

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

September/October 2021

From The Editor's Desk

Hello Friends,

To usher in a change in seasons, we thought it was time to freshen up our look. In the pages that follow, you will see some new images, headings and layouts, along with the same great content that you are used to finding in your monthly inbox. This issue is a combination September/October newsletter.

Whether you are looking for information, memoirs, encouragement, armchair traveling or just pure fiction, you will find it all contained herein! Tom starts us off with part 2 of his memoir, "The Day I Heard the News." Be sure to check out our last newsletter if you missed his part 1 introduction.

In VoicePoints, Dr. Kirtane from the Moffitt Cancer Center gives an overview of what immunotherapy treatment for head and neck cancer is all about.

The reading continues with Aaron's book chapter along with a lovely story to spark your sense of wonder and imagination. Wayne takes us to Peru for another armchair adventure and Don reminds us that while failure is a part of life, it does NOT have to define our WAY of life.

We are also pleased to welcome Erin Guidera, speech pathologist, as new co-coordinator for the VoicePoints column. Written "for professionals by professionals," this column aims to discuss a variety of professional topics related to voice and laryngectomy, written by people in various areas of specialty practice. Erin has already been instrumental in seeking out several of our recent contributors, including Dr. Kirtane, to provide us with new and engaging information.

Erin writes the following introduction: "I just wanted to take a moment to introduce myself. My name is Erin Guidera and I am the new co-coordinator for the VoicePoints column of the WebWhispers newsletter."

"I am a speech pathologist at H. Lee Moffitt Cancer Center & Research Institute in Tampa, FL where I have worked for 11 years. I am a board-certified specialist in swallowing & swallowing disorders (BCS-S) and have specialized training in oncology care including management of head/neck cancer. I have two young children, a 2-year-old daughter and a 5-month-old son, who are

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the light of my life. I look forward to connecting with you all and producing an educational column for our readers." Welcome, Erin!

I hope you enjoy our new look! Stay tuned for more great articles by this month's featured as well as our other returning newsletter contributors in the upcoming months. We would also like to personalize our newsletter by including pictures of YOU, our members. If you have a photograph of yourself or yourself with loved ones to share with the community, please submit jpgs to the editor. We will include images as we are able and as space permits.

Our goal as always is to provide engaging and accurate, up-to-date information and advice from those who have been there about head and neck cancer and life after laryngectomy.

Whether you are a patient, caregiver, speech pathologist, or other medical professional, we welcome your contributions and your feedback. Please consider taking a moment to reach out to us through email or the webpages. We look forward to hearing from each of you.

Kim, Donna, Tom, and the rest of the gang at Whispers on the Web.



The Scuttlebutt

The Day I Heard the News Part 2

(Continued from August 2021)

As I sat in the chair with the scope down my throat, I looked up and saw actually beautiful pink tissue, except for the charcoal gray cocoon-like mass covering about two thirds of one of my vocal cords. I suggested it was cancer before the doctor could get up the guts to tell me. He was surprised himself. He told me that I would need radiation and probably chemotherapy and that my chances of survival were in the high 90% range (that was not true). He mentioned that some people require

surgery but he didn't think I would need that. I still was not afraid, more like stunned.

As I got to my truck in the parking lot, the morning sun was facing the back of it. Except for the sun, it was slightly cool outside but would not be for long. As I leaned against the back of my truck absorbing what I had just heard and the warmth of the late morning sun, I realized the greatest fear I had ever known. Now, I have to tell people. How do I tell my wife and children, the grandchildren, my mom and dad, and so many others that I have just been diagnosed with throat cancer? Still not having the words, I

continued to stand there when suddenly another fear occurred to me. This could kill me! It was almost a fleeting thought.

Immediately, I connected or maybe re-connected with the faith in God I had known all my life. I contemplated everlasting life and thought about how I always knew that God was with me. I had been taught that and believed it. Then I asked myself " if you believe what you've always said you believe, then there is nothing to be afraid of. It's okay, either way". In a quick but sincere prayer, I told God "Finally, I get it, Lord. You are with me in my living and in my dying. Either way, this WILL be okay."

My wife, Julie was out and about with our daughter Bonnie and the first two grandchildren, Owen and Lydia, so she was occupied. I would call her soon. I thought about the fact that my parents knew where I was that morning and they were probably on pins and needles waiting to hear from me. I knew that forever I would remember September 3, 2013. Then I remembered this was my parents 58th wedding anniversary. Mother is sometimes one to overreact and to think the worst, and I knew that she would answer the phone quickly when I called.

"What am I going to say to her, I pondered, how do I say this to her?" How do I tell anybody? I can't just call and say "HAPPY ANNIVERSARY! , I have cancer", could I?

I don't quite remember what I said or how I said it but I did acknowledge the anniversary somehow, and she reacted to the news as I expected. Mom's silence told me she was crying but trying to keep me from hearing her. I made the announcement with as positive a flair as I could come up with and reminded her several times that the doctor had said my chances of survival were very high. (he was wrong about that). I tried to reassure her that the doctor expected me to do well with the treatment.

Being who she is and how she is , I am sure her first words were probably " O my God". As much as she may have tried, she undoubtedly

began worrying about me immediately . She continued to worry throughout my journey until just recently, but even now she still holds on to some concern for my health. She and daddy both worried but the time would come when they could rejoice in seeing how I came through the fight, still standing, even though things got much worse before they ever got better.

So I then called Julie and told her the news, with all the high survival stuff, it is treatable etc. in one long sentence before she had a chance to react. She simply said "I know you. You can fight this. We can fight this and we will beat it. We will beat it." Hey thanks, I thought, my first official cheerleader!

She continued to encourage me and cheer me on when I needed it. At that point we had been married 35 years and we had been through quite a lot together, but yep – This was the biggie. I had cancer. She encouraged me to join the four of Chi-fil-A them for lunch and of course we would not talk about anything around the kids. At 3 ½ and 2 ½ , they would be terrified that their "Poppy" was sick in any way.

While the kids took over the Chik-fil-A indoor playground, Julie, Bonnie , and I ate, me albeit slowly. We did not avoid "the " topic, but I don't think we talked about it much either, except for my daughter jumping on the encouragement wagon, every bit as positive as her mom. Of course, at that point we did not know what to say, what to think, or what to expect. Life would go on, and it has beautifully, but I did not know where I was headed; at that point, not a clue.

To be continued in our November issue.

***Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President***



Voice Points

Voice Points is written by professionals for the lary community and is coordinated by Kim Almand M.S., CCC-SLP and Erin Guidera, M.S., CCC-SLP. Please contact them with contributions or questions at Kalmand@uthsc.edu or Erin.Guidera@moffitt.org

New Treatment Options for Head and Neck Cancer

Immunotherapy is a relatively new treatment for head and neck cancers. It is a medication given through an IV that tries to get your immune system to attack the cancer. Even though cancer cells don't look like normal cells, they have figured out a way to mask themselves, thereby hiding from the body's immune system. Immunotherapies try to take off this mask allowing the immune system to recognize the cancer cells and then attack it.

When these therapies are given, the infusions usually take thirty to sixty minutes. The side effects of these therapies tend to be different than traditional chemotherapy. Sometimes patients can experience side effects where the immunotherapy overstimulates a person's own immune system and results in a rash, muscle aches/pains, diarrhea, fatigue, or breathing difficulties. It is important to keep in close contact with the healthcare team to tell them of any side effects since, in a small number of people, these can be life-threatening.

As of 2021, immunotherapy is only approved to be given to patients who cannot get surgery or radiation treatments for their head and neck cancer. The two immunotherapies currently approved for use in head and neck cancer are called Nivolumab and Pembrolizumab. They both work by blocking a special receptor called PD-1. When these immunotherapies are given,

it is not used for cure but rather to prolong the quantity and improve the quality of life of a person with head and neck cancer.

When immunotherapy works, it generally works well. Unfortunately, it only causes the cancer to shrink in about 20% of patients. There are several clinical trials involving immunotherapy that are attempting to figure out how to make these therapies work for more people. It is highly recommended to ask your doctor about what clinical trial options you may be eligible for before starting any treatment plan.

Kedar S. Kirtane, MD

Dr. Kirtane is an Assistant Member at Moffitt Cancer Center in the Department of Head and Neck-Endocrine Oncology. His clinical focus is patients with head and neck endocrine cancers. He is interested in working with the Department of Health Outcomes and Behavior and the Department of Cancer Epidemiology to help increase access to cancer care for racial/ethnic minorities with cancer. Dr. Kirtane's research interests include the development of innovative cellular therapies for HPV-related malignancies.



My Neck of the Woods

Don't Be Afraid to Fail: Be Afraid Not to Try

By Don Renfro

Have you ever thought to yourself "I won't do ... because I might fail"? I don't know about you but at some point, in my life, I believed I should only do ... if I could do it perfectly. Perfectionism was a way of life.

What I came to understand was, that was a built-in excuse why not to do.... Today I believe I am not able to do anything perfectly, but I am more than capable of doing the best I can. And in most all cases that is more than good enough.

When I look back on my life, I see that none of my best accomplishments were made perfectly. Most if not all of them had bouts of imperfection as well as pitfalls along the path of completion. The truth is, had I waited till I could complete them perfectly I would have never accomplished them at all. The reality is that failing is a part of life but for most of us it is not a way of life. The truth is that many times my failures are what lead me to some of my greatest accomplishments.

Failing to make a decent living without an education is what lead me back to school and my college degrees. I worked at different employment, gas station, factory, painting trucks at a beer distributor all before I entered vocational rehabilitation. I worked at a mental health facility as the vocational coordinator where I was exposed to the Department of Rehabilitation. The company I was employed with went out of business and a lady I worked with from the Department of Rehabilitation encouraged me to apply and offered to prep me to interview there. I began applying for employment at the Department of Rehabilitation in 1992. It was not until 1997 that I would be hired.

I said it was my failures that lead me to complete my education. When I first applied to the Department of Rehabilitation, I was told I needed more experience.

I've missed more than 9000 shots in my career. I've lost almost 300 games. 26 times I've been trusted to take the game-winning shot and missed. I've failed over and over and over again in my life. And that is why I succeed. – Michael Jordan

I got more experience. Then I was told I needed to complete my bachelor's degree. The problem with that was I was not making enough money to support my family, myself, and an education. If I could get a job at the Department of Rehabilitation, I could afford to finish my degree. I interviewed all over Southern California without success. At the time the Department of Rehabilitation was beginning to move toward requiring a bachelor's degree for employment. I had interviewed for a man in Los Angeles. I did not get the job. That same man called me back for another interview about a year or so later. I knew he knew I did not have my degree yet, so I figured it did not matter as the Department of Rehabilitation had not made it mandatory to have a degree to be hired.

He scheduled me for an interview at 8:30 am. The office was in Los Angeles which was about 45 miles from where I lived and I would be traveling in rush-hour traffic. To make sure I was there by 8:30 I would need to leave by 6:30 am. I got there and went into his office for the interview. It lasted what seemed to be about 5 minutes. He asked me did I complete my degree yet? When I said no, he ended the interview. I left the office and was so angry that he had brought me out there to Los Angeles in rush-hour traffic when he knew I did not have my degree. I had submitted a new application for the new interview that stated I did not have my degree. I left the office so angry I went straight to college and enrolled to finish my degree.

My failure to get the job led me back to school. I did not care that I could not afford it on my current income. I was determined to get my degree if I had to go broke doing it. I not only finished my bachelor's but then I would continue to earn a master's degree and then enter law school. It was shortly after that interview I was interviewed by another office and was hired. I was able to tell the supervisor I was in the process of completing my degree and was currently attending school.

It was my failure, to initially get hired, which led to my success in completing my education and working at the Department of Rehabilitation for over twenty years.

THE SILENT PARTNER

My First Year as a Laryngectomee

Chapter 7: Radiation & Claustrophobia

The doctors decided that I would not need chemotherapy but they did want me to undergo thirty radiation treatments. It wasn't mandatory, just highly recommended. I was informed that, with radiation, the chance of recurrence of the cancer was reduced from 40% down to less than 20%. That didn't make me feel too much like going through with it. By putting it that way they made it sound like I could expect a recurrence in any case. I finally decided that I would go through with it despite my aversion to sticking my upper body into an enclosed space.

I was given an appointment to be fitted with a plastic form that would cover my head and shoulders to keep me immobile during the treatment to assure that the radiation went exactly where it was supposed to go. This involved heating a plastic form to 160 degrees and then pressing it down over me to form it to my head, neck and shoulders. When finished, it would be placed over me when I lay on the sliding table that would roll me into the machine and fastening the form to the table securely with nine plastic snaps. Medicare was billed \$\$\$\$ for a 'Device' made from pennies worth of plastic. (They ended up actually paying only \$ plus my co-pay of \$) The thing looked like a fencing mask to me, and a photo of it I briefly used as a profile picture on facebook was mistaken for a fencing mask more than once.

It was then that I insisted on some sort of sedative to keep me from panicking and was prescribed thirty lorazepam 1mg tablets. Yeah, thirty – one for each treatment, to be taken before each of the thirty treatments. It usually took a little over an hour from home until I was fastened to the table, so I took a pill just before we left for the day's appointment. Naturally the machine broke down one day while we were underway to the appointment, effectively wasting one dose. Fine, I could get through one fifteen minute treatment



without it. So, at the very next treatment, I did. During every treatment they would play whatever music I requested, so for that session I requested the 'Moonlight Sonata', second movement. That is my favorite music to hypnotize myself by. As I usually did, I started counting off the seconds to pass the time, and when I passed seven hundred I started getting anxious and was seconds away from a panic attack by the time the machine shut off and started to roll me back out. By the time they got the mask unpinned, I had broken out in a cold sweat.

The machine broke down a couple more times, and I informed the technicians that if it ever broke down with me in it, that would be the last treatment for me. Ultimately I was able to finish all thirty of the treatments. Then, just to be sure, they had my neck and chest scanned some more to see if there were any more suspicious spots.

During the treatment, I was advised to use Aquaphor® on my neck to mitigate the skin irritation that the radiation caused. Toward the end of the treatments I was prescribed silver sulfadiazine cream and a dressing for the burns. There was also supposed to be something for the inside of my throat, but for some reason I never got it.

I had lived through the beginning of the atomic age when people were building bomb shelters and students were being taught to hide under their desks, through the Cuban missile crisis, and training in ABC warfare when I served in the U.S. Navy, but I never thought that I would have to be treated for third degree radiation burns in the twenty-first century!



This Lary Life

PERU '99

W. C. Baker

There seemed to have been an aura to Peru that infused me with feelings of anticipatory energy that were fulfilled. Maybe it was the coca leaf tea that I freely imbibed. Likely it was just in my mind, but that doesn't make it less real. Peru is in the same time zone as the Eastern U.S., but the opposite season, although that makes little difference because of its proximity to the equator.

Lima, *La Perle del Pacifico* (The Pearl of the Pacific) is vibrant, alive day and night. For the academics among us, it is the home of the oldest continuously functioning university in the Americas, The National University of San Marcos, founded in 1551. For the rest of us, it provides an interesting place for the study of Peru's history and culture.

From the Capitol Square with an armored anti-riot vehicle lurking nearby and Pizarro's final resting place to the museums with mummies, ancient fabrics, and jewelry, Lima is profoundly

interesting. At night it comes alive with music and dancing and seemingly happy people strolling the streets and parks.

"Lima", by the way, is derived from the native Quechua word "Lima", an Inca oracle, and means "talker" or "speaker". We stayed at Miraflores, an upscale district, and especially enjoyed Parque Kennedy. Like other Spanish places, it comes alive at night.

Our plane was tossed about quite significantly in the process of landing at Cusco airport. Planes are buffeted by side drafts, updrafts, downdrafts, and possibly inside-out drafts generated by the hills on either side of the approach. It made for the hairiest landing since my student pilot days in a two-seat taildragger.

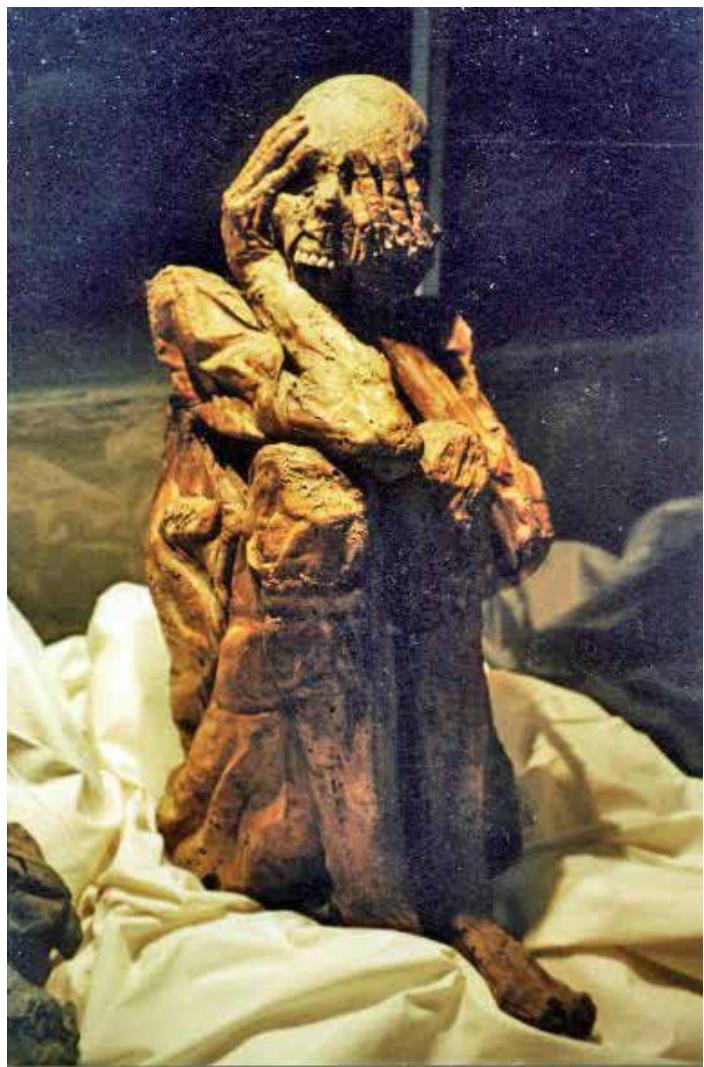
The favorable impression of Cuzco may have been influenced by the knowledge that it was the capital of the Incan Empire. It could also have been because of the New Year's festivities.

On June 21, the winter solstice south of the equator, the Incas celebrated the return of the sun with the Inti Raymi (Sun God) Festival. Long prohibited by the conquering Christian Spaniards, the celebration has returned with gusto. The grounds of the large fortress on the north edge of Cusco, are filled with formations of natives reenacting what were believed to have been the old Inca rituals. The huge stones are so expertly shaped that they fit together without cement so tightly that a piece of paper could not be inserted between them. At the plaza in town, there is a more Christian tone as saints are paraded in iconic form. Cusco was brought to popularity when nearby Machu Picchu was discovered.

A three or four-hour train ride will get you to Agua Caliente from which a bus can take you up to Machu Picchu. Alternatively, 4 days of hiking 25 miles on the Inca trail will get you to the Sun Gate of Machu Picchu. It might seem that 6 miles a day should be a snap for an experienced hiker, but hiking at altitude is more demanding and the high point Inca Trail is 13,776 ft. There is a shorter and lower one-day hike that can be a rewarding compromise.

I can't vouch for the longer trip, but the shorter hike is spectacular. Both end at the Sun Gate and give an amazing revelation of Machu Picchu. What is revealed is a panorama of levels of stone-walled, roofless buildings surrounding an extensive green that stretches to the familiar conic mountain and the buildings extending to the very edges of the precipitous drop to the jungle below.

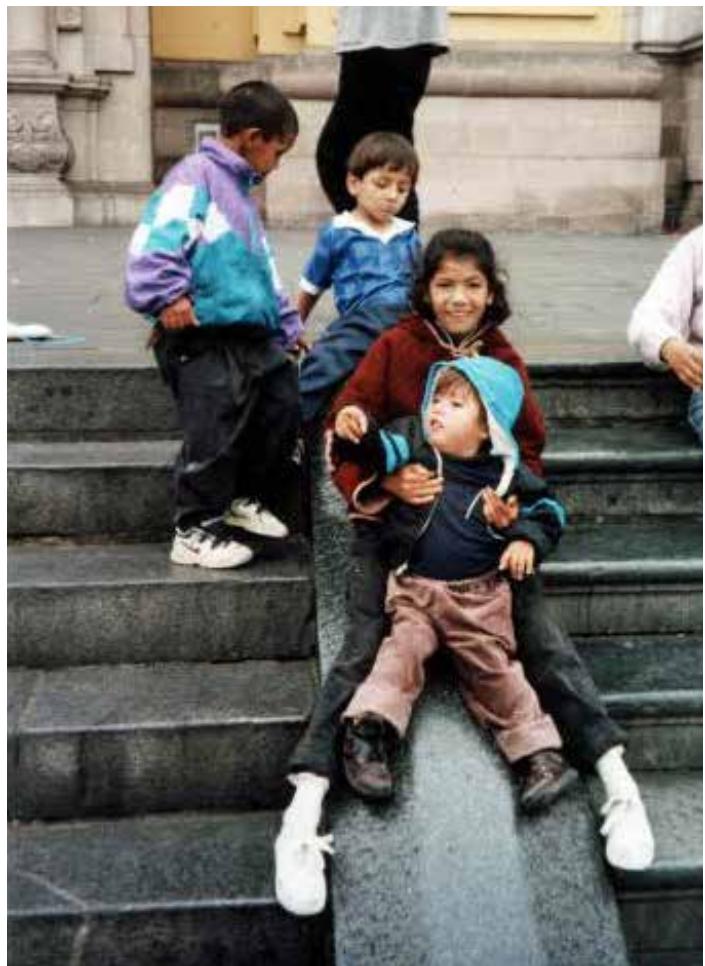
The mysterious and spiritual aspects attributed to Machu Picchu are largely the product of romantic imagination. Machu Picchu had a temple but was not a religious site to the Incas. Nor is it ancient. It was built some 3 centuries later than the great cathedrals of Europe. What it is, is a spectacular representation of what could be achieved by a culture that had neither the wheel nor iron tools. On July 7, 2007, Machu Picchu was declared one of the New Seven Wonders of the World.



It may have been the altitude, though we had been at altitude for about two weeks. More likely it was the drier air that caused the coughing spell that had to have irritated the other passengers on the overnight train through the Andes. Machu Picchu had been quite humid, and we had enjoyed the hot springs at Agua Caliente before boarding the train to Puno at the Bolivian border. Whatever the cause, it was one long night of coughing. The first time I had such an experience.

The most interesting thing about Puno is that it is on the shore of Lake Titicaca, at 12,500 feet the highest navigable lake in the world. Lake Titicaca is home to many floating reed islands. These are home to thousands of Indians from the Amazon who are said to have built the reed islands to escape oppression by the natives by moving their islands to the center of the lake.

Walking on these reed structures with their reed homes and reed boats is a unique experience: like walking on a sponge. These self-exiled Indians have done quite well for themselves, being visited by thousands of tourists every year. The 129-mile length of Lake Titicaca extends into Bolivia, but we walked from Puno to the border to take a taxi into La Paz, the world's highest capital city.



For me, La Paz was something of a love-hate relationship, sort of like New York. It is a whirl of jostling people, hawking vendors, and marching demonstrators, honking cabs, and spewing diesel minivans, but in the end, you gotta love it. After the raw energy of the place, what I loved most were the museums of ethnology, art, metals, fabric, and even coca. We joined a demonstration in the evening, but I don't remember knowing what it was about.

On to Ecuador.





The Silent Knight

by Aaron Wayne

Emily sat on the stone sobbing silently. She had been lost in these woods for hours now and was tired, hungry and scared. Emily had played in these woods often and she thought she knew them well, but this time she had wandered a little too far and had no idea where she was. More importantly, she didn't know where her Aunt Grace's house was, nor how to find it. She knew it would be getting dark soon and it was already getting cold. She chided herself for running off like she had. She knew Aunt Grace loved her and only wanted the best, but young Emily also thought that she knew what was best for Emily. So she had run into the woods to avoid the long boring drive into town for clothes shopping.

Emily was sure that Aunt Grace would be looking for her, but she hadn't heard anyone calling for her in hours. Not since she had fallen asleep where she had hidden herself

under a bush. When she woke up, she had been disoriented and had started back to Aunt Grace's house only to find herself in a very unfamiliar part of the woods.

Now as she sat on the stone and starting to shiver a little, she remembered the stories Aunt Grace had told her about the knights who came to rescue damsels in distress, and was praying that one such knight might find her in the woods and safely see her home.

She had never been afraid to be in the woods alone before this, but now it was different. The woods were different. It was quiet – too quiet. She couldn't hear a single bird. There was no wind to whisper in the trees, no chirping crickets. Just silence.

Then she saw a small movement out of the corner of her eye. She looked up to see a man stroll silently out from the shadows. He was wearing what looked at first to be a white helmet. Was this her knight? As he grew closer she saw that it was some sort of mask, made of a sort of plastic mesh, covering his head and the top of his shoulders. At his throat there was a hole in the mask and a small round plug in the center of it with a bright clear green stone on it.

The man quietly sat on the end of the stone a few feet away and gently offered her his hand. Emily wasn't quite sure what he wanted, but if he was really her knight there to rescue her, she decided that she would trust him and took his hand. Without a word, he soundlessly rose and gestured toward the direction he had come. Emily rose with him and they began the walk out.

Later, when Emily told the story of how she was found, her story was met with some skepticism. No one knew how she had gotten home safely or had seen anyone with her, so they had no idea why she called her rescuer the "Silent Knight".



See you in November!