

UPDate

A Mother's Day Campaign Honor a special mother in your life while helping us provide a "home away from home" to many others.

Jennifer, age 14, lung transplant recipient with mother, Laurel. There is no fonder childhood memory than racing into your mother's open arms and getting a warm hug. It's impossible to measure a love that broad and deep. For mothers of children going through the transplant journey, the bond they share is especially powerful.

As Mother's Day approaches, we celebrate the courage and strength of these special mothers, and how Gift of Life Family House has helped them in ways only they can describe.

GETTING HEALTHY IS A SPECIAL GIFT FOR MOM

When 14-year-old Jen Dunlea describes her mother, Laurel Wyner Dunlea, she uses just one word, "Amazing." The duo has grown exceptionally close during the past five years as they battled Jen's lung disease.

Searching for the best care led them to move from their Los Angeles home to Denver. When it became clear that Jen's only hope was a lung transplant, they came to Philadelphia and stayed at the Family House for many months.

Just seven months after receiving her transplant, Jen is flourishing. She is in eighth grade at her neighborhood middle school where she has made lots of friends.

continued on Family House page $m{2}$

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Claudia with her son, Josh, age 13.

MOTHER'S DAY, continued from Family House page 1

What special gift would Jen, who is wise beyond her years, like to give her mom for Mother's Day? "That my mom would never have to see me so sick again and that she could get her life back and do everything she wants to — have her turn."

MOMS FIND THEIR INNER STRENGTH

Raising a child is not easy for any mother. But caring for a chronically ill child truly tests a mother's inner strength. "Jen's the one who gives me my strength," says Laurel. "She's so courageous. She says I'm her hero, but she's my hero."

"In my experience," explains Talia Giordano, MSW, Family House Social Worker, "when a mother has a child with a chronic illness, regardless of the child's age, the child's pain becomes the mother's pain and the child's joy becomes the mother's joy. Their relationship grows and they form a special bond."

"I don't know what I would have done without the Family House."

Laurel was a marketing executive and became a stay-at-home mom after Jen was born. When, at age 2½, Jen was diagnosed with Cystic Fibrosis, Laurel decided not to return to work. "I couldn't think of not being the one taking care of her, advocating for her and championing her cause." Though she describes herself as always being a strong person, since Jen's illness Laurel says she has found a depth of love and perseverance she never knew she had.

What Jen admires most about her mom: "She's never given up on me." She describes Laurel as always looking for ways to make her feel better. Whether it's playing her favorite songs in the car on the way to doctors' appointments, or planning something fun to do afterward. And she praises her for "Trying to understand, as humanly possible, about being me and feeling what I feel. No one else can really do that." Jen says her dad, Tim, is pretty good at it, too.

The Family House became home for the Dunleas when they packed up their belongings in Denver to seek treatment in Philadelphia. "I felt that I had a home base there for a very long time." It meant a great deal to Laurel to be surrounded by people who were looking out for them. "I don't know what I would have done without the Family House."





A MOTHER'S LOVE CAN'T BE MEASURED

From the day Claudia Fernandez's son, Josh, was born weeks too early she knew that she would do whatever it took to make him happy. As a preemie, he contracted a virus that would set him on a path of chronic lung disease and result in his need for a transplant.

Now 13 and several months post transplant, Josh is living the life of a normal teenage boy. He's a shooting guard on his school's basketball team, the Warriors. A seventh grader, he studies hard so that he can go to college and play basketball. He dreams of one day playing for the Golden State Warriors, his favorite NBA team. He loves Ferraris and other fast cars, plays video games, and has lots of friends.

"The love you feel for your child, you cannot measure it. It just comes from somewhere," explains Claudia. "We used to cry a lot together. I used to tell him, 'If I could switch places with you I would.'"

Making the decision for Josh to undergo a transplant was hard for Claudia. She worried about all of the things the doctors told her could possibly go wrong. "I had to give him a chance and be strong for him. I had to say, 'You know what, this is going to work.' Even if inside you are broken, inside you are so fearful, you really need to be strong for them. A love for my son and my faith in God are what keep me going."

"The love you feel for your child, you cannot measure it. It just comes from somewhere."

Josh says he thinks his mom is "stupendous," though he says he doesn't always tell her so. "She's great at everything. And she's always there for me."

Claudia's husband, Olman, and Josh's brothers Matthew, 10, and Christian, 5, also stayed at the Family House as often as possible. While the kids enjoyed the game room, comfy beds, and meals, Claudia greatly appreciated being surrounded by people to talk to who understood her situation. "You feel like you are with your family there."

A special way to show your ICVE this Mother's Day

Mother's Day, May 8th, is just around the corner. To show your love this Mother's Day, please consider making a gift to the Family House.

In return, we will mail our beautiful commemorative Mother's Day card on your behalf to your special mother, spouse, sister, aunt, or friend.

Your gift will enable us to continue to provide a welcoming "home away from home" for all the mothers, children, and families who benefit from Gift of Life Family House. And, you will help us celebrate the love, courage, and strength of the amazing moms whose children are going through transplant journeys, or who are transplant patients themselves. Your tax-deductible gift will support our Adopt-A-Family Program, a fund for families who cannot afford our modest \$40 nightly fee. Since the Family House opened four years ago we have never turned away a family because of financial need. Your generosity makes this possible.

Go to **www.GiftofLifeFamilyHouse.org** to make your gift today! Or use the enclosed envelope. To ensure arrival by Mother's Day, gifts must be postmarked or made online by April 25th. One card per gift.

HELPING FAMILIES COPE

It's day 100 and counting for Crystal Grimm who is staying at the Family House while her daughter, Erin, 33, waits in the hospital for a heart, a liver and related blood vessels to become available. To find one compatible donor to provide all that Erin needs may take quite awhile. But thanks to the Family House, mother and daughter have been able to support one another through thick and thin.

Erin calls Crystal her best friend. She is a constant presence and a source of endless encouragement for Erin. "She always keeps me going, she will never give up. She planned a future for me. Sometimes I think that's how I got a future, because she just didn't stop planning for it." What word would Erin use to describe her mom? "Amazing. That covers pretty much all bases."



"She always keeps me going, she will never give up."_____

Knowing that her parents, Crystal and Jeff, who are retired, have an affordable, safe place to stay while she is hospitalized is a big relief for Erin. "It takes a lot of stress off of me because I'm not worried that they are spending hundreds of dollars on hotels, meals, parking, and more. The Family House offers families a chance to stay together during a really tough time."

Erin's life has been no less than a miracle. Born with a serious heart defect that was just "a fluke," she wasn't expected to live long. At $4\frac{1}{2}$ years old, she required a Fontan procedure where her circulatory system was rerouted to one functioning pumping chamber or ventricle. Her Fontan is now failing and the added circulatory pressure over time has caused her liver to fail. As she waits for her gift of life, Erin looks forward to picking up her life where she left off: attending college, living on her own, and enjoying life with her fiancé, Andrew, and their dog, Zeus.

Erin, age 33, with her mother, Crystal.





2nd Annual 40 HOURS FOR THE FAMILY HOUSE CHALLENGE

30 Teams, 70 Participants, 950 Contributors, and more than \$60,000 - in just 40 hours!

For its second year in a row, Gift of Life Family House held its 40 Hours for the Family House challenge in celebration of Giving Tuesday – a global day dedicated to giving back – and the success was amazing!

Participants rose to the challenge, joining forces to raise awareness and funds to support transplant patients and their families at the Family House – collectively raising a total of \$60,695 in just 40 hours for the Adopt-A-Family Program. That's equivalent to 1,517 nights of lodging for families in need!

Having shared their own personal stories, photos, and connection to the Family House's mission, participants were what drove the success of this year's challenge. With an original goal of raising \$40,000 in 40 hours, the bar was set high – but participants surpassed the original goal just 24 hours into the challenge.

Gift of Life Family House could not be more grateful to the participants who made this year's challenge so successful. Thank you for coming together in support of transplant families!

The Family House would like to recognize this year's 40 Hours for the Family House challenge winners: **Top Fundraising Team – Team Dhillon, and Top Individual Fundraiser – Kate Leong.**

Team Dhillon was spearheaded by Deborah Shah, mother of Dhillon Shah. Dhillon stayed at the Family House for 11 months with his mother – and often his sister, Serena, and father, Vijay – while he awaited a heart transplant. It was during this time that Dhillon, at just 12 years old, participated in the 1st Annual 40 Hours for the Family House challenge. Due to his enthusiasm for the challenge and persuasive and lovable nature, Dhillon became the champion of the first ever 40 Hours challenge, raising more than \$4,500 to help support his "home away from home."

The following summer, Dhillon received the much-anticipated call for his new heart. Sadly, he did not survive his transplant surgery. He was just 12 ½ years old. In honor of Dhillon, his family decided to participate in the 40 Hours for the Family House challenge in his name. As the Shah family wrote, "Dhillon was a special kid with a special heart, and the wonderful Family House saw those attributes and helped him shine: jokes, magic tricks, crafts, fundraising, sports and musical events, in-house games, cooking in the kitchen, working the front desk, getting to know Philly sights and foods and so much more!"

"We are so grateful to the Family House and want to help them provide a 'home away from home' for transplant families."

—The Shah Family

In just 40 hours, the Shah family and Team Dhillon collectively raised a total of \$13,053 for the Family House in honor of Dhillon.

Kate Leong was the Top Individual Fundraiser in this year's challenge – raising funds in honor of her son. Her team, "Celebrating Gavin Leong!" received world-wide support thanks to the popularity of Kate's wonderful and inspirational blog, *Chasing Rainbows*.

Kate's son, Gavin, died suddenly at the age of just 5½. His family made the selfless decision to donate his organs, which in turn brought the Leong family much comfort during a very dark time – knowing that their 'superhero' had saved many lives through his precious gifts of life.

Through this experience, Kate has not only become a strong advocate of organ and tissue donation, but has also become a strong supporter of the Family House. In participating in the 40 Hours challenge, Kate wrote, "We choose to honor our son's life by continuing to support those families that sit by their loved one's bedside waiting for a second chance at life. Many of those families find themselves in Philadelphia seeking medical treatment or, hopefully, getting a transplant. Gift of Life Family House is a 'home away from home' for those patients and their families. Help us celebrate Gavin ... who always celebrated life."



Caregiver *Life*line Spotlight

by guest writer, Lucia Cucinotta Director of Community, Anjali Power Yoga

5 Easy Steps TO MEDITATION

Take a deep breath in and a deep breath out and I am sure you will already feel a sense of ease. The key to meditation is breathing. Allowing yourself the opportunity to breathe helps relax the body, decrease tensions, and help the mind process. Meditation can be an easy, affordable, and effective way to reduce the stress and tension caused by being a transplant caregiver. If you simply take 3 to 5 minutes of your day on the meditation exercise below, you can make meditation a healthy life habit.

FIND A SEAT. Sit on the floor, sit on a chair, you can even stand. Finding your seat is finding a place where you can take a few minutes to clear your mind. If you are lucky to find a quiet space, go there. If not, see if you can face a wall or blank space to avoid visual distractions. You can find your seat anywhere, even in your car, the point is to find a space where you can be. If you have a timer on your phone, set it now for 3 to 5 minutes.

2. **GET GROUNDED.** If you are sitting, press your sit bones into the ground, lengthen your spine, and bring your shoulders up and back. You want to feel grounded to the earth so you can press down to

lengthen and straighten your spine. Engaging your lower core (abs) will help keep your spine long and strait. You can fold your legs or keep them long in front of you. Place your hands on your knees or the tops of your thighs, palms facing up if you need to feel lifted and palms facing down if you need to feel grounded.

CLOSE YOUR EYES. To focus inward for a few moments you must shut your mind from what is going on outside of you. As you close your eyes you will feel your seat shift as your body gets used to this new focus. Avoid squeezing your eyes shut. Close your eyes with ease and begin to relax your face.

4. FOCUS ON YOUR BREATH. Begin to take deep breaths by inhaling through your nose and exhaling through your nose. Start with a 3-count inhale and 3-count exhale until you build to a 5-count inhale and a 5-count exhale (ex: breathe in deeply and count to 3 in your head, breathe out slowly and count to 3 in your head). When you reach the 5-count inhale and 5-count exhale, imagine the sounds of your breath are waves of the ocean. Touch the ground or wiggle your toes to feel the sand. Smell the salt air. Perhaps even begin to hear the seagulls. Keep your eyes closed, focus on the center of your forehead, and keep your 5 count inhale and 5 count exhale. Envision the sun as it rises over the horizon in front of you. Allow the colors to paint the sky of your mind. When the sunrise reaches its most radiant point (or when the timer goes off), open your eyes. Sit there for a moment and allow yourself to feel the new sense of ease that has washed over your body and mind.

O. MAKE IT A HABIT. You can do this simple meditation exercise for 3 to 5 minutes or more. Remember, some say it only takes 18 days to form a habit. If you can take 3 to 5 minutes out of your day, every day, for 18 days, you can make meditation a healthy life habit!

For more resources and ideas on reducing stress, please visit our Caregiver *Life*line Program webpage at www.GiftofLifeFamilyHouse.org.

Kate single-handedly raised a total of \$10,610 for the Family House during the 40 hour challenge in honor of her son, Gavin.



Gift of Life Family House is extremely appreciative and humbled by the incredible success of ALL of the 40 Hours participants for breaking the record and far exceeding the goals.

Thank you again to the participants, team members, contributors and all those who shared or liked a page. Because of you, the Family House can continue to keep the nightly fee affordable for families, and also keep the promise to never turn away a family who cannot pay.

30Teams, 70 Participants, 950 Contributors, and more than \$60,000 - in just 40 hours ... Incredible!

The Family House team can't wait to see what next year's 40 Hours for the Family House challenge will bring. THANK YOU again for all your support.

OF THE Family House



A Letter from a Grateful Father

The transplant journey can be a very trying time, and some families endure circumstances beyond anything they had imagined. In order to ease their journey, Gift of Life Family House strives to provide rays of hope and comfort during what may often be a very dark time.

Peter Mansaray and his family, of Camp Hill, PA, are frequent guests of the Family House. In his letter below, Peter shares details of his family's transplant journey and how Gift of Life Family House has played an important role in their lives.

Dear Friends,

My wife and I left our family to move to the United States in the early '90s to escape the civil war in Sierra Leone. We witnessed horrible things: villages destroyed and people close to us murdered. I was sure that part of our lives was the worst we would ever go through.

We started over in the United States and my wife, Mary, and I had four beautiful children: Peter, Joseph, John and Beverly. Soon after our daughter, Beverly, was born in 2001, Mary was diagnosed with Cardiomyopathy. Although she was sick, we were able live a normal life. She and I both worked and our children went to school and loved playing soccer.

Over the years, however, Mary's heart worsened and we were told she would need a heart transplant. She was officially placed on the transplant list in July of 2015. At this same time, my second child, Joseph, who is 16 and was (we thought) extremely healthy, became unexpectedly ill. I immediately took him to the ER near our home in Camp Hill, and he was quickly transferred to a children's hospital in Philadelphia. Joseph was diagnosed with Cardiomyopathy – the same disease that my wife was diagnosed with.

Joseph was so sick that there were times when I didn't think he would make it. He spent about three months in the cardiac intensive care unit. I was with him every second, while Mary continued to work at home and care for our other three children. While hospitalized, Joseph received an LVAD and he was listed for a heart transplant, just like his mother.

When he was eventually discharged from the hospital, we were able to stay at Gift of Life Family House for his recovery.

A few weeks later in September of 2015, Mary was transferred to a transplant center in Philadelphia so that she could be closer to our son, who was still in the hospital. After her evaluation, the doctors told us she was much sicker than we had realized and she was quickly admitted and listed again for a heart transplant. She received her heart transplant just few days later. We were so thankful!

Mary remained in the intensive care unit for about four weeks posttransplant. Joseph, who was required to be with me 24 hours a day due to his LVAD, and I would spend many days at the hospital and nights at Gift of Life Family House. In order to keep my two

> youngest children's lives as normal as possible, they stayed with neighbors in Camp Hill so that they could continue school. Our oldest son, Peter, is a student at Temple, so he was close enough to be able to visit. We would be a family again on weekends when we were all together in Mary's ICU room.

I am very sad to say that Mary's recovery was very rocky and she passed away on November 4th with me and her children by her side.

While our story has been a sad one, we thank God for the Family House and people like you. I don't know how my family or I could have gotten through the last three months without the Family House.

Since all this happened, we have had no income. But thanks to the Family House, we haven't had to worry about the cost of staying overnight in Philadelphia, where to sleep or where to get food. The Family House has given us a place to stay, home-cooked meals and even provided us with gas cards to use to get back and forth from our home in Camp Hill. I also met a donor family [at the Family House] around the time of my wife's transplant and this gave me the strength to continue.

Thank you to *Gift of Life Donor Program* for coordinating Mary's transplant, which gave us one more month with her. Thank you for everything you do every day to help my son Joseph one day get his transplant.

And thank you, Gift of Life Family House, and all its supporters, for helping us through all of this – as I am not sure what we would have done without it.

With gratitude,

Home Cook Heroes Voya Financial

The Home Cook Heroes program at Gift of Life Family House is an important facet of our mission, providing much-needed support services to families who often don't have the time, resources or energy to prepare a healthy and home-cooked meal. This volunteer-driven program aims to bring comfort to our families in the form of warm meals and an engaging atmosphere, helping them feel at home and not alone during their transplant journey.

As the clock approaches 6 o'clock, inviting aromas of roasted pork tenderloin, breaded tilapia and berry cobbler beckon guests into the dining room. Even after three main courses, lots of sides and plenty of dessert there are rarely any leftovers from this particular group's Home Cook Hero meal!

Since its inception, the Voya Financial team has been nothing but committed. Greg Dommel, their team leader, learned of the Home Cook Heroes program through his company. Like many employers, Voya Financial strongly encourages staff to get involved in the community, offering incentives to encourage them to take advantage of volunteer opportunities, including 40 hours of paid time each year to volunteer.

The Voya Community Partners initiative presents several opportunities to get involved throughout the year. All opportunities are selected by employee nominations in an effort to interact with organizations and causes important to its employees. Because Gift of Life Family House was near and dear to Greg's heart, he has been ensuring his company's involvement in our programs since 2011, when the Family House first opened.

Greg has a personal connection to transplantation, as one of his own family members needed a heart transplant in the early 2000s. Greg remembers how commuting back and forth from Lancaster to the Philadelphia area for transplant care was a strain on his family. He understands the important need of the Family House and is thankful that families travelling to Philadelphia for transplant care now have a warm and inviting place to stay.

WE PROUDLY RECOGNIZE HOME COOK HERO VOLUNTEER GROUPS FROM NOVEMBER 2015 - JANUARY 2016:

Courtney Weiner and Friends

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Love in Action Compassion

When the opportunity arose, there was no question in Greg's mind about where he wanted to direct his time in volunteering. He quickly formed the Voya Financial's Home Cook Hero team and was excited to hit the kitchen.

The team's natural talent to "rebrand" has not gone unnoticed by Family House guests and staff! Greg recalls one day the team was scheduled to volunteer at the Family House. "Mark and I finished off our grocery shopping with a diverse range of desserts including a mixed berry pie with lattice top. During the car ride from West Chester to the Family House, contents shifted. When we unpacked our groceries, the pie was still sealed and fresh – but was no longer anything close to being pie-shaped." Being fast on his feet and thinking with marketing savvy, Mark took the object formerly known as a pie and placed it in a slow cooker. "Just like that, our pie was rebranded as 'mixed berry cobbler.' Interestingly, our 'cobbler' was one of the most popular items that night!"

Volunteering at the Family House means a lot to the entire Voya Financial's team. "It gives us the opportunity to connect directly with the people we help serve – in real time. Every time we've been there, the guests – and staff – have been so grateful for what we do."

For other companies looking to start a team, figuring out where to begin can be a challenge. Greg sheds some light on the issue: "I quickly learned to surround myself with people who enjoy cooking. Initially, most of our Home Cook Heroes team came from my Marketing group, but soon expanded to other departments. We have a revolving door of frequent volunteer cooks, but our lead chef, Mark Siciliano, helps coordinate the planning and execution of our meals."



Voya Financial Home Cook Hero volunteers L-R: Laura Kristof, Maddie Marchesani, Kim Higgins, Greg Dommel, Mark Siciliano.

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Cynthia Morelli

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The official registration and financial information of Transplant House d/b/a Gift of Life Family House may be obtained from PA Dept. of State by calling toll free 1.800.732.0999. Registration does not imply endorsement.

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