Anthony’s parents had been planning a family trip to the coast for months. Anthony, a precocious 4-year-old with excellent language skills, had been to the beach once before and could not stop talking about the upcoming trip. On a cool Friday morning in autumn, Anthony’s mother was busy packing the family’s things for their 2-week vacation. She had decided to take the day off from work while Anthony was in day care so that she could take care of all the last-minute details. When the day-care staff called to report that Anthony did not seem right, she figured he might have come down with an illness that would make the plane ride less pleasant, but she certainly did not anticipate that the vacation would never happen.

When she arrived at the day care, she learned that Anthony had been having problems with balance all morning and had fallen several times. She also noticed that his eyes were moist and that his head was tilted to one side. “Tears are falling from my eyes, Mommy,” said Anthony with only a slight hint of distress in his voice but still looking to his mother to somehow make it stop. Anthony’s mother felt her heart jump and quickly scooped up Anthony and shuttled him to the emergency department.

Within an hour, Anthony had been sedated and was undergoing a Magnetic Resonance Imaging (MRI) scan. Within 4 hours, a neurosurgeon was describing to Anthony’s parents the lemon-sized mass that had shown up on the MRI in the posterior fossa, the area of the brain that houses the cerebellum and critical brainstem structures. The neurosurgeon was personable but very serious, and Anthony’s parents consented to the recommended treatment, which consisted of creating a hole in the back of Anthony’s skull to remove the tumor.

By Sunday morning, the family’s vacation was a distant memory, and the neurosurgeon told Anthony’s parents that the surgery had gone well. They held Anthony’s hand while he was in the intensive care unit, counting their blessings that their child had survived, without realizing that the battle was not over.

Samples of the tumor tissue were analyzed and identified as medulloblastoma, a malignant and aggressive type of Primitive Neuroectodermal Tumor (PNET). As Anthony recovered from neurosurgery and became increasingly alert and active, his parents were learning about the risks and benefits of the proposed treatment plan. Specifically, they learned that Anthony would need to undergo a course of radiation...
therapy in which radiation would be delivered directly to his brain and spine, and
they also learned about the months of chemotherapy that Anthony would have to
endure following cessation of radiation. Still in shock from their realization of how
close Anthony had been to death, his parents did not really process some of the risks
stated to them with regard to radiation and chemotherapy, including declines in IQ,
learning problems, hair loss, and growth suppression. They also did not heed, or
perhaps even hear, the recommendation that they should have Anthony evaluated
by a neuropsychologist in the coming years in order to keep close tabs on his
neurocognitive development in light of the tumor and its treatments.

Fast-forward 8 years, and Anthony was in the middle of fifth grade and strug-
gling significantly. For years, Anthony underwent routine MRI scans and endocrine
treatments (e.g., growth hormone), and his parents were always relieved that there
was no recurrence of the tumor. For kindergarten through fourth grade, Anthony’s
parents had enrolled him in a small private school, where they believed that he
would get any extra attention he might need. The teacher-to-student ratio was low,
and Anthony had a series of kind teachers who always seemed to have a soft spot for
this first child they had ever known who had experienced a brain tumor. Anthony’s
parents felt that they were not being overprotective but simply providing Anthony
with a school placement that would give him plenty of time to mature as they
harbored lingering concerns about his ability to integrate successfully in an over-
crowded public school system that they perceived as overwhelming. They always
felt reinforced when his report cards said that he was making satisfactory progress
and underscored what a sweet and compliant child he was. Anthony’s parents were
well-educated professionals who had an inkling that he was not as strong in math as
perhaps other students in his grade might be, and they also noticed that he moved a
little slower and seemed a little more awkward than many other children of his age,
but otherwise the consistently positive teacher comments reinforced their belief that
Anthony was progressing well.

At the end of fourth grade, Anthony’s father was transferred by his employer,
and the family had to move. Anthony’s parents were devastated that he would no
longer be able to attend the private school where he had seemed so comfortable, but
circumstances dictated that they seek a new educational placement for Anthony.
After exhausting all options, Anthony’s parents determined that the only placement
for him would be their local public elementary school. They felt confident that
Anthony had progressed well over the years, and they knew that the elementary
school was highly rated. So with only a little trepidation, Anthony’s parents
enrolled him in the fifth grade.

Within the first few weeks, it was clear that things were not going well. Anthony’s teacher already had sent notes home about unfinished work in the
classroom, and Anthony was complaining that he had no friends and that the
work was very hard for him. He wanted to do well and please his teachers, so he
was adamant about completing all of his homework each night, though this was
taking hours, to the point of significant fatigue. Anthony’s parents were particularly
distressed after receiving results of benchmark testing showing that Anthony was
not keeping up with his classmates, particularly in math.