



## IN THE LINE OF FIRE

*How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving, and tolerant of the weak and strong. Because some day in life, you will have been all of these.*

—George Washington Carver

### COUNTERMANDING THE DOCTOR'S DISCHARGE ORDERS

While relatively young at age 32, Stephanie Marvis had already endured a long and grueling life. She had been involved in several abusive relationships that yielded offspring and in which the new fathers quickly disappeared. Stephanie and all four of her children were born with congenital dystonia. This genetic neurological movement disorder caused sustained involuntary muscle contractions that led to a lack of muscle coordination, cramping, and trembling.

The single mother of four lived in Truckee, California. There, she qualified for California's public health care benefits and always found temporary work at the casinos and restaurants that surrounded Lake Tahoe.

Historically, the living accommodations for the Marvises had been temporary and marked by frequent evictions from apartments after Stephanie fell behind in the rent. Currently, the family lived in a cramped three-bedroom second-floor apartment with poor accessibility and limited access to physical therapy facilities for the ongoing treatment of the dystonia. Despite this sub-optimal living environment, the family learned how to cope with their shared medical condition.

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Stephanie had actively researched dystonia and, six years earlier, had found Dr. Allen Fields. Dr. Fields was a world-class neurologist at Stanford University who was an authority on this condition.

When Stephanie's youngest child, David, was four years old, Dr. Fields implanted a medical device called a deep brain stimulator in the boy's abdomen. A series of wires ran under David's skin and up to his skull, where they were positioned in the deep brain at a location called the globus pallidus. Through electrical impulses, this device enabled David to relax and better control his muscles. After the operation, at the peak of his recovery, David was fully functional and playing normally with children his age.

### **The Patient's Arrival**

In July of 2008 David, who at the time was 10 years old, started experiencing a series of worsening dystonia symptoms. It began with a cracked voice, but soon also included grinding of the teeth, difficulty with swallowing, trembling in the diaphragm while breathing, and significant cramping throughout his body.

As his condition worsened, Stephanie repeatedly took David to Lake Tahoe's Barton Memorial Hospital's emergency room. While Barton's staff could help assuage some of David's symptoms, they did not have the expertise to treat the dystonia. On November 18th, Barton's emergency room staff decided to transfer him to Stanford.

David arrived at Stanford in a wheel chair. His muscles were so contracted that he was curled into a fetal position. Dr. Fields and his team quickly discovered that one of the deep brain stimulator's lead wires was broken, leading to the device's malfunction. This had led to David's slow deterioration.

### **The Personalities**

#### ***The Primary Physician***

Stephanie characterized Dr. Fields as "an angel." He had a friendly and easygoing demeanor around the mother and son and was one of the few people in the hospital with whom Stephanie felt extremely comfortable.

#### ***The Junior Attending Physician***

Dr. Mona Abbott had worked in the Pediatrics Clinic with Dr. Fields for more than eight years. She was Dr. Fields' "right hand" and was seen by everyone as the person who ran the clinic day-to-day. Dr. Abbott had been involved with Dr. Fields at the time of David's first visit when they had implanted the deep brain stimulator. However, she had not seen the patient or his mother during this most recent visit.

While Dr. Abbott could be friendly, she was better known for being blunt, somewhat arrogant, and not very tactful.

### ***The Student***

Dr. Fields had a student on his team, Claude Mattox. He had attended undergraduate school at Duke University and, before enrolling in medical school, had received a PhD in Immunology from Stanford.

Claude, a third year medical student, had been on clinical rotations for six months. Currently, he was in the seventh week of an eight week rotation in general pediatrics. He had developed a good relationship with Dr. Fields, his team (including Dr. Abbott), the nurses, and, especially, Stephanie and David.

Dr. Fields typically stopped by to visit the Marvises once a day. During the visits, Claude debriefed him on everything that had happened to David since his last visit and then implemented any new directives provided by the doctor.

Claude was likely to ask questions, tactfully speak his mind, and simply be more vocal than the typical medical student. Perhaps this was a function of his confidence (especially after receiving a PhD) and his age (28 years old versus 26 years for the average third year medical student).

### ***The Patient***

After repairing the lead wire malfunction, Dr. Fields expected David's recovery to take at least 4 – 5 weeks. Early in his stay at Stanford, a psychiatrist had evaluated David and found that he suffered from mild depression, probably caused by the deterioration of his health.

### ***The Patient's Mother***

Despite her limited high school education, Stephanie was intelligent about her disease and frequently posed sensible questions to Dr. Fields and Claude. She was, however, intimidated by the high tech environment of the hospital and the many "folks in coats." In addition, she felt defensive and protective of her family. Claude further elaborated:

Stephanie felt defensive for several reasons. First, she was marginalized by her economically disadvantaged situation. She knew that her apartment, while it was all she could afford, was not the best environment in which to raise her children. Second, she believed that the health care system had cast a negative judgment on her for having four children despite knowing that she had a genetic disease. Third, she was sensitive about the care that she provided for her other children since, at the moment, her three daughters (ages 16, 14, and 13) were at home and alone in the apartment. Lastly, Stephanie believed some of the medical staff had pre-judged her for waiting five months to bring David to Stanford.

Regarding the latter point, Stephanie confided in Claude that she had called Stanford two months before this visit and had spoken to a nurse who gave her "the run-around." Since she did not have access to transportation, she could not easily get to Stanford. Claude had checked with the nursing staff and a record of Stephanie's call did not exist.