



2004 Evening with the Eagles Speech

Presented by Frank Eliason

Dedicated to Gianna Rose Eliason

November, 2004



Good evening and thank you all for coming tonight. Yes, my last is Eliason, very similar to a famous former football player and TV and Radio Analyst, Boomer Esiason. We have another similarity; we are both parents of a child with CF. I'd like to thank the Cystic Fibrosis Foundation for the opportunity to share the story of my daughter. I hope Gia's story will educate you about the challenges of CF from a parent's perspective. First, I would like to introduce you to the most courageous, caring, loving and beautiful woman I know, my wife Carolyn. This is an abbreviated story about Gia, but the larger story truly demonstrates the amazing women in my life.

I would ask all parents, while I speak, to think about your own precious children. For those of you, who are not parents, let me tell you, it is the most amazing experience in life. When a child is born, your priorities change forever. Everything you do from then on is for your child.

For most parents of CF'ers, the first time they hear the term Cystic Fibrosis is during a "family meeting" informing them of their child's diagnosis. For me, I first heard those words on the radio. While awaiting a life saving lung transplant, a remarkable 18-year-old girl named Gretchen, was discussing her life with Cystic Fibrosis. She described the thick, sticky mucous that slowly takes over the lungs and the infections that may not impact you or me, but can take the life of a CF'er in a very short time. She also taught about daily breathing treatments, and enzyme capsules needed to digest food. Through this fight, Gretchen proved to be amazing, and full of life. She gave me a new respect for life. I remember thinking, if I had a child with CF, I'd hope to raise my child to be as spirited as she. Little did I know that I would soon have the opportunity.

Months after hearing that radio interview, I heard Gretchen again. This time she had a new set of lungs. She described her new regimen of medications to prevent her body from rejecting the lungs. She also discussed her ability to run and play like other healthy teenagers. She enjoyed this new ability to breathe. For the next few years, she continued to live life to the fullest, until one day she developed a fatal lung infection. Gretchen passed away just weeks before her 21st birthday. She was such a courageous young woman. Although I never had the opportunity to meet Gretchen in person, she will always hold a special place in my heart.

A few months after hearing about Gretchen the first time, my daughter, Gianna Rose Eliason, was born, prematurely, weighing in at 3 pound 14 ounces. This was probably the greatest, yet scariest moment of my life. I was now responsible for this little, helpless child. Due to her



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premature birth, and some necessary surgeries, Gia was transferred to CHOP's Neonatal Intensive Care Unit or NICU. Surgery was necessary to close a valve in her heart, and a second surgery was scheduled to correct a malformation in her intestine.

After the first surgery, we started to adjust to life in an intensive care unit. The first thing we noticed was that our baby was now attached to a machine to assist her breathing. The plan was to keep Gia attached to the vent until after the second surgery. Gia had a central line, similar to an IV, but designed for long-term use. She also had a tube going through her nose for food and medicine. For at least a week, doctors kept hinting that Gia might have Cystic Fibrosis, but refused to provide more detail.

Finally, it was time for a "family meeting." We were taken to a private room away from all the other families. In the room there is an intensive care doctor, a social worker, a nurse and a box of tissues. The professionals delicately provide an update on your child. Our news was promising, until they described a recent test. With great detail, they present the diagnoses of a life shortening illness. Although they attempt to provide great hope, it is difficult for any parent to see past the shock. Any CF parent can remember their child's diagnosis. Although we left our meeting full of tears, we immediately began our quest to know everything possible about this disease that would become our life.

The malformation in Gia's intestine, although rare, was a possible sign of Cystic Fibrosis. Intestinal blockages at birth are common among CF patients. Blockages often require immediate surgery for correction. Imagine your child requiring such a surgery at birth. Now imagine this surgery on a child weighing only 3 pounds.

After these surgeries, doctors left Gia's breathing tube in stating that this would help her grow and develop. The breathing tube remained in place for the next three months, at least whenever Gia wouldn't pull it out! She enjoyed pulling every tube out and frequently did so! During our 3-month stay in the NICU, we realized that NICU doctors were not used to dealing with CF. At one point the doctors prescribed too many enzymes, causing the worst diaper rash ever. In fact, they had to bring in a burn specialist to treat this.

You may not be aware but because of the manner in which CF bodies use salt, most CF'ers need salt supplements, even as an infant. One doctor actually refused to provide additional salt to Gia. With issues like this, we were grateful to have CHOP's pulmonary team join us as consultants. They taught us what we needed to know, and assisted us in educating the NICU staff regarding CF. We eventually had the case moved within the hospital, and 2 days after that, Gia was ready to go home!

Like most CF parents we worried about germ exposure. A runny nose or common cold for a healthy child could send Gia to the hospital. For the next 2 1/2 years we were able to limit Gia's germ exposure and time in the hospital. She had only one bad lung infection, resulting in a one-week hospital stay followed by a week of home IV antibiotics. Acting as a nurse, running IV antibiotics and changing bandages covering IV ports become second nature for many CF parents and patients. Can you imagine providing your own child IV antibiotics at the age of just 18 months?

Parents of CF'ers have to deal with many things that most individuals would never even consider, like expensive medicines, nebulizer treatments and chest PT. Breathing treatments and airway clearance must be done regularly and can consume hours of the day. Meds can cost \$5,000 a month, not including the cost of antibiotics, which can be more than 10 times that! Last year Gia was prescribed the vest for airway clearance. The vest is a jacket that vibrates to clear the thick,



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sticky mucous from the lungs. The vest costs \$17,000. Insurance may cover most of the cost, but often not without challenges. Many with insurance have to fight and/or appeal decisions to receive the appropriate coverage. Without insurance it would be nearly impossible to afford meds and equipment. Aid from government sources does not even come close to covering these extensive costs. So many CF'ers simply do without. CF parents quickly learn the necessity of becoming advocates for their children.

Please take a moment to look at the young girl in the picture that was dropped off at your table. You see a fun, healthy, highly energetic 3-year old. That picture was taken of Gia last fall, right before the Evening with the Eagles event. Shortly after the picture was taken, Gia was diagnosed with childhood liver cancer.

Cancer in a CF patient presented a whole new set of challenges. Gia had to go through multiple rounds of chemotherapy with already compromised lungs. The potential for dangerous lung infections was extremely high. Severe weight loss was also a strong possibility. Thankfully the dedicated CF team at A.I. duPont Hospital for Children offered us tremendous help and support and was able to educate the Oncology team. In fact, I am pleased that many of them are here tonight! With their assistance, a lot of hard work on our part, The Vest, and most importantly, Gia's positive attitude, we were able to keep her lungs clear during the 8 months of chemotherapy. Although the chemo significantly reduced the tumor, doctors advised seeking a liver transplant immediately. We wanted to avoid transplant, if at all possible, because transplant recipients have to take a variety of immunosuppressant drugs, which could have a negative longer-term impact on Gia's lungs. One world renowned hospital, which was out of our network, was willing to attempt to cut the tumor out, but they wanted a liver available just in case.

On July 26th, 2004 we received THE call. Surgery would begin in the early morning. Unfortunately they were unable to remove the tumor, so they proceeded with liver transplant. Around 6:30 that evening, the new liver was in and working. It was time to complete the connection and close up. Around 8:00 that same evening, the surgeon returned to report that Gia had a massive heart attack and passed away, weeks before her 4th birthday. (pause) Coincidentally, it was three years to the day that Gretchen, the amazing young woman on the radio, passed away.

Although Gia was only three she was able to affect many around the world; her life should be celebrated. Gia was the best present that anyone could ever imagine. Her life was filled with countless magical moments. Her smile was contagious and her energy was inspiring. Gia showed us what it means to live every moment as if it could be the last. We knew that each day was a treasure as it happened.

We were faced with unbelievable challenges, but not without help. Gia connected us with so many special individuals. We continue to meet many families living with CF, cancer and other challenges each day. Through Gia, we met Janet, a truly inspirational 46-year-old woman with CF. You may have heard Janet's life story during last year's event. The special friends we met kept us on the right path and gave us strength and courage every time we needed it. These people and this series of experiences made us who we are; they are our strength and courage.

Please support the CF Foundation in finding a cure for this life shortening illness. Wouldn't it be nice if the next time a family heard the diagnosis of CF for their child, they also heard about the cure? You never know, it could be you in that family meeting. After all one out of 30 people carry the gene for CF and one out of every 3,900 births in this country results in a child with CF. In addition to organizing and funding the research necessary to cure and control CF, the CF Foundation strives to improve the quality of life for CF patients. The CF Foundation is a resource



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of information for educating medical personnel, CF patients and their families. The CF Foundation works diligently to achieve these goals while keeping costs low. In fact, Smart Money Magazine has recognized the CF Foundation as a charity that will not waste your money. The CF Foundation has a lot of work to do, PLEASE be as generous as your means allow!

This is the 15th year for the Evening with the Eagles, and I want to make it the best yet. During last year's event, Janet challenged us to find a cure in Gia's lifetime. We were not successful in that, but we did raise over \$150,000. I challenge each of you to help make this year's event even more successful; let's find a cure in Janet's lifetime! Soon we will begin the "Bid for a Cure," and I challenge each of you to give as much as you can, so we can change the initials CF to mean: Cure Found.

Do it in memory of Gia! Do it for your children and grandchildren. Do it for the 30,000 Americans and their families living with CF every day!

Thank You!