Research Paper: Interview -- Cystic Fibrosis

Sitting on the cold concrete floor, my grandmother and I were going through old pictures that had piled up in her basement. All of them were family members who I had never seen before. Some were relatively new and others seemed to be falling apart. A few even dated back to the late 1800s when our family still lived in Ireland. One picture in particular caught my eye. It was of a young girl no more than 5 years old who had a faint smile on her face and looking at someone behind the camera. Her hair was unevenly cut but there was no doubt about her beauty. On the back it said, *Jane Doe.* My grandmother told me that she was my dad's cousin. You would never have guessed how sick she was by how lively she looked in the picture. My grandmother explained that her and her brother Michael had cystic fibrosis and died at a young age. She smiled and said that she remembered going on picnics with the family and teaching the kids how to swim in the lake. She said that they "died too young for such strong-willed children" (Doe). With that in mind I collected their photos and started researching cystic fibrosis and how it can take the lives of those who least deserve it.

Jane and John Doe were married in the early 40s. Soon after they had their first son, Philip Jr., or as he would later be known as; Chick. Chick was an only child for a large portion of his youth but in 1956 when he was 10, his younger sister Sheila was born. They were very happy together until Sheila became sick. It was clear to the many doctors that they met with that her symptoms of coughing, trouble breathing, and constipation what was wrong with her. When she was officially diagnosed with cystic fibrosis, her mother was already pregnant with her third child. Michael was born in

December of 1957 and like his sister he too was diagnosed with cystic fibrosis. The disorder completely changed the dynamic of the family. In order for them to receive the best treatment (which was not much at the time) they constantly were commuting to hospitals in Boston. Chick and their parents had to be with the children at all times to hit them on the back when they had difficulty breathing. My grandmother had just married my grandfather when Sheila died in 1961. She was five years old. My grandmother said that Sheila's death was one of the most tragic experiences of her life. Losing a child is an unimaginable feeling but to watch another child go through the same process is even more heartbreaking. Helen and Philip continued to bring Michael to different hospitals hoping for a treatment but at the time researchers didn't know what caused it, nevermind how to treat it. Michael struggled with the disorder until he died at the age of seven in 1963. RIght after Michael's death Helen had one more child, Mary. Mary, to the delight of everyone, was born without cystic fibrosis. My grandmother said that she was "a Hail Mary, sent from God himself". Despite the happiness that accompanied the good health of Mary, the death of any children in a family is enough to break any marriage. Helen and Philip tried for many years but ended up divorcing in the early 80s. Chick, who never forgot the suffering of his younger siblings vowed to never have children so that he would never be forced to relive it. Mary married later in life and had two healthy children (Doe). While they were able to live on with their lives Sheila and Michael's deaths had a profound and lasting impact on the family forever.

Since cystic fibrosis is a recessive gene that means that both Helen and Philip had to be carriers in order to pass on two recessive alleles ("Cystic Fibrosis: What Is

It?"). Since Mary and Chick did not have the disease they could either be carriers or not have the gene at all. There is no way of determining this however unless they were tested. Both Sheila and Michael had many of the symptoms mentioned in my original research paper. Their cases were both severe and their difficulty breathing, poor growth, and dehydration were factors that made their lives more difficult. During this time period very little was known concerning cystic fibrosis. The lack of information on the subject made it difficult to determine the exact cause and severity of Michael and Sheila's disease, since it is now known to have many different variations. In the past few years alone however, there have been many leaps in scientific progress with the disorder. Instead of hitting them on the back, patients can use a vest which vibrates their chest and more effectively clears the mucus from their airways. The medications they took, if any at all, were ineffective due to the lack of understanding about the disease. Today certain medications can target the abnormal proteins that cause the disease and helps them to function properly ("Cystic Fibrosis"). If Sheila and Michael had had the access to the treatments and medications that are available today they would most likely have lived many more years.

Hearing the struggles of this family through my grandmother's perspective, since she was very close with them, has shown me the reality of the disease. It is more than a missing or defective gene because how it affects the family means so much more. With today's scientific research families do not have to be torn apart by what once was a death sentence.

Works Cited

"Cystic Fibrosis." *American Lung Association*. American Lung Association, n.d. Web. 27 Dec. 2015. <http://www.lung.org/lung-health-and-diseases/lung-disease-lookup/cystic-fibrosis/>.

"Cystic Fibrosis: What Is It?" *Cystic Fibrosis: What Is It?* Josiah Macy Jr. Foundation, n.d. Web. 27 Dec. 2015. <http://www.yourgenesyourhealth.org/cf/whatisit.htm>.

Doe, Jane. "Cystic Fibrosis Interview." Personal interview. 7 Feb. 2016.