

UPDate

TWO transplant journeys, ONE place of respite AT THE FAMILY HOUSE

Help take care of families on their Journey to Hope this Holiday Season

It was a shock to 2-year-old Jude Ward's parents, Nicole and Josef, in 2017 when they learned that their young son's liver disease had become so severe that the only recourse was a liver transplant. That same shock was felt by Alice and Donnie Sellers in 2020 when they got the news that Alice needed a new liver. Both families traveled far to Philadelphia seeking state-of-the-art transplant care.

Fortunately, the Ward and Sellers families had a place of respite in the Gift of Life Family House where they had access to affordable lodging, meals and supportive services to help them through their transplant journeys. Now celebrating its 10th anniversary, the Family House provided them with a home away from home when they were far from their own homes.

A NEW LIVER for Jude

At just four weeks old, Jude Ward experienced seizures and a brain bleed, which his doctors determined was caused by elevated liver enzymes attributed to Alpha-1 Antitrypsin Deficiency (AATD). An inherited genetic disorder, AATD can affect the liver or lungs in infants, children and adults. Their youngest child, Lucy, was also diagnosed with AATD and continues to be closely monitored.



L: Alice and Donnie Sellers; R: Jude Ward

When Jude was listed for transplant in January 2017, the Ward family was living in Florida where Jude's father, Josef, was stationed in the Air Force. They then brought Jude to Philadelphia in March to get a second opinion. Explains Jude's mother, Nicole: "Jude ended up declining while we were there and it became clear to us that we weren't going to be able to go back and forth between Florida and Philadelphia. Jude was listed for transplant in Philadelphia and I was able to stay at the Family House with my older son, Josiah, until my husband could get transferred to a base closer to Philadelphia. The Family House was our home away from home until almost the end of May 2017."

"It's a place to feel taken care of when you can't take care of yourself." —Nicole Ward

"The Family House is amazing because it's a place for people going through what you're going through — the whole transplant journey," says Nicole about her experience at the Family House. "It's a place to feel taken care of when you can't take care of yourself because you're taking care of your loved one. Just being there was like a sigh of relief."

Thankfully, Josef was transferred to New Jersey and the Wards moved to a home within driving distance to Philadelphia. There they waited and watched in agony as Jude's health declined. Finally, on July 20th, Jude received his gift of life.



Josef and Nicole with their three children Jude, Lucy and Josiah

Alice's PERFECT MATCH

The last thing Alice Sellers expected after donating blood, which she did regularly, was to learn that her hemoglobin was "off." After a long period of watchful waiting, doctors determined that Alice's liver was failing. In 2015 she was officially diagnosed with non-alcoholic cirrhosis, most likely attributed to medication she was taking for other health conditions. She remained stable until September 2020 when doctors determined that she should be listed for transplant. During that time, the Sellerses' commuted to Philadelphia from their home in Delaware—a three-hour drive.

Then, in January 2021, Alice needed to have a procedure to remove aneurysms that were cutting off blood flow to her liver, and another three months later to remove excess fluid from her abdomen.



Donnie and Alice Sellers at the Family House

All this meant that she and Donnie would need a place to stay in Philadelphia rather than drive home. The Family House was their answer. Unfortunately, Alice's liver failed after the second procedure and, instead of going home, she was hospitalized for two weeks. Donnie was able to stay at the Family House during this time.

On April 26th, Alice was stable enough to wait at home for a liver to become available. "I had everything packed up in my hospital room ready to go home. At 10:30 that night, I got a call that a liver was available and that it was a perfect match," says Alice. That day also happened to be her late sister Billie Lynn's birthday, a coincidence that Alice finds especially meaningful because Billie Lynn died waiting for a kidney transplant. Alice received her gift of life at 3 a.m. the following morning.

Easing THE JOURNEY

It wasn't just the three-hour drive that weighed on Alice and Donnie Sellers when they came to Philadelphia for Alice's care. They were also a long way from the quiet farm life that they enjoy in their small, rural community in Delaware. And Donnie wasn't used to driving in the city. Negotiating taxis, learning to use ride-hailing smartphone apps, and even doing laundry were among the new experiences he had while staying at the Family House.

"I've always laughed and joked that I'm a 'kept man.' I still work full time and sometimes work long hours so I left a lot of things around the house up to Alice. Then, when she was hospitalized unexpectedly, we only had enough clothes for three days. So, I figured out how to work the washing machines at the Family House. I think Alice was impressed that I was actually able to do laundry without ruining everything—making everything a different color. And nothing shrunk," laughs Donnie.

The Sellerses stayed at the Family House for six weeks during Alice's transplant. "I'm thankful that the Family House was there. It's made the journey for us a whole lot easier because our basic needs were met, and then we could concentrate on getting Alice better and back home."

While at the Family House, the Sellerses' family and friends gifted them with room nights. Now they are paying it forward by making a monthly gift to the Family House to help subsidize a stay for other guests. Alice uses her bargain hunting skills to fill their car to the brim with staples for the pantry each time they come to Philadelphia for care. Soon, Alice hopes to become an ambassador for the *Gift of Life Donor Program*.

"It's made the journey for us a whole lot easier because our basic needs were met, and then we could concentrate on getting Alice better and back home."

—Donnie Sellers

Keeping life NORMAL

When the Ward family first came to Philadelphia to have Jude evaluated, they packed whatever warm clothing they had in Florida but were unprepared for late winter snowstorms.

Fortunately for Jude and older brother, Josiah, they got to experience snow for the first time. "I let them play a little out in

the garden. Then I got plastic buckets from the kitchen and filled them with snow and let them play with it in the dining area," explains Nicole.

Keeping life as normal as possible during their often long and difficult transplant journeys is a common desire among families. That's why the Family House makes it a priority to support families in this way. Explains Nicole, "We were there for Easter and did a little easter egg hunt. Jude also celebrated his second birthday there. We had a little Nemo birthday party in the dining room and the other guests helped us sing happy birthday." Jude also loves playing in the game room.

FEELING 'taken care of'

The Wards and their family members who came to stay with them were grateful for the evening meal and the well-stocked pantry. "The meals were wonderful," says Nicole. "And the pantry was great to have, especially when you have little kids. I had two toddlers and toddlers want to snack all the time. And even the toiletries, the things people take for granted, they have everything you need. Also, you don't need to put on a happy face. It's really a relief to be able to just kind of 'let your hair down' after a long day, to be somewhere that you fit in," Nicole explains further.

Donnie Sellers agrees: "It's just so nice to know that everything is taken care of so you can concentrate more on your loved one's health. I can get a good night's rest because I feel safe there and am around other people that are going through the same thing that I'm going through."

Our special gift to you!

Support families on their JOURNEY Gifts to consider include: TRIBUTE GIETS: Place a holiday greeting on our Online Tribute V

TO HOPE this Holiday Season

This holiday season, please consider making a gift to the Family House in support of our 10th anniversary Journey to Hope campaign. In doing so, you will be helping the Family House meet the needs of transplant families today and in the future. **TRIBUTE GIFTS:** Place a holiday greeting on our Online Tribute Wall when you make a tribute gift of any amount.

MONTHLY GIFTS: Become a member of our Welcome Home Club when you make a monthly recurring gift. When you give monthly at the Heart level (\$21) or greater, you'll receive our Family House luggage tag to use during your holiday travels.

JOIN OUR FAMILY CIRCLE: When you give \$250 or more in a single gift or cumulative gifts during the calendar year, you will also receive our Family House luggage tag.

Heart and Family Circle Members are invited to a special contributor event and are recognized on our contributor's wall, our website and in our publications.

To make a charitable gift to the Family House, please use the enclosed envelope or visit us online at **GiftofLifeFamilyHouse.org.**

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Spotlight

by Talia Giordano, LCSW
Family Services and Caregiver Lifeline Manager

Grief Emotions from Transplant— You're Not Alone

End-stage organ failure and the transplant journey bring both expected and unexpected changes or losses and it's not uncommon to experience difficulty coping and adjusting to these changes.

Examples of lifestyle activities that may change or be lost due to transplant:

- ability to work
- income and financial stability
- ability to perform daily activities such as cooking, cleaning or taking a shower
- feeling energetic and free from physical pain
- participation in leisure and exercise activities
- relationships with friends and family
- attending social activities such as going out to dinner at a restaurant or attending a sporting event

These changes or losses may cause a significant emotional impact which may lead to a grief reaction. "Grief over non-death losses often goes unrecognized, and can feel very significant" suggests Lara Moretti, Licensed Social Worker and Manager of Family Support Services at *Gift of Life Donor Program*.

Grief reactions can come in many forms, including physical, emotional, cognitive, and spiritual. Physical reactions may appear as appetite, sleep or even muscular changes. Emotional reactions may cause feelings of anxiety, sadness, or anger. You may experience forgetfulness, confusion or difficulty concentrating with cognitive reactions. Spiritual reactions may include questioning your faith or embracing your faith more tightly.

When experiencing grief, regardless of the type of loss, Lara suggests "acknowledging your grief and don't disenfranchise yourself!"

Disenfranchised grief is when a loss is not acknowledged therefore the grief reactions go untreated or unmanaged. To help recognize and normalize the losses and grief reactions you experience, try connecting with other transplant patients or caregivers who have also experienced losses due to end-stage organ failure or transplant.

Because the transplant may have impacted your ability to cope like you normally would, Lara suggests incorporating new, healthy habits such as:

- meditating
- spending time outside or incorporating exercise*
- proper sleep and nutrition
- practicing gratitude

There are several meditation smart phone apps that can serve as helpful resources. Some apps to consider are Insight Timer, Headspace, and Calm. Additionally, practicing gratitude daily is a great way to recognize the positive and good in your life. Try writing down three things you are grateful for each night before bed.

Regardless of incorporating new coping techniques or talking with others, we recognize that transplant can still be a very challenging journey. If you require additional help managing the emotional impact of transplant, there are professional support networks available for you or your loved one. Please reach out to your hospital transplant social worker, a Family House Caregiver Lifeline social worker, or a private therapist to schedule time to discuss how to move forward.

*Please consult your transplant team prior to trying new activities.

The Caregiver Lifeline Program is supported in part by TD Charitable Foundation and Bridge to Life. We are thankful for their partnership and generosity.

Charitable Foundation





Sponsor-A-Room It's not too late to secure your sponsorship for 2022.

With the sponsorship of a guest room or common room at the Family House, you can help hundreds of families who come through our doors in search of a place full of hope and support along the transplant journey. Your generosity to sponsor a room will support families by keeping our nightly fee low and covering costs for families who cannot afford it. Rooms may be sponsored for up to 3 years at a time with a tax-deductible gift.

By sponsoring a guest or common room at the Family House through our Sponsor-A-Room program, we will proudly display your support for our mission with a sign next to your room during the sponsorship period. For more information visit GiftofLifeFamilyHouse.org or call 267-546-9812.

Deadline for 2022 sponsorship is December 31, 2021



Great opportunity for the community to support the Family House





FAMILY MEALS

VIRTUAL FUNDRAISER!

Mark your calendar now for #GivingTuesday, November 30th. On this national day of giving back, we're asking you to join us in helping keep our kitchen fully-stocked and running and to ensure that this program remains a key part of our supportive services despite the setbacks caused by COVID-19 pandemic.

Over the last 10 years, the Home Cook Heroes Program has provided transplant patients and their families home-cooked meals prepared by volunteers and staff, as well as access to a full-service kitchen, dining room and a fully stocked pantry. Guests are encouraged to eat together, make friends and share their experiences. Eating meals together also helps families feel less alone during the transplant journey.

"Knowing that you're coming back to a place that's peaceful and understanding is priceless...It was so comforting to come home from a long day of physical therapy and have spaghetti waiting for you."

—Nicole Kohr. past guest

This service lifts tremendous burdens off the caregivers and family members. Because of the Home Cook Heroes Program, they don't have to worry about grocery shopping, preparing meals or spending additional funds on food.

The Home Cook Heroes Program has many operational costs that need to be covered such as building costs, staffing, and utilities, and for that reason, we're looking to our community for help **BEGINS:** Tuesday, Nov. 30 at 8:00 a.m. **ENDS:** Wednesday, Dec. 1 at 11:59 p.m.

this Giving Tuesday. Your participation will also help support the purchase of food staples, kitchen supplies, and new appliances including a new dishwasher, microwave and industrial freezers and refrigerators.

Due to COVID-19 pandemic restrictions, community support directed to the program decreased and more staff resources were required to ensure that our families can continue to rely on this important service. Through your participation in the 40 Hours for Family Meals virtual fundraiser this Giving Tuesday, meals and food supplies will continue to be provided to transplant families in a safe and caring environment.

IT'S EASY TO SET UP your personal or team fundraising page at **GiftofLifeFamilyHouse.org**. Then, on 11/30, enlist your friends to help you meet your online fundraising goal! The whole virtual event lasts just 40 hours, and you can participate on your own or with a team.

IT'S ALSO A GREAT WAY TO HONOR or remember a loved one by creating your personal or team fundraiser in their honor.

PLUS, WHEN YOU REGISTER for the 40 Hours for Family Meals virtual fundraiser, we'll send you a free Family House t-shirt when you receive your first gift! Register today to not miss out on this important and fun fundraising opportunity that will help support transplant families!

For questions about the 40 Hours virtual fundraiser, call us at 267-546-9812.



17th Annual Kidney Open Golf Outing was a Hole-In-One!

On August 23, 2021, Gift of Life President and CEO Howard M. Nathan and Gift of Life Governing Board member, Dan Sinnott co-hosted our 17th annual Kidney Open Golf Outing at the



L to R: Dan Sinnott, Howard M. Nathan, Dr. Michael Moritz and Tim Daley



The Home Cook Heroes program at Gift of Life Family House is essential for our guests, providing them with a home-cooked meal every evening, along with brunch on the weekends

Consider signing up to provide a meal or baked goods for transplant families. Visit GiftofLifeFamilyHouse.org for more information or call 267-546-9800.

Thank you to all the sponsors, golfers, volunteers and attendees who helped make the outing a success! More than \$134,000 was raised in support of the Adopt-A-Family Program at Gift of Life Family House. To all our sponsors of this event, thanks to your generosity, our mission to support transplant families remains strong.

2021 Kidney Open Sponsors

Golf Carts Bridge to Life

Shot Gun Start and Dinner **DWD Mechanical** Contractors

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Transport Alliance **Transplant Community** in honor of Dr. Howard M. Nathan

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Howard M. Nathan

Apparel Community Tissues Service

Lunch The Arthur Jackson Company

Beverage Cart CTI - Clinical Trials

Registration **Baker Tilly Virchow** Krause, LLP

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Support Future Journeys for Transplant Patients

Have you considered making a provision for Gift of Life Family House in your will? When you make a bequest to the Family House, you will help to ensure a "home away from home" for the transplant families who will need us for years to come. And you will have the satisfaction of knowing that your deeply held values will live on through the loving care we provide. You will also help to ensure that the Family House is able to maintain the affordable fees and broad array of services for all who need support—now and in the future. It is an easy and simple way that you can support the future of the Family House and continue care for transplant patients and families. Bequests can be a percentage of the remainder of your estate or a specific dollar amount.

Visit GiftofLifeFamilyHouse.org for more information.

Please consult your attorney, tax advisor or financial advisor before making a bequest or updating your estate plan.

for supporting families during their transplant journey.

Contributions of \$250 or more received between MAY – AUGUST 2021

Founders' Circle [GIFTS OF \$10,000+]

New members who have made gifts of \$10,000 or more

The Estate of Joseph Kozlowski Jenn's House, Inc. The Estate of Flizabeth Rizzotte

Current members who have made renewed gifts of \$10,000 or more

Anonymous James and Paula Duva Jean and Sam Jones

2021 Family Circle [GIFTS of \$250+1

to support the annual fund HONOR IN PLATINUM [\$5,000+]

Anonymous in memory of John Moretto **James and Paula Duva** Joseph and Beverly Forling

Neshaminy Ice Hockey Lori Nicoletti Peruto, Esq. Drs. Steven M. Rudich and

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ITALIC = upgraded member BOLD = renewed member

The Legacy Garden **Paver Program** Thank you to those who dedicated an engraved paver

Neshaminy Ice Hockey in memory of Patrick Gannon and Phillip Oseredzuk Deborah Borden in memory of Peter Cristin Nicoletti in memory of George Gibbs Friends and Family of Brooklyn Taylor Krohe Friends and Family of Amy Corona

fundraisers and donating wish list items to support the mission of Gift of Life Family House.

Fundraising Events

17th Annual Kidney Open Golf Outing

Archmere Academy, Inc. Tag Day

Bobby's Celebration of Life Event and Fortuna Family

Bensalem Economic Development Corporation Golf Outing in memory

First Annual Gift of Life Memorial Golf Tournament in memory of Allen Proper and in honor of Rick Pearson

No Shower Happy Hour in honor of Keith Hodge and in memory of David Nelson, Jr. and Joyce Ann Gwin

The Gannon Cup in memory of Patrick Gannon and Phil Oseredzuk

Wish List Drives

Bobby's Celebration of Life Event and Fortuna Family Colton, Stone, Jessica, and Rvan Smith Alice and Donnie Sellers

Further Her Judy Keely Lower Moreland High School Gift of Life Club Lynette and William McDuffie

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Olivia Shaffer

Patricia Coscia

The Kenneth "Sid" Hopkins The Lauman Family Thomas Jefferson Rehab William Penn High School

McCloud Family and

Sharon Stoney

Rvan's Shamrocks

Higgins Family and Friends

Temple University Hospital -

Welcome **Home** CLUB Heart Members

Recognizing monthly contributors who donate \$21 or more per month

NEW Members Karin Doherty

James and Mary Lavery

Arnetta Ragland Richard Waechter

We apologize for any errors or omissions and ask that you contact us at 267-546-9812 to report any corrections.

To make a contribution to Gift of Life Family House, please visit GiftofLifeFamilyHouse.org or use the enclosed envelope.

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.

