

## Claire's Story

While watching this video, I was amazed on how positive this young lady is. She never wanted to be known as a "sick" individual or to be felt sorry for, instead she wanted to empower those who have a terminal illness to know they have the ability define the illness and not allowing the illness to define them. Regardless of the situation life gave her, with continuous shortness of breath, having to take medications continually, breathing and percussion treatments, daily insulin injections, and having to eat a high calorie diet daily she remained positive. This young lady had to deal with a chronic cough, fatigue, chronic weight loss (hence high calorie diet), in and out of the hospital for three-quarters of her life, enduring 35 surgeries (not including her lung transplant). Her sputum and phlegm was very dense making it difficult for her to clear her airway without assistance. She had so much medication, such as pancreatic enzymes every time she ate something to decrease the number of stools she had daily, monitoring her glucose levels in order to keep her blood glucose levels to keep levels her provider wanted her to maintain.

Most likely Claire needed a physical therapist, occupational therapist, psychologist, dietician, nurses, doctors, and respiratory therapists involved in her care. This family had to endure high costs of medications, therapies, and the cost of her lung transplant. She started her own foundation to help other families who are dealing with cystic fibrosis to assist them financially while their child was being cared for.

The one thing I learned from watching this video was how to utilize a different approach to my patients. Not feeling sorry for them but encouraging them they have a choice to have their disease to prevent them from accomplishing their life's desires, or they can do the best they can to accomplish their dreams and desires. Claire was an inspiration to others by stating, "I can't wait for someone to give me permission", "health itself is never going to make your life better. Being healthy doesn't matter, it's what

you do with your health.” The one thing she stated really sticking in my mind is, “I have lived the kind of life that all of you have been running from all your life. I am dying,” and “how do we stop pitying people who are sick and start empowering them,” “most of us go our entire lives without knowing ourselves.” Claire had a dream to go clubbing just one time, she never got to go clubbing. Her mother stated, “her surgery went perfect.” When she passed away her mom thought everything would be ok, because Claire was a “beater of the odds” “larger than life,” and she changed and touched a lot of people.

My goal is to empower others. Encouraging them they have control to a point to live happy and as courageous as Claire was.