Brooke's PAIGE

NEVER LET SUCCESS GET TO YOUR HEAD; NEVER LET FAILURE GET TO YOUR HEART.

Brooke's passion for volleyball is contagious. From her bedroom décor, to the scuffs on the living room ceiling where she and Paul "pepper," to the hours she spends watching old matches...she pursues her dream of playing on a Division 1 team with everything she's got. Unfortunately, in a sport that reveres the vertically gifted, those who stand a head shorter than others frequently go unnoticed or spend time on the bench. Brooke could easily get defeated and give up. Instead, she works harder and expects more of herself, all the while cheering for her teammates. Author Wilfred Peterson said, "Success is focusing the full power of all you are on what you have a burning desire to achieve." Brooke Marlee, thank you for reminding me to pursue my dreams and not lose faith when the going gets tough!

COURAGE IS NOT THE ABSENCE OF FEAR BUT THE POWER OVER IT.

Raising teenage girls isn't all about rolling eyes, exasperated sighs, and sneaky lies. It's a terrifyingly exciting and exhilarating process in which parents watch their sweet, immature children morph into impressive, independent adults.

The knowledge that one bad choice could have life-long consequences has me overreacting more often than I should. Much to my chagrin, this behavior impacts Paige's willingness to open up to me. Thankfully, my private Paige let's me in every once in a while, and when she does, I am blown away by her courage.

She has the ability to gently but honestly share difficult feedback. She openly defends others when they are not able to defend themselves. She knows her own mind and does not bend to peer pressure. She is uncomfortable talking to people, yet excitedly shares her knowledge of gymnastics with the kids she coaches. She works hard on the dance team to fit in among girls who have been dancing since birth. Paige Ella, thank you for showing me how God is there to strengthen, help, and uphold us when we face that which we fear most!

IMAGINE A WORLD WITHOUT cystic fibrosis

Can you imagine a world without cystic fibrosis? It's easy if you try. Living life without daily treatments and medications, breathing without effort, no need for lengthy hospital stays or lung transplants…

You may say I'm a dreamer, but I'm not the only one. I hope you'll join us:

SATURDAY, FEBRUARY 29TH
McNamara Alumni Center
200 Oak Street SE, Minneapolis, MN
6 pm—midnight

Enjoy live music (including Roger Clyne & PH, a Beatles tribute band, and more), games for prizes, tastings, and hors d'oeurvres!

Tickets go on sale November 1, 2019!
www.withonebreath.org

with one breath

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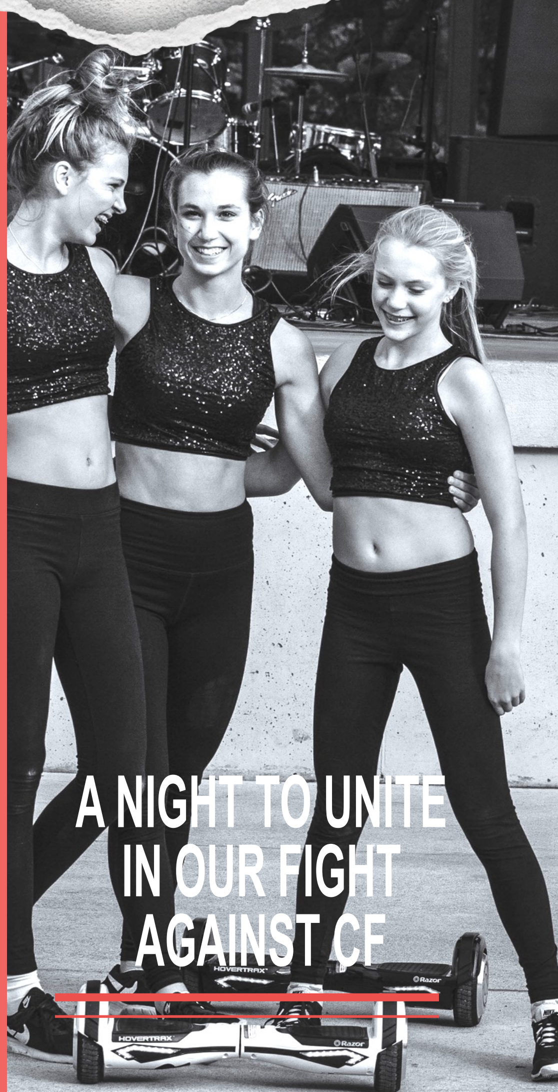
WITH ONE BREATH

TOGETHER WE WILL DEFEAT CYSTIC FIBROSIS

HOPESTOCK 2018

NEVER BE AFRAID TO TRY SOMETHING NEW, BECAUSE LIFE GETS BORING WHEN YOU STAY WITHIN THE LIMITS OF WHAT YOU ALREADY KNOW. A heartfelt thank you to Roger Clyne's Mexican Moonshine Tequila for being a Platinum sponsor of HOPEStock 2018—we couldn't have done it without you!

Our foray into an outdoor music festival, called HOPEStock, was what I endearingly call a successful "flop." We could not have found a more beautiful venue than Hilde Performance Center in its fall attire. We could not have asked for better performances from Forte, Lester River Boys, Tim Sigler, The Billy's, Rob Olson, The Belfast Cowboys, j. bell & The Lazy Susan Band, Sabrina Ness, and the Gear Daddies. The games and graffiti wall made the night memorable for all, and I can still taste the succulent cheeseburger Gess' What's Cookin' grilled up for my late night snack. I am pretty sure HOPEStock 2018 will always be my favorite event. Unfortunately, icy temperatures and busy schedules led to atrocious turnout with fewer than 350 people in attendance. Our gratitude goes out to those who came out to, sponsored, or made a donation to support the event. Thanks to you, we managed to raise $40,000 for our CF research and hospital support programs! On the off-chance our supporters prefer the indoors, our night of FUNdraising is back inside come 2020. We hope to see you there!



Photos courtesy of Nicole Ulrich and Eric Sabo of Nicole Leigh Photography.

ISSUE HIGHLIGHTS

VISIT WITHONEBREATH.ORG TO PURCHASE YOUR TICKETS TO WITH ONE BREATH 2020!

with one breath

INTRODUCING JULIE

each breath is a blessing

LIFE IS ALL ABOUT CHOICES. EVEN IN THE WORST CIRCUMSTANCES YOU CAN CHOOSE JOY. PEOPLE ARE DRAWN TO JOY, AND THE CLOSER PEOPLE GET, THE MORE ENCOURAGEMENT YOU RECEIVE.
—JULIE THIRY—

In her youth, Theo’s Place resident, Julie Thiry, didn’t think much about her diagnosis with cystic fibrosis (CF). Her parents never told her doctors predicted a life-expectancy of 2 years of age, so she viewed the manual bronchial drainage treatments her medically -trained mother administered as “part of life.” She found a career she loved, had a beautiful daughter, and married her best friend. It wasn’t until Julie reached age 40 that CF started filling her lungs with sticky mucus and taking her breath away. While Julie required numerous hospitalizations over the course of the next decade, she was shocked when doctors sat her down, started talking “end of life,” and asked if she was interested in pursuing a double lung transplant.

As Julie confronted death she wondered, “Am I really this sick? Don’t others deserve lungs more than me? Am I strong enough to do this?” While her husband and daughter wanted more time with the woman they loved deeply, Julie’s faith-filled parents had taught her not to fear death. Unsure of what to do with an impossibly difficult decision, Julie passed the reigns over to God: “If He thinks I can do this, then I’ll make it through the evaluation process.” She passed. “If He wants me to pursue this, I’ll qualify for listing.” She did. “If this is His will, I’ll get ‘the call’ once listed.” It took only 6 days.

On January 24th, at 50 years of age, Julie received a new set of lungs. She was celebrated as the 1000th recipient of a lung transplant at the University of MN with cardiothoracic surgeon Stephen Huddleston, MD leading the procedure. Recovery was brutal with pain, weakness, and memory loss rendering her disabled for the next four months. But even on the worst days, her family and friends were there to carry her. Kind strangers, like the cashier at Cub Foods who came around to give her a hug, were always there to encourage her. In time, Julie’s donor lungs introduced her to a whole new world; one filled with effortless breathing, amazing energy levels, and a belly laugh that no longer led to coughing fits.

Amidst joy, Julie is ever-aware her blessing came with a price. She shared, “I am always thinking of the donor and their family and what they are missing. Life is not fair. Why did I get that gift and they had to suffer? I now want life to be simpler and more purposeful, and [I want to] give to others. This changes your perspective. It’s good.”

RESEARCH updates

COLON CANCER RESEARCH

The studies you helped fund in Dr. Khoruts’ lab the past 3 years recently enabled his team to procure 1.2 million dollars in funding. This substantial grant will be used to launch 7 additional studies that fall into two main areas: the role of the microbiome (microorganisms that live in the gut) in people who undergo intensive chemotherapy or blood/marrow transplants, and the relationship between the microbiome and colon cancer. Once Dr. Khoruts’ team identifies what goes wrong in the microbiome, they will be able to devise strategies to treat colon cancer for people with and without cystic fibrosis.

CYSTIC FIBROSIS FOUNDATION (CFF)

Thanks to your ongoing support of the CFF’s life-saving research program, Vertex Pharmaceuticals submitted a New Drug Application to FDA in July 2019 for the approval of the first triple-combination therapy for cystic fibrosis (CF) patients who have one delta F508 mutation and one minimal function mutation (this includes Paige!). Vertex is seeking priority review, which, if granted by the FDA, would shorten the regulatory review to 8 months versus the standard review time of one year.

In clinical trials, patients who used the 3-pill therapy experienced an average 14.3% increase in lung function, a 63% reduction in pulmonary exacerbations, and significant improvement in quality of life. Approval of the triple-combination drug could, over time, expand therapies which treat the underlying cause of the CF to more than 90% of people with the disease. This incredible milestone, that we’ve been working toward for over a decade, will catapult the average life expectancy for those battling CF.

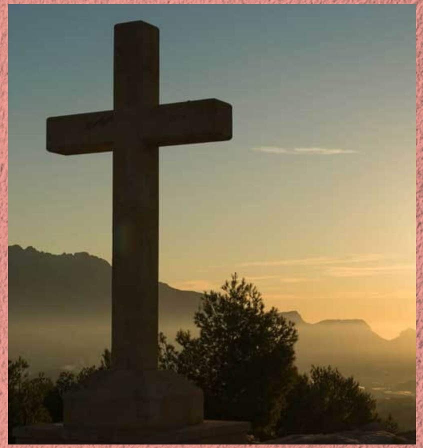
AND NOW ABIDETH FAITH, HOPE, CHARITY, THESE THREE; BUT THE GREATEST OF THESE IS CHARITY.

1 Corinthians 13:13

OUR PROGRAMS ARE CHANGING LIVES!

Hello WITH ONE BREATH family! We would love to introduce you to Melody Morse. Our daughter has the delta double F508 mutation of cystic fibrosis (CF), and our family has been living at Theo’s Place since February of 2019 while we look for housing closer to Melody’s incredible team of CF doctors. We are beyond grateful to have the opportunity to provide her with the proper care and medical resources she needs to stay well; which was a real challenge living two and a half hours from Children’s Hospital. Since coming to Theo’s Place, Melody’s speech has drastically improved due to schooling in the Spring Lake Park district, her health has become stable, she has been able to experience science museums and zoos, and her new favorite place is Valleyfair where she loves to ride her pink truck! Theo’s Place has allowed us to enjoy Melody’s childhood without worries or concerns for her health. We are so thankful a loving home like this was available during our time of need! *Written by Kaitlin (Melody’s Mom)*

the power of LIFE-GIVING LOVE



Christ’s willingness to walk into suffering out of love for others amazes me. I mean, how did He find time in the midst of His crazy, busy, short lifespan to take on such a feat? Why would He choose to willingly take on more stress, anxiety, worry, and fear? Why give everything to people who don’t appreciate or deserve the sacrifice? He gave His own life because acts of love that reach this magnitude have the power to change lives and save people.

For me, nobody on Earth exemplifies Christ’s love more than my sister. She has dedicated her life to supporting our family. She put hours into managing WITH ONE BREATH’s financials and tax reporting, and has always been an avid donor. But what blows my mind is the financial and care-giver support she provides my sister, who battles schizophrenia, and my aging father. Her life-giving love effectively inspires us all to do better; be better. By denying herself, she effectively takes up Christ’s cross and follows His example.

Dear sister, may your reward be great here on Earth and in Heaven.

YOU GAVE YOUR LIFE TO GIVE ME MINE. TAKE MY LIFE AND LET IT BE YOURS.
—LAUREN DAIGLE—