

## UPDate

# SPE HASCLETHIS (MUCH.

#### This Mother's Day,

#### honor your mother and help Family House mothers, too!

Mothers are special 365 days a year, but on Mother's Day, we pause to acknowledge just how special and dear they are to us.

This Mother's Day, please consider making a gift to the Family House to show how much you care. In return, we will mail our beautiful commemorative Mother's Day card on your behalf to your special mother, spouse, sister, aunt, other loved one, or friend, to arrive by May 14th.

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.

#### Sharing the power of positivity

Merida Bourjolly and her 16-year-old daughter, Yani Barrow, are two peas in a pod. They both laugh easily and are often told they look and sound alike. They have been through many difficult moments during the past three years as Merida underwent kidney dialysis and then transplant. And yet they remain upbeat and inspire those around them.

Though Merida was born with two healthy kidneys, at three weeks old she developed a kidney infection and her left kidney had to be removed. Three years ago, during a routine doctor visit, she was told that her right kidney was failing. Not long after, she was listed for kidney transplant. Merida received the gift of life in early December.

Merida's laugh and smile helped Yani throughout their ordeal. "She has positive energy around her," says Yani. "I want to be around people like my mom. I try to take her positivity with me to school."



LEFT: Merida with her family Jay Leitzsey and her daughter Yani making gingerbread houses during the holidays at the Family House.

RIGHT: Valerie with her daughter Cora in the library at the Family House.

Merida credits the Family House with helping her maintain her optimistic outlook. "I felt no negativity there, nothing but encouragement to feel better and to get well. There's so much love that you experience from the staff, from volunteers who come to cook for us, and those who shuttle us to the hospital. You can't help but feel happy during your stay. I was never scared, or felt like I was far from home — particularly due to the staff. They went out of their way to make us comfortable," adds Merida. "They were an important part of my care, recovery and well being."

#### 'I can't believe how which she is'

Yani is studying ballet and modern dance at the prestigious Frank Sinatra School of the Arts High School in New York City. Merida is a cosmetologist and has her own salon where she encourages her clients to pursue a healthy lifestyle. She continued to work three days a week while undergoing dialysis.

Merida and Yani would leave their home in Queens at 5:30 in the morning so that Yani could catch a bus and two trains to school and Merida could make it to dialysis early and be home to help Yani with her homework. During Yani's school breaks, she went with Merida to dialysis so she could see firsthand what her mother was going through.

"I couldn't have done it without her," says Yani. "She's a really strong

woman. I can't believe how strong she is."

## A healing environment Merida stayed at the Family House for two months while she was

Merida stayed at the Family House for two months while she was recovering from transplant surgery, with family members coming in from as far as Haiti to be at her side. She credits the healing environment there for her peace of mind. "It allowed me to not have to think of the things that I would have to think of if I was home. It allowed me the comfort of being able to go to the hospital using the shuttle services. The shuttle drivers wanted to know how I was feeling. The social worker wanted to know how I was feeling. The staff really looks out for you and your needs."

"Staying at the Family House also allowed me to grow spiritually. I experienced a lot of things that I wouldn't have gotten the chance to otherwise, like hearing the stories of the people who volunteer there and why they come there to give back."

"I've made so many friends at the Family House, people I would not have otherwise been able to get to know or to hear their stories. That was huge for me. Finding out about their transplants and how it affected them and their families. It really was a growing experience for me to be there."

## "I want to be around people like my mom. I try to take her positivity with me to school." —Yani Barrow

Merida coped with cold extremities, pain and cramping brought on by many hours of dialysis, which she needed to stay alive while she waited for a kidney to become available. Regardless of her discomfort, she went to all of Yani's dance recitals and school meetings.

Yani explains, "God blessed my mother to have this positivity. When I had a show or a meeting, and her muscles were cramping and her body was hurting because of dialysis, instead of her saying 'No, I don't feel good,' she'd always say, 'I'll be there.'"



In 2015, during her sophomore year, Yani asked Merida if she could be in a pageant. She thought it would help build her confidence. Merida agreed. Yani competed first at the state level in the Miss New York Junior Teen pageant, where she was among the top 10 finalists, first runner-up for talent, and second runner-up for modeling. Her success qualified her to go to the National American Miss pageant in California, where she also did well. These were remarkable achievements, especially

since she was new to such competitions. Merida arranged to get dialysis while she was in California, so she could be there to coach Yani and do her hair and makeup.

ABOVE: Yani and Merida at the National American Miss Pageant, National Final in Anaheim. California.

The affordability of the Family House also provided peace of mind for Merida, a single mother. "It was very important to me, knowing that I'm self-employed and was going to have to stop working during my recovery process. Not having to stay in a hotel was really major for me. Then to find out how affordable the Family House made it for us was really a blessing to our family."

#### A rough start in life

Valerie Guerin has been thinking and praying about hearts for a very long time. When she was 20 weeks pregnant, Valerie and her husband, Mark, learned that their baby girl, Cora, was missing her entire left ventricle. The condition is known as Hypoplastic Left Heart Syndrome (HLHS).

From the moment she was born, Cora underwent multiple surgeries to enable her heart to pump enough oxygen-rich blood through her body to sustain her. Though she had a rough start in life, she thrived. She loved to run and go horseback riding, learned to play the piano, and was a wonderful big sister to her bother, Stephen, and sister. Amelie.

When Cora turned 10, it became harder for her to breathe and she was listed for a heart transplant. In spite of this, Cora continued to participate in an after-school club, Character Strides, which incorporates character building and life skills into a running program.

It was difficult for Cora to understand how she could compete in the club's 3-mile race and still need a heart transplant. That summer Cora was in and out of the hospital and doctors were contemplating putting her on a ventricular assist device (VAD) to buy her time until a new heart became available. During that hospitalization, Cora received a heart transplant and miraculous second chance at life thanks to a charitable act by a donor family. Now 11, Cora received the gift of life nearly a year after she last ran. She's looking forward to running again soon.

"I loved the proximity to the hospital of the Family House and the fact that we could focus on Cora's recovery there." —Valerie Guerin

Valerie and her family live in Connecticut where she is a stay-at-home mom. She made the decision to stop working in order to devote herself to managing Cora's care. Now the mother of three, she describes motherhood as, "The best job I've ever known, with three wonderful little employers and a great colleague."

#### Keeping Cawilies together

Though Cora's heart transplant was successful, the process wasn't easy. She endured setbacks that kept her in the hospital for over two months. Thankfully Cora's siblings, and other family members, were able to stay close by at the Family House.

"When Cora was well enough that Mark or I could leave her bedside, we got to spend time at the Family House with Steve and Amee, which meant a lot to us," says Valerie.

On January 11th, Cora was discharged to the Family House. "I loved the proximity to the hospital of the Family House and the fact that we could focus on Cora's recovery there," explains Valerie. "It was wonderful that I didn't have to bring her to crowded public places. We appreciated the volunteers who came in to cook and those who allowed Cora to cook with them."

Cora says she also enjoyed visits with the therapy dogs who regularly visit the Family House while her own dog, Waggles, who she rescued, waited patiently for her to return home. She and Valerie also enjoyed getting haircuts from the stylist who visited the Family House.

Adds Valerie, "The Family House is a safe, comfortable place to recuperate and a really great transition to home. We went from the structure of hospitalization to the freedom to relax — when not running to appointments."

Four weeks after Cora came to stay at the Family House, she and her family got the good news that she could go home.

Mother and daughter have shared lots of hugs throughout the transplant journey. "I admire the way she's always taking care of me," says Cora.

Valerie's wish for Mother's Day: "That we can stay together as a family and not have to be separated again."

#### Mother's Day, a time to celebrate

Yani has one word to describe her mother — "amazing." For Merida, the feeling is mutual. She and Yani have become close friends in addition to being a devoted mother-daughter team. The icing on their cake has been Merida receiving the gift of life.

"I'm much healthier, much more alert. I just feel so good. And I look forward to feeling that way when Mother's Day comes," says Merida. Her surgery was right before Christmas.

"Whether it's Christmas or Mother's Day, I feel that I've already received such a beautiful gift. It's the greatest gift, the number one gift that I wanted and I received it. That will make Mother's Day even more special."

# MAY 14TH, IS JUST AROUND THE CORNER.

To show your love on this special day, and help the Family House,

please consider making a gift to enable us to continue providing affordable lodging and services to people like Merida and Yani, Valerie and Cora, and all of the families who need us.

In return, we will mail our beautiful commemorative Mother's Day card on your behalf to your special mother, spouse, sister, aunt, other loved one, or friend, to arrive by May 14th.

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 five years ago, we have never turned away a family in financial need. Your generosity makes this possible.

To make your gift today, visit us at www.GiftofLifeFamilyHouse.org, or use the enclosed envelope.

To ensure arrival by Mother's Day, gifts must be postmarked or made online by May 1st. One card per gift.

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**Home Cook Hero** Spotlight:

The sweet smell of freshly baked goods straight out of the oven is something that makes a house feel like home. Whether it's a crisp and delicious apple pie or warm chocolate chip cookies - most of us can remember a time when our mothers, grandmothers or someone we love made our favorite treat at home. One Home Cook Hero volunteer baking group makes sure that the Family House is filled with these delectable indulgences for families to enjoy at their "home away from home."

The "Four Ladies and Friends" started baking for the guests at the Family House over a year and a half ago. Sandy Kelly, a retired nurse of 30 years and founder of the group, heard about the Family House after attending a conference at Gift of Life Donor Program. She and three of her friends wanted to honor their friend's son, who tragically passed away and selflessly donated his organs to save others. What was once four ladies has now grown into a group of people who are eager to help. "We started out as the Four Ladies. Now we call ourselves the Four Ladies and Friends because we have all kinds of people who want to contribute," explains Sandy, "we were connected because of my girlfriend's son. It really hit home to help here."

Sandy and her husband have stayed at similar hospitality houses like the Family House when her husband needed to receive care. "To me, it's really important. You know a lot of people who are really sick, and they need a place like the Family House." As Home Cook Hero volunteers, the Four Ladies and Friends bake a variety of sweets that are irresistible. You name it - the group can bake it. Guests enjoy their pies, cupcakes, brownies, scones and a variety of different cookies. During the holidays, families also help themselves to themed baked goods, such as Halloween cupcakes, Valentine's Day cookies, St. Patty's Day donuts and much more! "My step-daughter helps us schedule a time to visit and also bakes. Some of my grandchildren get involved too. We like to volunteer together – it's really become a family thing," said Sandy.



Four Ladies and Friends L-R: Colleen Cairns, Claire Green, Gail Barranger and Sandy Kelly

When asked of her fondest memories as a volunteer, Sandy said, "The most memorable moment for me was when an elderly woman and her husband, who were staying at the Family House for many months, turned to me and said 'I'm so impressed with it here the doctors come in and cooked for us! My husband's doctor who did his transplant came and cooked!' You can tell people are so thankful for the Family House." The woman was referring to her husband's transplant team who also signed up to be Home Cook Hero volunteers. One of the many reasons the Home Cook Heroes program is so important to guests is because they can connect with others on a more personal level.

Part of what makes Gift of Life Family House a "home away from home" are volunteers like the Four Ladies and Friends who generously dedicate their time, talents and resources to serving families. Whether it's baked goods or a home cooked meal, Home Cook Heroes volunteers ensure transplant patients and their families have a little taste of home while they stay at the Family House. If you're interested in becoming a Home Cook Hero, please visit www.giftoflifefamilyhouse.org/volunteer/homecookheroes.

## **CONNECT WITH US!**

Join the Family House conversation by connecting with us on social media! Gift of Life Family House is active on the following platforms – visit and like us today to help us spread the word about our mission!











youtube.com/familyhouse1

Gift of Life Family House

new

#### The Four Ladies & Friends "Mom's Chocolate Cake"

FROSTING: 2 cups all-purpose flour

1 1/3 cups heavy cream 2 tsp baking powder 1 1/2 cups sugar 2 tsp baking soda

6 oz. unsweetened chocolate. 1 tsp salt 2 cups of sugar

1 stick + 2 tbsp unsalted butter 4 oz. unsweetened chocolate, 1 ½ tsp vanilla extract chopped Pinch of salt

6 thsp unsalted butter 2 eggs lightly beaten 1 tsp vanilla extract

1. CAKE: Preheat oven to 350 degrees. Butter and flour two 8" round pans,  $1\frac{1}{2}$ " deep, and line the bottom with waxed paper. In medium brown bowl, sift together flour, baking powder, baking soda and salt.

2. In saucepan, bring the sugar and 2 cups of water to a boil, stirring until the sugar dissolves; pour into a heatproof bowl. Add the chocolate and butter and stir until chocolate melts and the mixture cools slightly. Beat in the vanilla and eggs, add the dry ingredients and beat until smooth. Pour batter into pans and bake for 30 minutes until \*cake tester comes out clean (\*use a toothpick to test cake by sticking it in the center then gently removing).

3. Cool cakes on a rack for 25 minutes, then invert them onto the rack to cool completely. Peel off waxed paper.

4. FROSTING: In a medium saucepan, bring the cream and sugar to a boil. Reduce the heat to a low and simmer, stirring until the cream reduces slightly (6 minutes). Pour the cream into a heatproof bowl and add the remaining ingredients. Stir until the chocolate and butter

5. Set the bowl in ice water. Using a handheld electric mixer, beat the frosting at medium speed until think and glossy (5 minutes).

6. Set one cake on a platter, right side up. Using metal spatula, spread one third of the frosting event over it. Top with the second cakes and spread with the remaining frosting.

### We Proudly Recognize

#### **Home Cook Hero Volunteer Groups** from November 2016 - January 2017:

Alpha Delta Mu. Social Work Honor Society

Al's Pals Amber's Angels

American Culinary Federation - Philadelphia Chapter

> Arcadia for a Better Community **Aria Jefferson Health Frankford Campus Emergency Department**

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**Breaths for Brookie Brownie Troop 02674 Brusich/McGinty Family** Butterflies, I.N.C

**Carole and Friends CHOP Pulmonary Nurses Cokesbury UMC Youth** 

**Community Evangelical Church Youth Group** Congregation M'kor Shalom

**Courtney Weiner and Friends** Daisy Girl Troop 7507 **Donna's Darlings Drain Family** 

Drexel Phi Mu **EAPA Community Outreach at Episcopal** 

Academy Ed's Eyes **Flhanna Family** Ellie's Mitzvah **Episcopal Academy Family House Staff** Fisher Family

> **Four Ladies and Friends** Franklin Towne Charter High School National

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Hearts of Gold Helen's Helners **Holy Family University HUP Cardiac/Transplant OR Team** 

**Handy and Friends** 

Hyatt at the Bellevue In Memory of Shawn Camenzin

Jefferson **Jefferson Hospital for Neuroscience ICU** 

Jeremie's Memory Jewish Federation of Southern NJ JHN NICU

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**Riddle's Unit Council Rowan Studen University Programmers** 

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Thank you to our generous community partner for their ongoing food donations: Starbucks at the Bellevue



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## Caregiver *Life*line

by Talia Giordano, MSW, LSW Gift of Life Family House Social Worker

#### **Managing the Many Roles** in Your Life

Transplant caregivers are not only caregivers – they may also be a mom, dad, daughter, son, sibling, spouse, significant other, friend, peer, boss, coworker, etc. We all wear many hats in our lives – some of those roles may be long-lasting and some may come and go depending on our stage of life. Excelling at these many roles can be very gratifying and even enhance performance in those roles. However, multiple roles can also mean difficulty managing time, potentially disappointing someone or yourself, creating stress, and even feeling burnt-out. It is important to identify ways to manage each of our roles to avoid becoming overlystressed or burnt-out.

Begin by writing down your different roles and important values and responsibilities within those roles. Think about which are most important and current. It's helpful to be specific here. For instance, instead of writing family, write the specific roles within your family. Family may be very important to you, but your responsibilities related to each role may vary - example mom, son, or spouse. As you think meaningfully about your roles, you begin to identify the values you place within those roles, which can help to better prioritize and manage them.

#### Example

- 1. Spouse spending [quality] time with my spouse, being an attentive and supportive spouse, feeling loved and providing love.
- 2. Caregiver providing support and care to my spouse's transplant needs such as transportation to appointments and medication help, encouraging them by being positive and bringing hope to my spouse.
- 3. Work/employee accomplishing something important, feeling financially stable, helping people.
- 4. Parent spending quality time with my adult child, providing support, feeling connected.
- **5. Friend** laughing with friends, having someone to listen, enjoying hobbies with someone.



Plan ways to fit important tasks and responsibilities into your schedule and write them into your calendar. If being a spouse and spending time with your spouse is important to you, then plan on ways to spend time together doing meaningful things. At this time you can also begin to think about whether you want to integrate certain roles, or keep them separate from one another. Integrating or separating is completely up to you and what you feel works best. For example - does spending time with your spouse by going to a clinic appointment also count as "spouse time?"

Sometimes we spend time on tasks or responsibilities that are not meaningful to us. It is important to reflect on how you feel about the different roles you play and how you are managing them. After some reflection, you may realize some tasks should be prioritized higher than others. Some tasks may be integrated with others, while some may not. For instance, if you feel your role as a spouse is weakening because your role as a caregiver is strengthening, then you can begin to identify ways to try and separate the two example: spending meaningful time with your spouse separate from your transplant-related care time together - going to a movie vs. visiting the doctor. Reflecting on this can help you understand where changes might be best made to better manage the many roles you have as well as reduce stress and improve your overall quality of life.

#### Looking for additional support or information?

Please reach out to our social worker, Talia Giordano, at caregiverlifeline@giftoflifefamilyhouse.org or 267-546-9817.

ONLINE TRANSPLANT CAREGIVER SUPPORT GROUP If you are a transplant caregiver and would like to connect to other transplant caregivers, please request to join our Transplant Caregiver Support Group on Facebook. Our Caregiver Lifeline Social Workers post weekly discussion topics and resources and members are encouraged to participate as much or as little as they are comfortable with.

To join please visit: www.facebook.com/groups/caregiverlifeline.



## ARE YOU Gelling Married THIS YEAR?

Include Gift of Life in Your Special Day!

In lieu of traditional wedding favors, consider giving a charitable gift in honor of your guests or in memory of a loved one. In appreciation of your gift, we will provide you with

a personalized 8" x 11" framed message to display at your reception as well as your choice of:

personalized bookmarks for each guest's place setting

personalized table signs to display on each wedding table.

You can also order a complimentary supply of green Donate Life bracelets and brochures with information about Gift of Life Family House, Gift of Life Donor Program and Donate Life. Beyond weddings, the Family House is happy to help you celebrate any occasion, such as birthdays, Bar and Bat Mitzvahs, graduations, and more!

Order your special occasion favors today!

For more information, visit www.GiftofLifeFamilyHouse.org

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## Thank You

for your loyal support and continued generosity in helping us care for transplant patients and families at Gift of Life Family House.

#### Contributions of \$50 or more received between OCTOBER 2016 - JANUARY 2017

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Thank You to our volunteers in the community for coordinating fundraising events Wish List Drives and CrowdRise fundraisers to support the mission of Gift of Life Family House.

#### **Fundraising Events**

Ally's Breakfast & Blood Drive hosted by Angels for Ally Dessert Auction coordinated by Woodside United Methodist Church Dress Down Day coordinated by George Hardy Group Fundraiser coordinated by Old York Road Temple Beth AM School of Early Learning Preston and Sophia's Lemonade and Cider Stand coordinated by Stephanie Zadzura Trinkets for Transplant Families coordinated by Shannon McKinsey Stroud Regional Police/FOP Fundraiser

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A special thank you to the participating teams of the 40 Hours for the Family House 2016 Challenge and to all those who contributed in their honor in celebration of Giving Tuesday. Together, you raised a GRAND TOTAL of \$54,553 to benefit the Adopt-A-Family program which will support over 1,363 nights of lodging for families in need.

#### 2016 40 Hours Teams:

#NotWithoutMvDonor 40 HOURS for the FAMILY HOUSE 40 Hours for the Family Hou Daddy's 3 Girls Donate for Raelyn Eileen's Entourage FunRaising for Evelyn Lopez DeNicola

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