

“What is wrong with Patty?” that was the first question that I asked Mrs. Izzo when I first came home from my first day of school. For the only thing that I was excited about that day was seeing my friend that I had not seen for the past few months. I knew that she was in my English class, and I was looking forward to asking her how her summer had gone and see if we could hang out that weekend. However, that same level of excitement had dropped like a pile of bricks when I saw my friend Patty come into the classroom, except this time she was in a wheelchair and had a woman pushing her. I found out what was wrong with her when I called her mom that evening. She explained to me that Patty had been diagnosed with Lou Gehrig’s disease, a neurological disease that weakens her muscles specifically. I was in utter shock, for I found out at twelve years old that one of my best friends was sick and was eventually going to die. I am now nineteen years old, in college and have been supporting Lou Gehrig’s disease organizations over the past few years. Except I am becoming more and more disturbed at the fact that there really isn’t a lot of knowledge on Lou Gehrig’s disease out there. Lou Gehrig’s disease can kill even you. Yet the chance of the average everyday person like you doesn’t truly know anything about the disease, let alone how much of a killer it is. An explanation for this lack of knowledge is caused by the low awareness there is for this disease. Lou Gehrig’s disease is being silenced, hidden in the shadows of society. However, about 25, 000 people have Lou Gehrig’s disease in the United States on any day (Bloom, Beal, and Kupfer 537).

One of those people that just randomly got affected by this disease was Patricia. It all began when she went on her fifth grade trip to *Outdoor Ed* in March of 1999. Everything started fine, she did the rope course and ran around like all the other twelve and thirteen year old kids were doing. But then she began to notice a problem, she began to fall down for no apparent reason as well as feeling numerous trembling sensations in her arms and fingers. She couldn’t understand why all this was going on and was starting to get nervous. As soon as Patricia got home she told her mom what was happening with her and how she knew something was not right. “*She just came home and said Mom, something is not right because I kept falling and trembling over the weekend.*” (Mrs. Izzo). What Mrs. Izzo didn’t know yet was that her first born child was contracting the terminal illness of Lou Gehrig’s disease also known as ALS. What was starting to happen to Patty was that her motor neurons were beginning to die off at a rapidly progressive rate. “Motor neurons are nerve cells located in the brain, brainstem, and spinal cord that serve as controlling links between the nervous system and muscles of the body” (Judd 315). The neurons were being affected by the disease and were detaching themselves from her muscles leaving them weakened and near the point of losing all power. This is the start of a long process of degeneration of the voluntary muscles of the body; however Lou Gehrig’s disease has the possibility to start in two ways. One is called limb onset which relates in Patty’s case, where the first things to become weakened are the arms and legs. The other type of onset is called bulbar onset, which means that the things that are affected are the muscles that control the tongue, mouth, or even one’s jaw. The first signs of this particular onset can be trouble speaking and swallowing. Patricia was only a young twelve year old girl that grew up in what could be considered a normal, everyday family with her parents, her brother and her two sisters. However, this disease is known to affect people who are usually between the ages of forty and seventy, and to get it when you are young like Patty is considered a rare case. “ALS occurs throughout the world. Currently 350,000 people worldwide have the disease. It attacks persons without regard to race, ethnic group, or economic status, but occurs more often in temperate zones (Wade 48).” It also doesn’t care which sex the person that it affects, which shows the scary thought that this hideous disease truly has no preference on the people it harms.

In April of 1999, her family took her to a neurologist in Chicago where they ran every test they could to figure out what she had exactly; diagnosing Lou Gehrig’s disease is a process of elimination. They made her take every neurological test possible to see if it was some type of syndrome or other neurological disease.

One of the first tests that Patty was given was an MRI scan which was “ can reveal evidence of other problems that may be causing the symptoms for example a spinal cord tumor, or even a herniated disk in the neck (Judd 319).” Patty took other tests such as an EMG and an NCV, which are tests that are design to detect the activity in the muscles and the nerves of the body. She was also made to take blood and urine tests to eliminate the possibility of other diseases. The Doctors that worked with the Izzo family always had some discrepancy over what was actually wrong with Patty. *“The doctors that worked with us always would rule out Lou Gehrig’s disease because she was only the age of thirteen years old and you never see it in kids because kids don’t get Lou Gehrig’s disease (Mrs. Izzo)”*. Patty was finally diagnosed in July of 1999 with sporadic, limb onset, Lou Gehrig’s disease. Sporadic Lou Gehrig’s disease is one of the two types of the disease out there, and it is also the most common and is known about the least. *“There is no identifiable reason why the disease attacks a particular person... Sporadic ALS is sometimes referred to as classical ALS (Wade 50).”* This form was described by Charcot, the French doctor who discovered the neurological disease all the way back in the year 1878. This form of disease, *“it accounts for 90 percent of the cases (Wade 50).”* For the doctors that were diagnosing Patty at the time made the family look through their genealogy just to see if there were any signs of Lou Gehrig’s disease in their family, which if there was then Patty’s Lou Gehrig’s disease would be considered familial Lou Gehrig’s disease.

The Familial type of the disease only accounts for *“five to ten percent of ALS cases (Wade 51).”* However, this type is known about more than sporadic for they are actually able to see the reason for how the disease was contracted. In 1993, Lou Gehrig’s disease had a break through on this type of the disease. *“Scientists identified a defect on chromosome 21. This chromosome contains a gene that normally produces an enzyme called super oxide dismutase (SOD1). Researchers now know that a mutant SOD1 gene is associated with ALS (Wade 53).”* Even when Patty was diagnosed, the doctor asked the Izzo’s wanted to have their other three children to give blood samples to see if there was a chance that they as well could get the disease as well, but they turned down the offer. *“We had the opinion that we had gone through our whole genealogy and no one has had any sign of the disease except for Patty and they were planning to use it for research if they did get it and we didn’t want to put our children through that (Mrs. Izzo)”*. Patty’s parents had their fear become a reality when Patty was diagnosed, and now they had to figure out how to tell not only their other children, but Patty as well. *“The hardest part was for us, having the thought that there really wasn’t any cure, there are things like cancer where there are options that can cure someone, but that isn’t the case for Lou Gehrig’s disease (Mrs. Izzo).”* Mr. and Mrs. Izzo waited two days after they found out to sit their children and tell them the conclusion. They had to tell Patty that she had a fatal disease and tell her siblings that their sister was sick and there was no way to make her better. *“ John and I told them to the best of our ability but honestly there is no way to tell your children, no matter what age they might be, that kind of saddening news, the only other thing I know about that evening was crying a lot with my husband and my children (Mrs. Izzo).”* Talking with the family after that moment, I knew and understood as well as all of you could imagine that no matter what sadness and pain that I felt, their sadness and pain was at least quadrupled if not more.

From that moment on, for Patty everyday came a new struggle, and every new struggle came another feeling of sadness of losing the ability to do the simple things that every thirteen year girl was able to do. *“The best way to explain it for Patty was it would be like one day I can hit the buttons on the remote and the next day I can’t but I still have some feeling in my fingers (Mrs. Izzo).”* After a little while the Izzo family went to search for help so they had not only some other form of support, but a solid source where they could get what they needed for their daughter. The place where they found some form of help was the Les Turner foundation. However, because of how quickly Patty was weakening the foundation really couldn’t help a

lot, so the family had to use other places as resources. *“Well it just seemed like they were always a step behind the degeneration that Patty was experiencing, I mean where normal ALS patients usually have the life span of at least three to five years from the time they were diagnosed, Patty really only had **six months** (Mrs. Izzo).”* However, Patty was not left in the dark, there was treatment and equipment that through her illness that she was given helped her as much as could have been expected.

The common treatments out there for people with Lou Gehrig’s disease consist of medication for pain in their muscles as well as muscle cramps. However, Patty lucked out and didn’t have any muscle cramps. Another treatment that was made specifically for those with the disease was a drug in the form of a pill called Riluzole. The drug has been made available since 1996, however the drug is not that big of a success, for the only thing that it does is prolong the life of the patient with the disease by a few months. However, Patty wasn’t even given the option to really even take, that drug, but her family was against it anyway. *“We had heard about the drug but since it had very limited success we really didn’t want to give it to her, but she didn’t even have that option to take it because they said she was too young to take it. So even though she was an ALS patient, she was not allowed to be given it because of her age (Mrs. Izzo).”* However, the one medication that Patty was given throughout her disease was a drug that was almost like a steroid to try and slow down her quick degeneration. That is why in most of her later pictures of her with the disease she does not look like the thin and petite girl she started out to be. She had become a little bit thicker, which wasn’t a bad thing in Patty’s eyes, just different. However, Patty was also given some equipment, a wheelchair that was conformed for her body type so she would be comfortable. Then she was given some machinery to get her up the stairs since her father couldn’t carry her anymore. *“Honestly, when you carry a toddler, they are actually holding onto you, you can’t really tell but they are. Well, when John would carry her it was basically carrying dead weight because Patty had lost full control to hold on. That is when we got something to bring her upstairs, but she would always flop over because she also lost her ability to sit up on her own, so we eventually moved her downstairs into the dining room and we made it like her own room. We gave her a TV, a computer, and a radio so it was like her own and we put up bi-fold doors to close off the room so she also had that teenage sense of privacy (Mrs. Izzo).”* Later on they got her a hospital bed to make her more comfortable for when she slept, and in her last few months she had an oxygen tank and was paid visits by a hospice nurse on occasion. Other equipment that is out there, but for more normal conditions of the disease is aerobic equipment to help try to strengthen muscles for a longer period of time. *“Physical therapists can recommend exercises that provide benefits without overworking the muscles. Occupational therapists can suggest devices such as ramps, braces, walkers, and wheelchairs that help patients conserve their energy. ALS patients who have difficulty speaking may benefit from working with a speech therapist (Judd 321).”* However, even with all these options are out there for ALS patients, its very disheartening that Patty went to fast to try these options out, maybe then she could have lasted longer than six months.

While Patty was in my eyes, wasting away, I spent as much time with her as possible. Sometimes I would go over there to talk and play on her computer, as well as listen to Backstreet Boys music. The most vivid moments that I had with her was the Halloween of 1999, when I came over to her house and painted pumpkins with her since she was unable to go trick or treating that year and couldn’t go to my party. Other than that, it was the week before Christmas and her mom through a party for her since that December she was so weak she was unable to go to school anymore. I sat right next to Patty and talked to her as I got my hair done in four random braids since the theme of the party was crazy hair. Throughout our conversations, one thing at this time that she told me was that she was so happy to be able to communicate with her friends and family, for she said if she lost that she would already feel nonexistent. One time I asked her, *“Patty are you afraid to die?”* Surely enough Patty replied in her sweet and weak voice, ***“I am not afraid to die***

because even though I will not be here, I know that all my hopes, dreams and wishes will come true through the lives of my friends and family. As that happens, I will be an angel watching from heaven and experiencing that with you except it will be up in the clouds." The only funny part of her answer is that she said she had the dream of becoming a scientist that could cure diseases, and she doesn't believe that will come true for anyone else for she didn't think we were smart enough, and then she giggled and said that she was just joking. However, some of Patty's wishes did come true through the Make a Wish foundation, where she got to go to a Cub's game and talked to her favorite player Mark Grace. She got to go to the Backstreet Boys Millennium concert. Lastly, and her favorite, she went to Disney world and also met the Olson twins when they were normal. That was the only experience that I had a small remembrance of because two days after she got back she came to my house in the van and gave me a Disney key chain that had my name on it and she said that she thought of me. That is why I think our sadness about what was happening was hiding for we had all those experiences that seemed to make them go away for a long enough period of time so we could enjoy ourselves.

However, all the experiences that we had was not about to diminish the pain I felt that January of 2000. It was the morning of the seventh of January and it was supposed to be another regular day at the Izzo house. For the past few months, Patty's parents had been sleeping in her room since Patty's breathing had gotten worse since Christmas. So that morning Patty's mom knew that she was fine through the night. However when Patty's dad came to try and wake her up to come and eat breakfast with her siblings before they went to school, he felt her and he called for her mom Rosemary. He said to her, "I don't think she is breathing, Rosemary." So they called their hospice nurse to check her so that they didn't jump to conclusions, sadly enough the moment that was going to be the hardest for them to face had finally become a reality, their baby had died. Patty Rosemary Izzo was confirmed dead at 8:15 am on the seventh of January. She had died from breathing failure which is the most common form of death that a person with Lou Gehrig's disease experiences. That day I was sitting in my seventh period class when an announcement came over the intercom: "Students, teachers, and faculty, we regret to inform you of saddening news that we have received earlier today. Our beloved student Patricia Izzo passed away earlier this morning so let us have a moment of silence in honor of her. A few minutes went by. Teachers, if any of your students wish to see their counselors at this time or any time throughout the day please let them be excused." Then they went on to tell more about when the wake and funeral were and said that there was going to be a tree planted in memory of her at the new park that was going to open up that spring. Then the teachers passed out these copies of a letter that Patty wrote for her fellow students. However, I didn't pay much mind to the letter, I was thinking more about all the times I had with Patty and how much I missed her.

I went to the wake that Friday, and it was the most beautiful thing I had seen. There were pictures of her everywhere, from the time she was a baby to the times before she passed away. They also had flowers everywhere, mostly yellow which was her favorite color, as well as backstreet boy and cubs pictures from all her friends. All I did was say good bye and placed a yellow rose on her right side as my gift to her. Honestly, I think today that I could have done more but I was only twelve years old and didn't know what else I could have done. The next day was the funeral where I broke down the most because all I kept thinking was that Patty, my friend, was in that coffin and I am never going to see her again except in my memories and my picture I have of us together. I cried on my mom's shoulder because that was the only thing I knew to do. Then I said goodbye to her by kissing her coffin at the cemetery, and that was the last time I saw my first best friend. Many families go through this pain and sadness when they lose their loved one from this killer disease. However, nothing can truly prepare you for the lost of a child. As that old saying goes, your children are supposed to bury their parents, not the parents bury their children.

Well Patricia's wish has come far but not as far as it could be by now for the greatest feat of research dealing with Lou Gehrig's disease was back in 2000, when the Human Genome project came out. Scientists had announced that they had all but completed mapping out the genes in the human body. This helped out ALS research by being able to look deeper into what triggers the disease especially on finding more on the familial type of Lou Gehrig's disease. Research has now reached a plateau it seems for the most part, they have been researching with mice, and looking for ways to find new supplements and drugs, as well as more on what causes the disease on a sporadic level. Now on they are looking into stem cell research they said on one organization website, "Stem cells engineered to make excess amounts of a helper molecule can aid the survival of sick motor neurons in a rat model, providing hope that new approaches will bring success by combining stem cell and other strategies to ALS (alsa.org)." Now all this progress is trying to get done, but where are they getting all the support and money to keep researching to finally try and find a cure. Well first there is the NINDS, or in longer words the National Institute of Neurological Disorders and Stroke. "NINDS focuses on cause, diagnosis, treatment, and prevention of neurological diseases. Its budget for 2000 was nearly \$891,000,000. These funds provide for the study of disorders such as ALS, Parkinson's, and Alzheimer's, multiple sclerosis, stroke, and brain tumors (Wade 100)." Other than the NINDS, there are many organizations that are out there that help support not only the research, but the ALS patients like Patty everyday.

For example the Les Turner foundation which was created in 1977 in honor of Les Turner, a great Chicago business man who was diagnosed with Lou Gehrig's disease in 1976. The family created the foundation for they were "frustrated by the lack of information and research on ALS at the time... it began with on patient and now serves six hundred patients annually. The foundation has raised more than \$33million to fight Lou Gehrig's disease (lesturnerals.org)." Then there is also the ride for life organization that is based in New York and once every year takes as many patients and members on walk for a few days to raise money for ALS research. There's also the ALS organization, which offers help for the ALS patients that join and try to help raise money for research and is the most common ALS organization. However, one thing that puzzles me and should puzzle you as well is, with all this money being raised for research and great fighters dying from this quiet disease, why is it not really in the media anywhere except for the internet? Well, there really isn't a good answer. For there really has never been any talk on the radio stations about anything related to ALS research. Not to mention the last recorded talk of Lou Gehrig's disease on the TV was only when Stephan Hawking was on Larry King live which was aired in December of 1999. Since then there has really been nothing unless you try to find an organization on the internet that can increase the awareness of the average human being like you who should care that thousands upon thousands of people die and are diagnosed with Lou Gehrig's disease everyday, yet your only resource is the internet. If the media, for instance has enough time to talk about shootings and robberies in the U.S. as well as the new diet fads for this year, couldn't they look at something that kills just about as many people as cancer does daily. Our media should offer more news on things that could save people's lives, not what can make them worse.

Lou Gehrig's disease already has a small voice due to mostly the life span of those whom it affects, but the voice can become greater with heightened awareness. The only voice that is technically out there is the great Stephan Hawking who has been diagnosed with Lou Gehrig's disease since the age of 21; however he is very old which give off the controversy whether he really has the disease. "I am quite often asked: How do you feel about having ALS? And the answer is, not a lot. I try to live as normal a life as possible, and not think about my condition, or regret the things it prevents me from doing, which is not that many (hawking.org)." However, the people like Stephan Hawking and Patricia Rose Izzo would probably have or

have lived different lives if the awareness to help research was better. Greater awareness equals more research being done and the more research the faster the cure will come to save the lives of millions. Before Patty died she said that another one of her wishes was that a cure will be found for Lou Gehrig's disease in the next millennium so that her death will mean nothing for awareness to help find a cure. However, at the plateau that it is at now it is scary to think, how many other people are out there thinking like Patty right now thinking that they will die in vain without a purpose? That all it could take to change that thought by a one minute commercial clip talking about Lou Gehrig's disease and ways to help donate for research. Yet that still goes unseen.

While Patty was sick she explained to me how when she died, she hoped that more eyes would open up more to awareness. So far in society it appears that that hope is slowly dimming. Some people know and understand this cruel disease that has no preferences, and others like the media seem to turn a deaf ear when so much could be done. Patty's hope along with those other brave fighters of this disease will only become a reality when awareness of Lou Gehrig's disease is greater than it is now. For if awareness increases, maybe people like Patty would then truly make a difference, by helping educate others to support a search for a cure. Awareness needs to become greater and society needs to do better. Then maybe the researchers will reach their goal, and Patty has been granted her dream for there will be a cure found for Lou Gehrig's disease.