



Dear OLGC Family,

My name is Jilian and I am the mother of two beautiful angels, Riley (6) and Delaney (2). As some of you may know, Riley is in first grade at Our Lady of Good Counsel School. Riley is a very bright and cheerful little girl. She is an amazing big sister to Delaney and was so excited to take on this nurturing role. After a complication free pregnancy with Delaney, she was born on a warm, sun-filled day in May 2008. The sun would soon set as we were delivered shocking news one week later. Delaney was diagnosed with a terminal disease called Cystic Fibrosis. With no history of major illness on either side of the family, my husband and I were devastated.

Cystic Fibrosis (CF) is an inherited disease that affects the lungs and digestive system. The CF genes cause the body to produce abnormally thick, sticky mucus that obstructs the airways of the lungs and clogs the digestive tract of the pancreas and stomach. These obstructions can lead to life threatening diseases, surgeries, and many long hospitalizations. Currently there is no cure for CF, but there are many drugs, gene therapies and vitamins that are used to help treat a child or young adult and keep them as healthy as possible. We pray often that Delaney will maintain a healthy respiratory and digestive system as she grows therefore avoiding the emotional wait of being placed on the organ transplant list. There are 30,000 children and young adults affected with CF (and numbers are rising) making it the most common fatal genetic disease today. A cure is imperative. Cystic Fibrosis is not contagious and currently there remains no cure.

My husband Bernie, is currently a Detective with the Maple Shade Police Department. I retired from the law enforcement family in August of 2010 after a sudden brain illness that has left me incapable of working. Both of us share a passion for making a difference. Having a child in our lives that is stricken with this incurable disease challenges us to reach out and do all that we can to help the many others that suffer from this disease. Since Delaney's diagnosis, we have been leaning on several outlets for encouragement and support as we try to understand Cystic Fibrosis and its effect on our little girl and our family. Our normal parenting worries are amplified, especially during cold and flu season. A common cold for a typically healthy child could quickly turn fatal for our sweet "Laney Bean".

Our organization, *Hope 4 Delaney*, arranges and participates in numerous events each year to raise funding and awareness for Cystic Fibrosis. Through the generosity of friends and family we have had the opportunity to give a charitable donation of over \$20,000 to the Cystic Fibrosis Center at the Children's Hospital of Philadelphia. The center provides advanced care for patients with Cystic Fibrosis as well as making every effort to ensure all hospital admissions are comfortable for the families. The extraordinary doctors and nurses assigned to care for the CF patients at CHOP make living just a little easier for those who fight this battle to breathe on a daily basis.

Our 3rd annual ***Hope 4 Delaney Chug 'N' Chew 4 CHOP*** will be held on Saturday, April 16th from 7pm until 12pm at the Lenola Fireman's Hall in Moorestown, NJ. This event is made possible through generous donations from individuals, companies and corporations like yours from across the tri-state area. The event is an enjoyable evening to eat, drink, dance and raffle the night away for a great cause. We have incredible silent auction items, great giveaways and a 50/50 raffle. Tickets will be sold in advance for \$25 each and \$30 at the door. Last year the event raised over \$10,000 in just one night and we are hopeful to have another amazing turnout this year.

The closer we are to a cure, the better chance Delaney has of seeing a long healthy life without battling to breathe. With all of the challenges we have faced, we learn to live life for each moment, listen to the lesson and embrace it. Delaney has taught us that life isn't about waiting for the storm to pass, it's about learning to dance in the rain.

It is our hope that the strength our little fighter has each day will instill a lasting message to all that come within her path. Embrace life . . . have Hope 4 Delaney.

Thank you in advance for your support as we continue to dance.

Sincerely Yours,
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