



(Left to Right) Rusty Morris, Crystal Morris, Rachael Morris, Suzi Morris, Benji Morris - brother.

## Going Green

By Emily Brown

“It’s not that easy being green.”

It is a lesson from Kermit the Frog and the adopted mantra of 26-year-old Rachael Morris. Rachael, like Kermit, can relate to the green puppet’s feelings of wanting to be different.

Rachael’s biggest lesson in being different came in the form of a diagnosis at age 15: neurofibromatosis, type 2. Neurofibromatosis is the term for three distinct genetic disorders: NF1, NF2, and Schwannomatosis. NF2, Rachael’s diagnosis, occurs in 1-25,000 births.

She likes to say that Kermit is her idol because Kermit did not like being green -- green was boring. He wished he could sparkle. He couldn’t though; he just had to be green.

Her introduction to the disorder began just before starting high school at summer camp. Pain began building in lower back pain. The sensation differed from anything she had experienced before – like razor blades in combat with her left thigh muscle.

“The pain, I can tell you now, was like sharp nerve pain,” Rachael said. “I could never really put into words what it felt like at the time. It was a burning pain deep in my muscles.”

When she would lift her left leg, the burning pains would fire into her back in full assault. On many camp nights tears fell on her pillow. Sometimes, in the morning, she used both hands to raise, pick up and lift her leg to crawl out of the lower bunk bed.

By the second week of camp, she swapped daily camp activities with time in the infirmary. The camp doctor said that she had a Charley horse, another name for muscle cramps, and that she should just rest and eat bananas.

Rachael finished her camp session but the pain never completely subsided, instead coming and going much like the forthcoming school year.

Some nights, however, after dance class, the pain returned and she found herself cradled by the warmth of a heating pad. The best she could figure is that it was muscle cramps.

By November, as she was getting more involved with community musical theatre, she noticed the pain interfering with her singing and dancing. The soreness started impacting her sleep again.

During the Saturday night performance of “Big River” Rachael knew something was not right. After the opening number, Rachael walked off the stage crumpling onto the sofa layered with costumes, sweatshirts and coats. “I was hurting, bad!” she said. “Bless my fellow cast members...they did everything they could to make me comfortable but all I could do was moan and cry in excruciating pain.”

That night her parents were not in the audience but were called immediately. Rachael could still hear the show going on as she was being carried out in her father’s arms to the car. She didn’t make the Sunday performance either.

On Monday morning Rachael returned to her pediatrician’s office. This time he did not say she had a Charley Horse and instead referred her to a local neurosurgeon.

She endured test after test but there seemed to be more questions than answers. Was it a ruptured disc? Was it a pinched nerve?

She went in for an MRI at Wake Forest University Baptist Medical Center in Winston Salem, N.C.

There was a reason for the back pains.

The images revealed a tumor shoving against her spinal cord.

The solution? Surgery.

It was when Rachael was in the operating room that doctors discovered that there were many tumors. She was diagnosed with neurofibromatosis type 2.

“I was like ‘Huh? Neuro-what?’” Rachael said. “I remember being told all that could happen with this disease. At that point, little did I know that is what would happen.”

Even though there was a reason for the pains, the diagnosis brought many questions because it was something new not only for Rachael, but for her family as well. “She is the only case that we know of in our family,” said Rusty Morris, Rachael’s brother.

As a freshman in high school she accepted the conclusion with the mentality that the things the doctor said could happen, like deafness and balance loss, would not happen to her. “I really did not think much about it,” Rachael said. “I had more important things to worry about like [whether or not] N\*SYNC or Backstreet Boys [were] going to be No. 1 on “TRL” that day.”

Rachael did not let the diagnosis prevent her from pursuing her education. She received her associate’s degree from Peace College in Raleigh, N.C. before transferring to the University of North Carolina at Greensboro to pursue deaf education.

Rachael wanted to help children with impaired hearing.

At the age of 20 she lost hearing in her left ear due to Ghamma Knife therapy. Ghamma Knife therapy is a treatment using gamma rays that can deliver a large dose of radiation to a tumor without exposing large amounts of normal tissue, according to the National Cancer Institute.

She still had good hearing in her right ear but the development naturally evoked change and forced modifications.

The tumor continued to grow on her auditory nerve. At the age of 24 she wore hearing aids. “They were pink and very in style!”

But even with hearing aids the sounds she was able to once hear began tapering. The TV and radio had to be blasting in the background. Conversation began to gather into collective drones. “All I heard was ‘Wha wha wha wha wah.’”

However, during Rachel’s last semester of student teaching, Rachael’s hearing completely faded away. NF2 stole her ability to receive sounds. Rachael was deaf.

NF2 tumors grow along the vestibular nerve that controls balance. Deafness occurs in virtually all patients that have neurofibromatosis, type 2, Dr. Kim Hunter Schaedle, chief scientific officer of the Children’s Tumor Foundation, said.

“This is adjacent to the auditory nerve that conducts hearing,” Hunter-Schaedle said. “So when vestibular tumors have to be removed, the hearing nerve is unfortunately often damaged, and causes deafness...the 7<sup>th</sup> cranial nerve, the facial nerve, is nearby and can get damaged which is why some folks with NF2 have facial palsy.”

With Rachael losing hearing she had to learn different forms of communication. She had limited sign language abilities. She did not live in a strong deaf community where signing is needed nor had she taken classes when she still had partial hearing.

And, to complicate matters, the tumors in her wrist made it difficult to form certain hand gestures and spell with her hands. Rachel did not get to finish her last semester.

But she hasn't given up. Her desire and eagerness to learn helps how she adjusts to a different approach to life. "I have learned to deal with the emotions I face," Rachael said. "It has gotten easier with time, but it will never be easy. I am still adjusting and all I can do is make the best of it. This is how it is going to be from now on."

She finds way to incorporate her goals of sharing education by teaching sign language to her younger cousins and children she used to babysit. "I love feeling like a child. Just making people feel 'good' is me. I love teaching and seeing the end result."

Rachael's perseverance and determination are ingrained in her personality. She volunteers in her community as a member of the Junior League of High Point. In addition, she works out at the YMCA four times a week to stay active and maintain energy.

In many ways she is like a lot of females her age. She enjoys shopping, cooking, writing, and reading. "I love a cheesy love story," Rachael said.

And, she admits that she is hooked on a few certain television shows like "Grey's Anatomy" and "Deal or No Deal." "I remember being in the hospital after surgery about a year ago and the nurses laughing at me because of me yelling at the TV while watching "Deal or No Deal."

She also likes to be silly. "Nothing brings me more joy than seeing someone smile," Rachael said. "A smile on someone else's face because of me makes me feel fulfilled. I love making people laugh through my random humor and corny jokes."

She listens to an iPod. She often bursts into song and jokes around with her friends that she is listening to her implanted iPod.

Her attitude provides inspiration to her friends and family. "Rachael is the most positive and cheerful person I know and her glass is always half full," Rusty said. "After she learned of the severity and possible effects of this disorder, her attitude never changed."

Maybe it's part of being different; being green. "I can relate to Kermit's feelings of

wanting to be different,” Rachael said. “I do not want to be deaf, have a walker, have facial malfunctions, etc. I do not want NF2! But, I have NF2, it does not have me.”

On October 27, 2008, the second annual Rachael Morris – Wildwood Green Pro Am Tournament was held in Raleigh, N.C. in honor of Rachael. Proceeds from the tournament go to the Children’s Tumor Foundation, which is dedicated to enabling neurofibromatosis research.

The biggest obstacle was the weather. It was rainy and cloudy with overtones of gray at Wildwood Green Golf Club. However, even with temperatures in the 50s and sleeting conditions, people from all over the east coast came to participate in the 18-hole event, Rusty said.

The event drew PGA Golf Professionals from across North Carolina as well. Bob Boyd, No. 21 on the European Senior PGA Tour money list, and a resident of Wilmington, N.C., highlighted the field of more than 80 golfers.

Sandy Watson, Rachael and Rusty’s aunt, started the tournament when Watson decided that she wanted to help raise money and awareness about neurofibromatosis.

“Watson and her husband Roger have been staples in the golf community for the last four decades,” Rusty said. “They have built and managed golf courses and currently own Wildwood Green Golf Course. Their dedication to finding a cure [to neurofibromatosis] is very strong, and they have applied their knowledge of the golf business to help this cause.”

Rachael went to the tournament but she did not play. “I went to golf camps and tried golfing growing up, but I was just challenged in my golfing skill! I make a great cart driver and passenger though!”

Tournament sponsors, including Pepsi and E-Z-Go, helped raise more than \$3,000 for the Children’s Tumor Foundation in their quest to conquer neurofibromatosis through research. Tommy Pegram won low professional honors and his team captured the competition with a score of 10-under par to take home first place.

The tournament means many things to Rachael: love, support, strength and family. “When I was standing outside, with all 80-plus participants the morning of the event, I thought, ‘Wow, this is love!’ This is what life is all about.”

And the part about having a life altering genetic disorder? “I am deaf and have physical differences unlike my friends,” Rachael said. “I will deal with it and be fine...I look at things

like Kermit. It seems silly, I know, but we need to love who we are and be proud, no matter what. I see now the good things coming out of the struggles and obstacles I have faced.”

Whoever said green couldn't sparkle has never seen an emerald.