



Evening with the Eagles November 17, 2003 Janet Napoli

Good evening and thank you all for coming tonight. I'd like to thank the Cystic Fibrosis Foundation for the opportunity to share my story.

Several months ago while I was sitting in my doctor's office waiting for my appointment I happened to pick up and read the CF newsletter called "Commitment." When I finished it I thought "What could I ever do to help raise money to find a cure for CF"? Two days later I received a phone call asking if I would be the guest speaker at tonight's event. So here I am!

Typically people think of CF as a "children's disease," but after tonight you will realize that you can never be too old to be diagnosed with CF. For now, because of the many wonderful people such as you who donate their time, talent and money to fund research for CF, the average life expectancy for children with CF is 32 years. But we still have far to go, because too many young people are dying before their 21st birthday and that's why we're here tonight.

I don't want to bore you with every little detail of my past but if after I'm done you have some questions you would like me to answer please feel free to approach me later or send me an e-mail. My e-mail address is VisaJanet@_.com. Yes, that's Visa, like the credit card. Actually, if there's a perk to having CF for me it's this. It's when that monthly Visa bill arrives. While my husband is fretting over it, I give a few good (cough here) and never is a word mentioned about the balance. (Pause) Although some months I have to cough more than others.

I'll start by answering a question that probably most of you have on your minds. I'm 45yrs old. At 19, I had half of my left lung removed because of bronchiectasis. That's the lung condition that all CF patients have. But at that time, they did not think I had CF. They just thought it was an unexplainable case of localized bronchiectasis. I've always had a cough growing up but that year I had several episodes of bleeding from my lung. After all the usual tests, including three sweat tests within the normal range, it was determined that I was otherwise healthy. The surgery went well and I continued my education to become an x-ray technologist and then married my high school sweetheart Rich.

Over the next few years, both my cough and moderate bleeding returned. Further tests showed that I had developed more bronchiectasis in what was left of my left lung. This was treated with oral antibiotics on and off for the next 17 years. During that time we had three healthy children all of whom are CF carriers.



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About 8 years ago, just after moving to Philadelphia, I began having larger episodes of bleeding and frequent lung infections. Because of the bronchiectasis, my last doctor recommended that I go to a CF specialist since he would be the best to treat this type of condition. It was at that time, at the age of 37, that they seriously tested me for CF. The genetic test at that time showed that I carried one gene, which meant I was a carrier. My sputum cultures on the other hand revealed that I had some of the more serious infections in my lungs normally associated with CF. These infections required long-term multiple antibiotics and nebulizer treatments. Did I have CF? They couldn't say yes for sure. I didn't fit the usual CF pattern. My insurance forms read bronchiectasis. These bleeding episodes didn't stop. I was in and out on the hospital many times and on 5 different occasions I had pulmonary embolizations preformed hoping to stop the bleeding. When these procedures weren't successful I had no choice but to have the rest of my left lung out.

I had my surgery preformed at HUP on 7-14-99. They did an outstanding job and within 5 weeks I was on our yearly family vacation to Lake George, New York. One and a half years after surgery I changed doctors to the adult CF department at Presbyterian Medical Center. I would like to say thank you to all the wonderful doctors, nurses and staff who treat CF across this country, but especially to the ones that I have had the good fortune to encounter at Presbyterian Medical Center. Going for my appointment is like going to a social event. Yes they examine me, perform tests, and treat me but in between it all they ask about my family and interests and then they share theirs. I consider them friends who truly care about me and that makes going for my checkups pleasurable.

So now, at 42 I was being retested for CF and the latest genetic test discovered my second gene. My sputum culture showed that I developed another serious infection in my lung but an 18 month course of antibiotics cleared this up. Since my surgery, which was 4 years ago, I have been on one 18 month course of antibiotics for a serious infection and 3 very short term courses of antibiotics for minor infections. I speed walk every morning, use an inhaler twice a day and the nebulizer at night. I've also recently added the vest therapy to my routine. My energy and quality of life are excellent. I never expected to feel so well after my last surgery. But the story doesn't end there.

You see I am one of five children. I have an older brother George who is now 49yrs old. Unlike me, my brother was a born athlete. Growing up, while other little boys slept with their teddy bear, George slept with a basketball. Well, actually he slept with his basketball and his teddy bear. He loved sports. He played basketball in high school and college. Up until the age of 34 my brother never exhibited any signs of cystic fibrosis. Because of a bad knee injury he went out on disability from the NYC police force and then moved to Florida.



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For the next 12 years, from age 34-46, he suffered from what his doctors diagnosed as severe allergies, asthma and sinusitis. When genetic tests found my second gene I called George and begged him to be tested. My brother said to me “Janet, Whoa! I couldn’t possible have what you have -- your much sicker than I am. My brother’s condition only got worse. He was eventually tested and it showed that he too had the same CF genes that I do.

He is now being properly treated at an adult CF center. Recently George had a portion of his right lung removed due to a micro resistant infection in his lungs. He really suffered for over two years taking multiple antibiotics and nebulizer treatments to clear this up. This type of deadly infection does not affect a healthy person because they have the defenses to fight these germs off. In fact these bacteria live all around us in the dirt, air and in the water. But for a person with CF, these germs find a perfect, fertile growing medium in our lungs that make the bacteria thrive. And that perfect medium is mucus. Mucus that our bodies produce too much of. Mucus that we try to beat out of us daily through chest therapy, exercise and vest treatments. Mucus that allows these deadly germs to flourish.

I asked my doctor if I could go to my brother to be with him for his surgery. After all who would know better than me what he was going through? She said, “Even if you were gowned and masked and stood at either end of a football field, I couldn’t let you go.” Obviously she was trying to impact on me that with only one lung, I couldn’t take chances.

This infection, and even lesser types, have such a great impact on all CF’ers that individuals with active infections may not be anywhere near another CF person. If you want to know the most difficult part of having CF for me it’s that when George needed me the most I couldn’t be there for him. Sure I called at least once a day but not being able to go to him, sit with him and hold his hand through this difficult time-- that was and still is, most painful. The sad truth is that George and I will never be able to hug or kiss each other again--not at holidays, weddings, baptisms, or funerals—not ever.

In fact all CF’ers must maintain at least a three-foot distance from each other at all times and try not to be in confined spaces. Several months ago I met Gianna, a sweet and feisty little 3 year old with CF. Knowing her, her parents and her extended family has been a real blessing in my life. They helped me understand a great deal more about this disease. I look at her, and I want her to have everything life has to offer, and then some. She was born 10 weeks early and spent 3 ½ months in the intensive care unit. Gia has faced many challenges already in her life and has many more ahead of her. She regularly does her nebulizers and vest therapy without any complaints, as long as her favorite videos are on.



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Emotionally I feel a very close bond to Gia. I've come to love her but unfortunately I will never be able to experience that physical bond with her. The closest I have come to showing affection is by blowing her a kiss from afar. When I see others take her hand, pick her up and kiss her I look on with envy.

So how has finally being diagnosed with CF affected my life? My mother always taught me to be grateful for what I have. So what do I have? I have my parents, my brothers and sisters, my husband, my children, my old friends and my new friends. These are people who love and support me and together we always look for the rainbow. And above all that I have my faith in God. A faith that comforts me and lets me know that I never walk alone. Every breath I take I feel Him with me. I trust in His will for my life and I know that whatever difficulties I go through He will always bring a greater good out of them. One of those greater goods in being with you here tonight.

Right now I ask you to take a moment, close your eyes and picture someone you love. Now think about what it would be like to never be able to give that loved one a hug or a kiss ever again because you would never want to be the reason that they contacted a infection. Possibly even a deadly infection that would compromise their health. I do not know what the future holds for George or I, well maybe I do know, but I choose not to think about it. I'd rather think about the very real possibility of finding a cure for CF in Gia's lifetime. I ask tonight that you be as generous as you can possibly be because you can make happen for Gia and others like her to be able to enjoy all that life has to offer and then some. Without you this dream will never become a reality.

Thank you

And by the way - I hear that they are accepting Visa tonight! Cough Cough