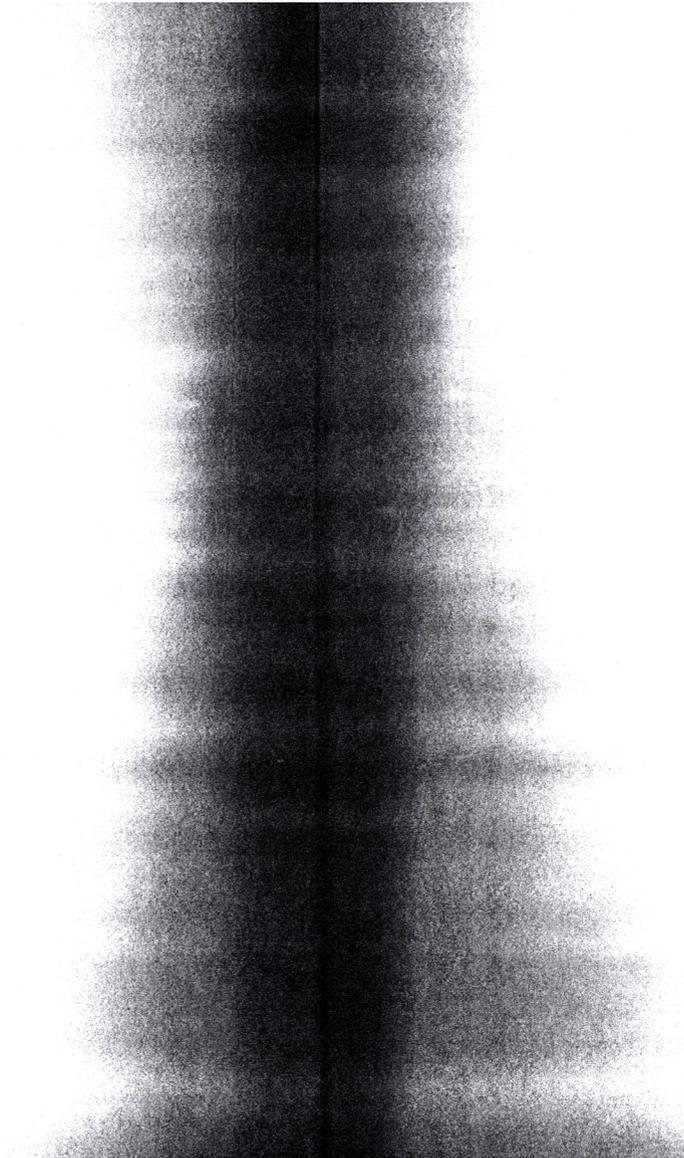
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Like I said at the beginning, August 27th, 2008 changed my life forever. That day, we got the results from my MRI. They had discovered the problem, my doctor said. She showed us a picture: it was a brain tumor. My brain tumor. It was huge: a 9-by-12-centimeter grapefruit. It covered the entire frontal lobe of my brain. The doctor said the tumor had probably been growing for a long time, but they needed to get it out soon. It had run out of room to grow, and if left alone, it threatened my life. The hospital scheduled the operation for a month later because they had never performed an operation on a tumor of this size. They had to rehearse for it first. Apparently, mine was the third-largest meningioma brain tumor in VA history. Because of its size, there was a good chance that I would bleed out during surgery. My chances of survival were seventy percent.



There is a connection between my brain tumor and my military service. Exposure to uranium, and a heightened prolonged sense of stress from living in a combat zone, contributed to the tumor's rapid growth. Studies have shown that exposure to burn pits can cause serious health risks. Many service members, including myself, lived and worked near burn pits. Everything from trash to human waste to hazardous chemicals were burned. Asthma, shortness of breath, and even brain tumors, have been linked to burn pit exposure. According to a January 15th, 2010 article in the "Army Times," a "46-year-old nonsmoking airman was diagnosed with asthma and sleep apnea, and now has chronic bronchitis and problems taking a full breath. X-rays show signs of chronic obstructive pulmonary disease. The medic who treated him at Balad now has a brain tumor" ("War-Zone Burn Pits"). Just as Agent Orange caused unintended consequences for service members in Vietnam, today's soldiers are dealing with the fallout from mismanaged hazardous waste, pollution and lack of basic environmental health standards.

The surgery was listed as an emergent, rather than an urgent, matter. I was to be hospitalized for the time being. They kept me on Trazadone and Abilify. By this time, the size of the tumor and the side effects of these drugs hindered my ability to make decisions or comprehend what was happening. I was clueless. Luckily, my wife has a medical background as a pediatric occupational therapist. She navigates the medical realm for a living. This made her an amazing advocate. With the help of her sister who works at a local hospital, and my brother-in-law, who is a doctor, Marno ultimately decided to seek a second medical opinion. She did not think I could wait a month for surgery. She obtained power of attorney from my father, and showed up at the VA to request my immediate discharge.

It was Labor Day weekend. I had just finished dinner and was watching TV: Arizona Senator McCain had just announced his vice presidential running mate, Sarah Palin. I sat around for a while wondering what was going on. Were they going to let me out of here? Why was I here? Around eight o'clock, Marno showed up. She told the nurse that she was here to pick me up and take me home. After an hour of discussion, my doctor and nurses allowed my discharge. The next day, a call was placed to the hospital I was transferred to stating that Marno had acted in an irrational manner. We were "on our own," according to the VA. These phone records have since been changed to cover up the original tone and intent.

Chapter 7: Surgery, Timing, Team and Family

They were surprised when I walked into the ICU unit of United Hospital in Saint Paul. They expected me to arrive on a stretcher. Within fifteen minutes, I was in a hospital gown, and had multiple tubes in my arms monitoring my vitals. A second MRI was done, and they discovered the tumor had grown larger still. I was immediately taken off my medications. Finally, my tumor was being treated with a sense of immediacy.

That night, my sister, Stephanie, showed up from Kansas City to be by my side. That felt good for a brief moment. I, however, had such a warped sense of reality at that point that I failed to appreciate her and my wife being there as much as they were. Without them, I would still have been sitting in my room, wasting time at the VA.

Doctor Jerone Kennedy, my new neurosurgeon, ordered surgery for that week. We no longer had any time to waste. On September 4th, 2008, I underwent brain surgery to remove the tumor. When it was time, the Chaplain came to my bed and read a prayer. I think it was Psalm 90.

PSALM 90
BOOK IV Psalms 90-106

A prayer of Moses the man of God. Lord, you have been our dwelling place throughout all generations. Before the mountains were born or you brought forth the whole world, from everlasting to everlasting you are God. You turn people back to dust, saying, "Return to dust, you mortals." A thousand years in your sight are like a day that has just gone by, or like a watch in the night. Yet you sweep people away in the sleep of death — they are like the new grass of the morning: In the morning it springs up new, but by evening it is dry and withered.

We are consumed by your anger and terrified by your indignation. You have set our iniquities before you, our secret sins in the light of your presence. All our days pass away under your wrath; we finish our years with a moan. Our days may come to seventy years, or eighty, if our strength endures; yet the best of them are but trouble and sorrow, for they quickly pass, and we fly away. If only we knew the power of your anger! Your wrath is as great as the fear that is your due. Teach us to number our days, that we may gain a heart of wisdom.

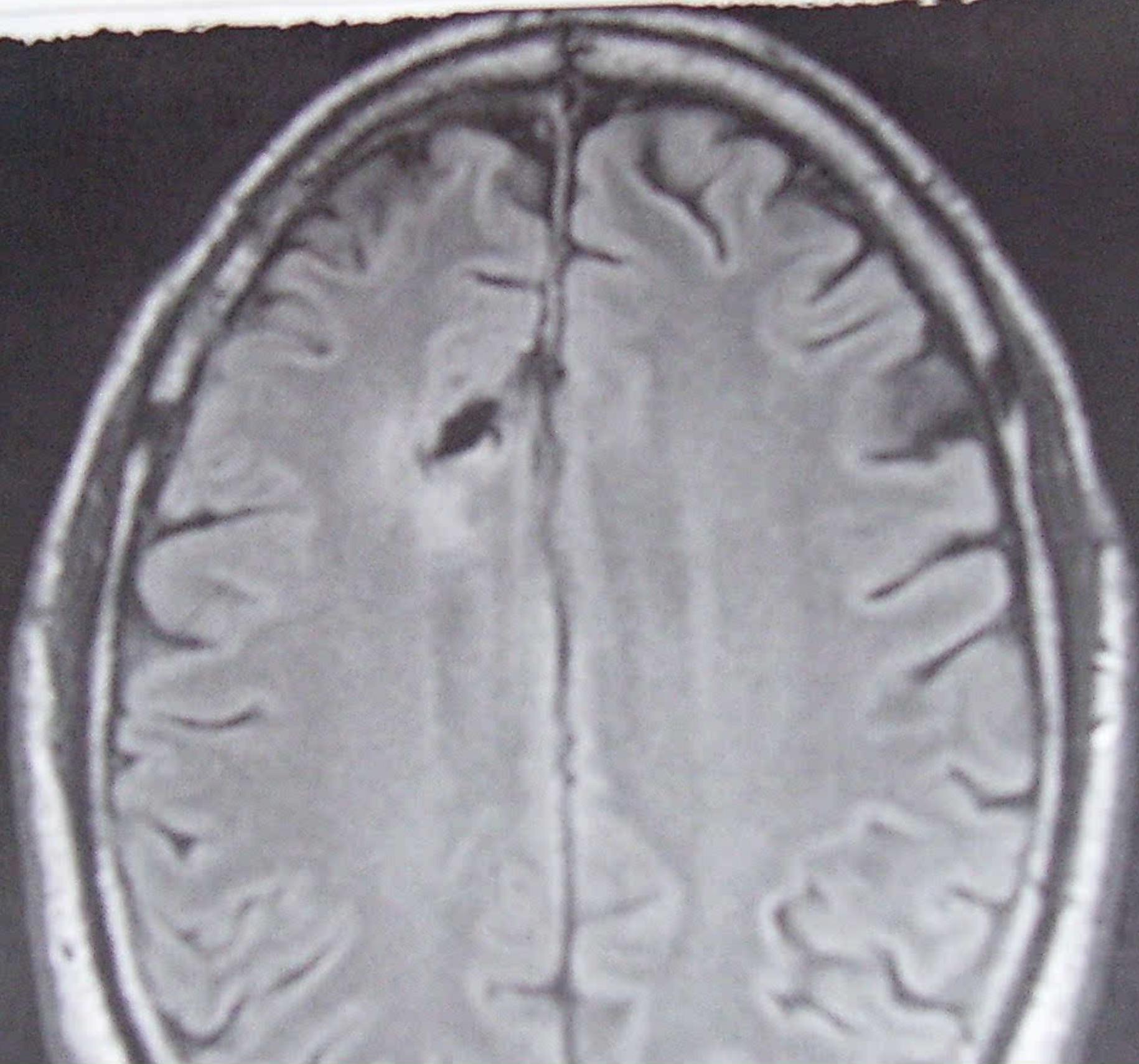
The surgery was a success, thanks to Dr. Kennedy and his amazing team. He is one of the best neurosurgeons in the upper Midwest, no question. I don't remember a moment of the seventeen-hour ordeal. I do remember taking my hand and running it across my head, feeling the big gash and staples. The next day, I had very little strength, but I was cognizant. Family members came to see me, one at a time. This was when I started to realize how horrible I had been and how I had treated people. It didn't take me long to get really emotional. I cried immensely. I apologized and told them how sorry I was about how I'd acted, how I hadn't acknowledged my stepsister, Sarah's, recent death. I felt the most remorse toward my stepfather, Nat. He had needed my support through Sarah's death, and I had missed it all. I felt awful.

Chapter 8: Aftermath

The first couple of days, I couldn't sleep. They had me so pumped full of steroids, I couldn't calm down enough to rest. Sleeping pills eventually helped. Rehabilitation began right away. I had an initial assessment from an occupational therapist. The nursing staff and doctors came in a few times a day to test my short-term memory. One time, Dr. Kennedy himself came by. Each staff member asked simple questions like my name, what year it was, what hospital I was in... I got a few of them wrong, but I could remember things that had happened twenty years ago, so that was good.

I struggled with short-term memory issues. I still do. I have had to learn how to find ways to compensate for this deficit. The area of my brain that was operated on was still refilling and I could hear it. It sounded like saline solution moving around. Because of this, I also could not exert myself in any way, meaning I had trouble with many daily activities. Physical, occupational and speech therapy helped me regain everyday skills, like shaving, dressing and organizing. Speech was by far the hardest and most tiresome skill to regain. I could communicate verbally and was thinking more clearly every day. But, speech therapy was exhausting and I had a hard time remembering material that I'd practiced in my exercises. The forty-five-minute therapy session totally wore me out.













Chapter 9: A Second Chance

After my initial therapy and assessments, I was discharged from United Hospital and transferred back to the VA on September 17th, 2008. Going back to the place where I was misdiagnosed and the scene of so many bad memories (including three commitments to the psychiatric ward) was frightening. We were told that the VA had a wonderful rehabilitation program, however. Thankfully, the polytrauma rehab unit is nowhere near the units I had previously been familiar with. Once we met Dr. Michael Armstrong, we knew things would be different this time. He was aware of my history with the VA and wanted to do everything possible to make things right this time around. I began rehab as an outpatient. Marno agreed to be my caretaker at home. I was signed up for physical, occupational and speech therapy here, as I had been at United.

I also saw a psychologist, not to talk about how crazy I was, but to talk about what had happened over the past four months – to try to process things for the first time since they fell apart. This was an important step in my recovery. Nevertheless, outpatient rehab was intense. I still really struggled with my speech. I had gone from being able to negotiate sales deals in Spanish a couple of years ago to struggling to finish a simple memorization quiz. I learned some humbling lessons during this time, though. I was surrounded by people who had deficits that were similar or worse than mine. Through this, I learned that I was not the only veteran who was suffering setbacks.

At the end of September, a couple of weeks into my outpatient rehab, Marno and I met with a patient advocate at the VA. We typed up a letter outlining our grievances with the mistakes that had been made and the quality of care that I had received. We had gone through hell – the loss of a child, the loss of a job, the breakdown of our marriage – because of careless medical decisions: the original misdiagnosis and timeline for my brain surgery among them. We knew that we could not sue the U.S. government, and we didn't necessarily want to, but we did want to hold responsible parties accountable for their actions (or lack of actions). We wanted to make sure that this never happens to another veteran.

Chris, my patient advocate, told us he was aware of our case. They had formed a committee to review it. He gave us some forms and explained our options, including filing for service connectivity – a one-time lump sum claim. We did this, and ultimately got it. It was determined that my tumor grew significantly while in Iraq due to uranium exposure and stress.

I was in outpatient rehab for only a few weeks. During this time, Marno drove me to my appointments, I worked with my therapists, came home and slept. I took a two-or three-hour nap five days a week for the first six months. When I didn't take a nap, it showed. My fatigue was due to the recovery process and my new cocktail of medications. The good news was that when I was awake, I thought more clearly than I had in years.

Many family members, friends and neighbors were very supportive during this time. They sent prepared meals, gift certificates and cards. They invited us to dinner and went out of their way to make us feel cared for. We are especially grateful to Amy Anderson, the wife of Lieutenant Anderson, my superior in the Guard. She was very supportive of Marno and me during this whole process. That is a real sign of a solid friendship. Marno's coworkers were also very generous.

During these initial weeks, I made every possible effort to apologize to folks for the way I had behaved. I did this through phone calls, emails, and a few in-person visits.

Chapter 10: Outpatient to Inpatient

I was transferred to inpatient rehab because my doctors felt that I could progress faster if I stayed overnight five out of seven nights a week. This was tough for Marno and me. We had been separated by war, my tumor and now this. This was a good step for me, though. Here, I was surrounded by other veterans who had similar experiences to mine – we had all been in combat zones, and we were all recovering from brain injuries. A lot of the symptoms and side effects from my surgery were invisible. Yes, I had physical scars, but I also had trouble expressing myself, and I lacked stamina and patience. Parts of me had changed. It was hard for people to understand these deep changes when they couldn't see them. The other vets on the rehab ward understood the extent of my injuries and deficits, though, and that helped me deal with those who did not understand.

My inpatient therapists helped me develop strategies for overcoming my deficits. For example, I began to use a Palm Pilot to record appointments, meetings and medication reminders and notes. It gave me the structure and organization that I needed. I took the neuro-psychological test for a second time. This time, it was broken into two half-day sessions and, again, I was mentally fried by the end. The results showed that I had improved incredibly since the surgery. I still had some deficits, but the test administrators told me that I had improved. I took the test a year later for a third time with nearly identical results. This means that the deficits I currently have will most likely be permanent.

I was on this unit for a little over a month before I moved to the Transitional Rehabilitation unit. Here, I had group therapy with other brain-injury patients. We talked about how our injuries have affected our lives. We also talked about the challenges we face with our families, friends and the general public because of our situations. We were each assigned a coach whose job it was to motivate and guide us. My coach was named Marnie. She noticed that I had a lot of leadership potential – both in my civilian workforce history, and in my military history. For the first time since my deployment, I realized I had potential. I was getting my confidence back after having been beaten down constant bad news.

As a vocational development exercise, Marnie suggested I do a research project about something of interest. I had always wanted to start my own business. I knew at this point that I was never going to return to my old post in corporate America, but I still wanted to be involved in the business process. I had recently learned about Marno's family barbeque sauce venture. Her aunt and uncle had been making their award-winning sauce and selling it to friends and family. I used my sales experience to design a business plan to manufacture and market the barbeque sauce to grocery stores. Marno's family was supportive of the idea, and I also was excited to get involved. Marno and I began attending food shows, and I researched the existing market. Eventually, we launched Triple Crown Gourmet BBQ Sauce, LLC.













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Physical Therapy
Rehabilitation Services
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Chapter 11: Thank you!

I want to close by recognizing the people who saw me through the trials of the past few years. The first people I want to thank are the men and women of my unit, the 347th RSG Unit of the Minnesota National Guard, based out of Roseville, Minnesota: Lieutenant Anderson, my commander, acting First Sergeant Joe Vogel, Sergeant Major Kevin Sands and Chaplains Mike Lotzer and Luke Leonard. They stuck by me through the roughest parts of misdiagnosis – even when I was most unpleasant to be around.

Secondly, I'd like to thank Joan Lally, one of my original therapists. She believed from the start that my original diagnosis was incorrect, and she went out of her way to communicate her professional opinion to my other doctors. She knew how to fight for me before I knew how to fight for myself.

My sister-in-law, Shannon Swanson, is responsible for introducing me to my "dream team" of specialists who performed my brain surgery at United Hospital. To Stephanie Rahman, my sister, who used her human resources background to help Marno and me navigate all the insurance issues associated with my illness. We couldn't have done it without her.

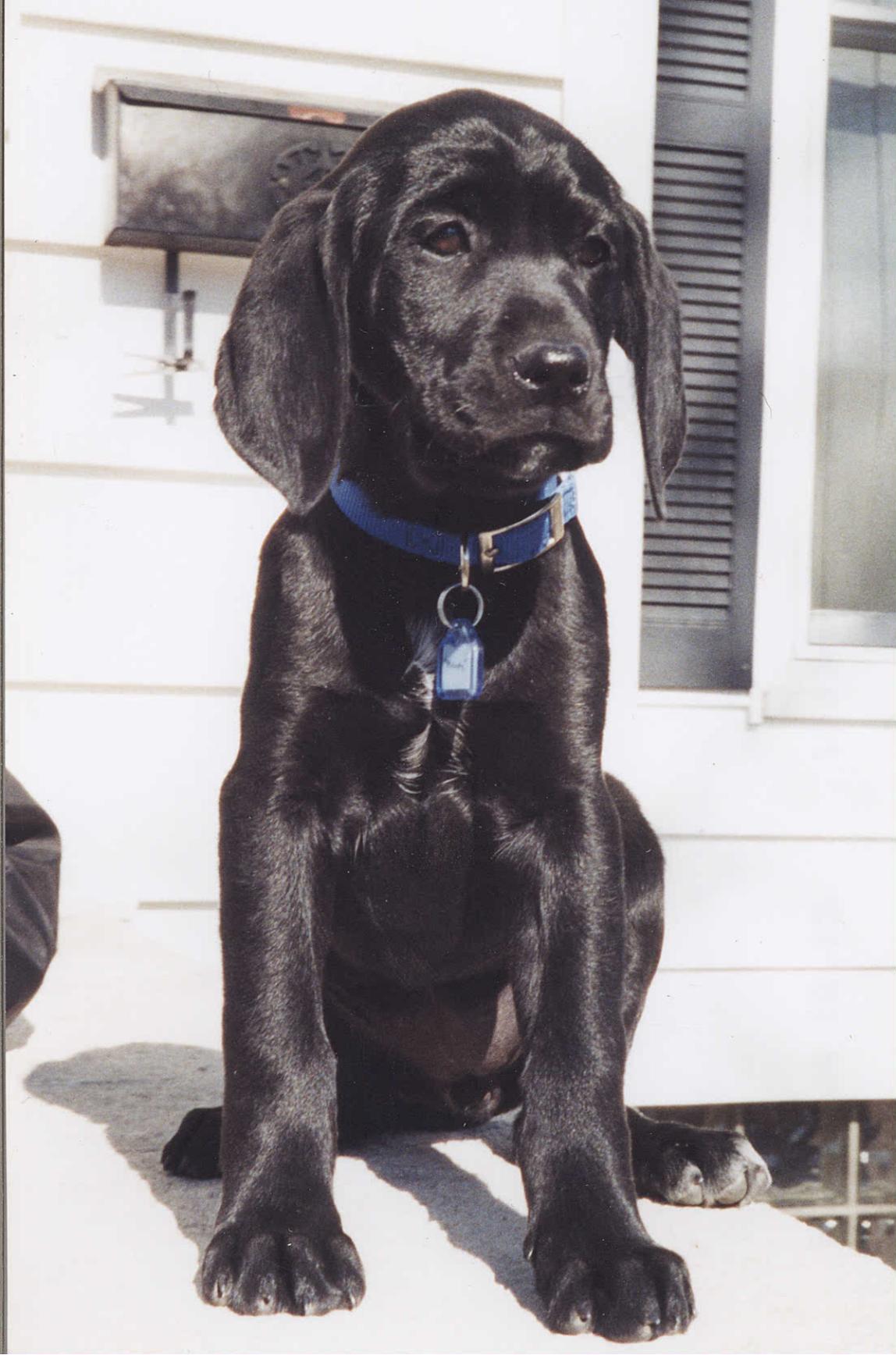
To my VA doctor, Deborah Suvolsky, and VA social worker, Debbie Done, who listened to Marno and ordered the neurological testing that ultimately revealed my tumor. To retired Colonel Geraldine Longfellow who walked us through the VA benefits system. If it wasn't for her, we would not have been able to turn the initial negative experience into a positive one. To Doctor Jerone Kennedy, my neurosurgeon, who pulled off the miracle surgery. The way we see it, nobody could have done a better job. He saved my life.

Last, but not least, to Marno. Someone who could stick by me through all those dark hours is definitely a keeper. Along with Dr. Kennedy, I owe her my life. I love you, Marno.















CHAMPIONS

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Congratulations
Mike & Mamma











Agape Moments



Works Cited

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Suggested Reading on Brain Injury

"23: Time to Choose." Nicholas P. Dennen.

"In An Instant." Bob and Lee Woodruff.

COLOPHON

A PROJECT BY
Monica Haller

BOOK BY
Michael G. Simon

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Michael and Marno Kay Simon, Agape Moments

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This book is the result of the author's courage and focus at the Veterans Book Workshop, where we work to make manageable and material personal archives of images, words and memories from the current wars.

This book is one of many made in the Veterans Book Workshop. Each emerged from different circumstances and each finds its own unique use. One veteran may reference this book regularly, while another may set it aside in order to move on.

Regardless of the ways they are used, no dust settles on these archives. This book contains a powerful living collection of data, memory, and experience that is so relevant it trembles. You must pay very close attention to hear its call.

We made this book for listening. Please accept our invitation. We made this book for deployment. Please pass it along and invite someone else to listen.

Thank you,
Monica Haller

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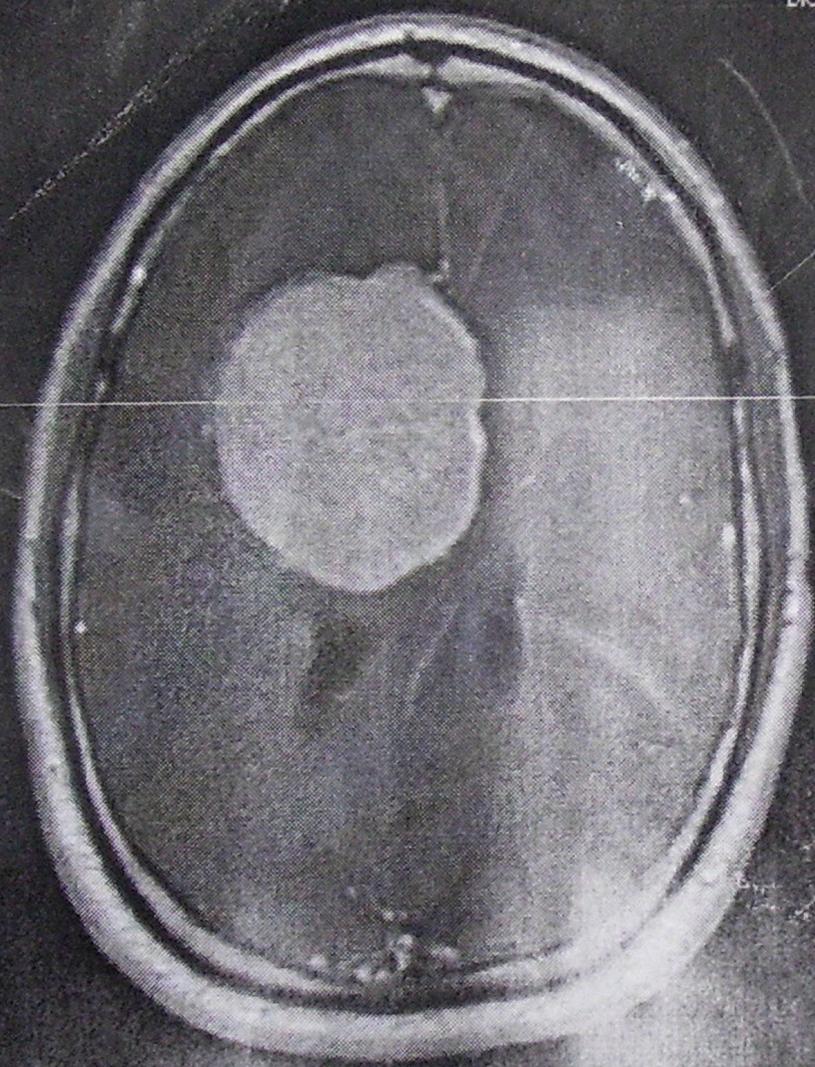


Michael Grant Simon was born in Columbia, Missouri and moved to Minnesota to attend college. He studied management and history. After working as a sales professional and receiving his Masters in International Business, Michael enlisted in the Minnesota Army National Guard as a Signal Support Specialist. He served in Iraq from April 2006 to July 2007. Michael had a large brain tumor that was discovered a year after his return from Iraq. He now lives in Stillwater, Minnesota with his wife. They are looking to adopt their first child. He is using his sales background to help expand a start-up, family business.

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Slice 11
Zoom:

x 24.0cm

P