Cancer can’t keep a smile off of Simon Jones’s face

By Kabao Lor

It all started on the day of Simon Jones’s first swim meet. As he swam back and forth in the McMillan Middle School pool, his mother noticed that his stomach was bigger than usual.

“I had no idea what it was, so I swam anyways,” Simon said.

He was taken into the hospital the following day. The doctor pressed on his stomach in the area where a large, thing was bulging out. Afterwards, they took a CAT scan and two days later, on January 30, 2013, it was official.

At only age 13, Simon was diagnosed with desmoplastic small round cell tumor (DSRCT), a rare malignant cancer that has only been found in about 200 people, mostly young adults and adolescents.

DSRCT occurs when the 11th and 21st chromosomes are switched. The cancer is found in the abdominal cavity, the largest hollow space in the entire body. It grows extremely fast.

Lily Jones, senior, remembers clearly the day she found out that her little brother had cancer. She had gone to visit him at the hospital the day of his diagnosis.

“My parents meant to tell me at the hospital so that they could do it in person, but they forgot and ended up calling me,” Lily said.

She also remembers attempting to speak as her Aunt Becky approached her when she hung up the phone, but all she could do was cry.

Their little brother, Theo, is eight years old, and his knowledge of his brother’s illness is limited.

“We had to tell him that it was just aliens laying eggs in his body, and we were trying to kill them,” Lily said.

This turned her life upside down. The littlest things were no longer normal. Everything had to change, including Lily and Simon’s relationship.

Before, the siblings would always bicker. Both of them wanted to be right all the time, but his diagnosis raised his level of maturity.

“It was hard at first but I have adapted to him having cancer,” Lily said, “I care for him in a way I can’t show. He is a 14-year old who wants to be independent.”

Simon takes a different look at his condition.

“This device was necessary to make procedures such as chemotherapy, blood transfusions, and antibiotics simpler.

During chemo, it was necessary that Simon gained weight so that the treatment would be more effective.

His chemotherapy routine was two-five-two-five, which meant he’d do two nights of chemo in the hospital with a two week break in between before going for five nights.

This routine was repeated three times before they moved on to the next method.

“I had a weird craving for flavored foods, but I didn’t really want sweets,” Simon said.

Eventually he also found out that he had Graves’ disease which is a disorder that makes the thyroid gland overactive. It also increases metabolism.

This disorder caused him to have to go on a iodine and dairy-free diet. He disliked it, but it made finding the tumor a lot easier.

In early spring, Simon and his parents flew to Houston and New York City all in a week’s time. They visited different hospitals for possible treatments.

They found little to nothing helpful in Houston and decided on NYC.

The Joneses revisited the MD Anderson Cancer Center in mid-June. There, the doctors cut the same incision to look for more tumors. Simon named every one they found, from the very first surgery to now.

“Felt like I was having a C-section every time, so I named the tumors as though they were my children,” Simon said, “I had to deal with it one way or another.”

Nigel the naughty nodule was the first one found in NYC, and the fourth altogether.

He received radiation treatment at the cancer center as well. They injected drugs and nutrients into his system that would serve as bait to the cancer cells.

“It reminded me of a worm on a hook when you go fishing,” Lily said.

At the end of the five weeks, they returned home, only to send Simon away again to a camp for cancer patients called Courage and Hope.

Finally, he came home for the beginning of his freshman year. Even still, they continued on with radiation for 20 days.

Now, Simon is on maintenance chemo where he stays at home. Every third week of the month he gets medication that comes in both a pill and liquid form.

Simon is at war for his life but he shows the rest of the world a smile. Even though this is one of the scariest things a 14-year old could experience, he keeps his head up.

“I have inspired myself,” Simon said.