

UPDate

Give the GIFIOE HOME



Help families find HOPE AND COMFORT at the House this holiday season.

7-year-old Jocelynn Poirier can make friends wherever she goes. She's bubbly, talkative, and as her mom describes her, "is so joyful you would never know that she's been through anything." It's hard to believe that just over 8 months ago, Jocelynn could barely walk, eat or play like a regular kid.

Jocelynn's parents, Melissa and Ben, knew from birth that she had a heart, liver, and kidney defect. This was later to be diagnosed as Alagille's syndrome, a rare liver condition found in young children that causes liver damage and symptoms like itchy skin and bone fragility. "It affected her way of life greatly," Melissa says. "She was so fragile because the vitamin D in her liver was not able to absorb so she started having bone fractures."

Around the age of two, Jocelynn's doctors suggested they start looking into organ transplantation as a next step. The family began seeking medical care in Philadelphia, an almost 9-hour drive from their rural hometown in upstate New York. Thankfully, Gift of Life Howie's House was there when they needed it most.

A breath of FRESH AIR

For the Poiriers, driving back and forth for every appointment would be impossible. Before they stayed at the House, they lodged in a hotel almost 45 minutes outside of the city for Jocelynn's appointments. They came to the House for the first time in November of 2021 and said it was like a "breath of fresh air."

"After we first opened the door to the room, we literally had to close the door because we couldn't believe it was real," Melissa remembers. Ben adds, "I just remember how it was a very friendly and hospitable atmosphere. The facilities are great and clean, and it's so convenient to be here."

After experiencing years of different medicines, multiple operations, and suffering from her condition's side-effects, the Poirier family was incredibly grateful when a generous friend offered to be Jocelynn's living liver donor and was fully approved to move forward. Melissa recalls with gratitude one evening during a church meeting where

their church family felt motivated to take time to pray for Jocelynn and her living donor. Remarkably, at 9:30 the next morning a call came from the hospital that a liver from a deceased donor was available and a more suitable match. The Poirers moved quickly into action and took Jocelynn to the hospital, their thoughts on the family who's loved one had passed. Following a couple months of waiting, Jocelynn received her gift of life.

Keeping FAMILIES CLOSE

Before staying at the House, the Poirier family often had to give up important traditions like eating together around the dinner table due to long travel days. Now, they don't have to sacrifice those special moments together.

"It's such a blessing to sit and enjoy each other and decompress during meals. There is always a tranquil spirit when we're there," says Melissa. Ben adds, "The food is absolutely delicious, we love how the volunteers come in and commit their time to make food and take care of us."

Apart from having a warm meal, Melissa says that being able to connect with other families added a special layer to their stay. "Being here and being around people is a really important thing," she says.

For Jocelynn, the House provided her with a place to relax, heal, and play like a normal child. She could often be found in the playroom and making friends with staff and other guests. "I love everybody at the House," Jocelynn exclaims.

Jocelynn is now walking regularly and even started the first grade! The Poiriers have much to be thankful for this holiday season and say the House has been a true blessing along their journey. "Without places like this, a lot of people will just be sitting in their cars or spending extra amounts of money to be able to get the care that they need... when you have a facility like this that's geared for transplant families there are similar things that you can relate to, and I think that's a wonderful gift in itself."





A caregiver's difficult **JOURNEY**

Before Crystal Patton checked in to Gift of Life Howie's House, she already had a lot weighing on her shoulders. Her brother Rodney had been diagnosed with end-stage liver failure and was told he needed a transplant to survive. Rodney was placed on the waiting list in the spring of 2022 and Crystal had to pause work to become his primary caregiver— driving him to appointments, monitoring his diet, administering medicine, and much more.

—Melissa

Both Crystal and Rodney live in Delaware and had to travel almost two hours back and forth for all his appointments. This, on top of Crystal's other duties of a caregiver, started to take its toll. "It's hard on the person that needs the transplant, but it's also hard on the person responsible for them...me showing my pain was not going to help him, so I really had to be strong."

After about two months of waiting, Crystal finally got the call that a liver was available for her brother. Rodney received his gift of life, and Crystal checked in to the House that same night.

EASING her worries

"When I initially got there, I was totally stressed out and upset. I just wanted to go home... I needed some place comforting, and when I got in the door, they greeted me with smiles."

It wasn't just the friendly faces at the House that relieved some of Crystal's worries. Time away from work, transportation and food costs had all started to add up. Crystal and her other four siblings all came together to help pay for her stay, but she still needed extra help. The House stepped in and further subsidized part of her room fee to make her journey a little easier.

"It was a strain on me financially. I went a whole month and a half without a paycheck, and I was spending money that I wouldn't normally have to spend...for them to say I could pay an extra reduced amount was just amazing."

A place to FEEL AT HOME

Crystal stayed at the House by herself for two weeks until Rodney was discharged from the hospital and joined her. She says that having all the necessities of home helped her to feel more comfortable and less alone. "I had a TV, a bed to sleep in, a kitchen to cook in. Everything was comfortable and I never felt like I didn't belong. I felt like I was home."

The services the House provided helped Crystal to feel more comfortable, but it was the compassion from the staff and volunteers that really left an impression. She remembers one instance where she had a billing issue and had to call one of the House's social workers after hours. They were quick to answer her questions and reassure her. "It was the most memorable thing how she just cared and explained everything to me."



"You don't know

Past guests Crystal Patton and Rodney Mills

She stressed that the kindness she experienced at the House was vital to her overall journey with transplant. "You don't know how important kindness is until you encounter someone who is exceptionally kind, and that's everyone at the House."

This holiday season GIVE A GIFT THAT WILL LAST Families of transplant patients often have no idea how long

they will need to stay at the House. So much depends on the success of their loved one's progress after transplant. The longer a family is uprooted from their everyday lives, the more assistance they will need from the House.

Charitable support from friends like you enables the House to provide financial subsidies to families who can't afford the \$40 nightly fee. Your generosity also helps to keep the fee low by bridging the gap between the nightly fee and the actual cost, which is \$175 per room per night. You can help give the gift of 'home' this holiday season and year-round to families in need by making a tax-deductible contribution to the Adopt-A-Family Program. For just \$40, you can provide a family with lodging, meals, transportation, counseling, and more for one night, \$80 for a weekend, or \$120 for three nights. Gifts of every amount are appreciated and will make a difference in the lives of the families we serve.

If you are able to give a special gift of \$250 or more, you will become a member of the Family Circle.

To make a contribution to the Adopt-A-Family Program, please use the enclosed envelope or visit GiftofLifeHowiesHouse.org

1) NIGHTS FUNDRAISER

Give the Gift of Home this #GI₩INGTUESDAY

SPECIAL ONE DAY CHALLENGE!

Help us give the gift of 400 NIGHTS for transplant families this Giving Tuesday and reach our fundraising goal of \$16,000 for Gift of Life Howie's House!

This #GivingTuesday, share your passion for Gift of Life Howie's House as you help raise funds so that families have a "home away from home".

Mark your calendar now for #GivingTuesday, November 29th. On this national day of giving back, Gift of Life Howie's House is launching a new 400 Nights Fundraiser — a challenge for caring people like you to put your compassion into action and help raise \$16,000 to support transplant families for 400 nights!

For some families, even our low \$40 nightly fee is out of reach, that's why every gift during the fundraiser benefits our Adopt-a-Family Program, which helps families who can't pay our nightly fee.

Every \$40 you help raise provides them with a night of safe, peaceful lodging and access to all the other services of the House: home-cooked meals, a fully stocked pantry, transportation to and from appointments, an on-site social work team, and a whole community of caring people like you.

It's easy to set up your page at support.GiftofLifeHowiesHouse.org/400Nights, share your story, and make your own gift. Then, on 11/29, enlist your friends to help us meet our fundraising goal! The fundraiser lasts just one day, and you can participate on your own or with a team.

All fundraisers will receive a **FREE**GIFT OF LIFE HOWIE'S HOUSE HAT!

It's a great way to give back this holiday season. It's also a great way to honor or remember a loved one by creating your personal or team fundraiser in their honor.

Remember, every \$40 raised together is another night of safe, cozy respite for families going through some of their most difficult days. Don't miss this great opportunity to give transplant families hope in their hardest times.

For questions about the 400 Nights Fundraiser on Giving Tuesday, call us at 267-546-9812.

Spotlight Spotlight

by Jessica Cooper, LSW, MSW, MEd
Lung Transplant Social Worker, Hospital of the University of Pennsylvania

Transplant's Impact on Self-Image, Self-Esteem, and Intimacy

It is common to identify the changes that occur to patients and caregivers throughout the transplant journey. However it is less common to identify how those changes impact a patient's or caregiver's self-image and self-esteem, which are important components to emotional and mental health. What causes a transplant patient or caregiver's self-image and self-esteem to be affected?

Physical, emotional, and social changes:

There may be many physical, emotional, and social changes a patient and caregiver experiences throughout the transplant journey. Physical changes may include differences in mobility, body function, appearance, new medical equipment or medication side effects. Emotional changes could look like changes to mental health status (anxiety, depression, fear), or managing new roles (patient/caregiver), while social changes may come in the form of having to modify hobbies or activities, changes in job/career status, or impact on financial situation and resources. How do these changes impact our self-image and self-esteem?

Self-image, self-esteem:

The changes a patient and caregiver experience throughout transplant can impact our self-image and self-esteem both negatively and positively. Self-image is the idea, conception, or mental image one has of oneself. Someone experiencing a negative self-image may sound like, "I feel sad because I am no longer the person I was before transplant." Positive self-image may sound like, "I feel good about the things I can do once again since transplant." Both responses are normal and can impact our overall self-esteem.

Self-esteem is confidence in one's own worth or abilities and self-respect and is a component to emotional wellness. A heightened self-esteem can help us mentally and emotionally navigate challenging situations, whereas a lower self-esteem can do the opposite and inhibit resilience. An example of positive self-esteem may sound like, "If I am strong enough to get through this, then I can get through anything!"

Finally, how we see and feel about ourselves can influence our relationships and intimacy with others. This can make it difficult to maintain healthy relationships as we may not feel worthy, and also may hinder healthy communication and behaviors with loved ones.

<u>Supporting healthy self-image, self-esteem,</u> and relationships:

- Allow yourself to grieve the changes and losses you've experienced, like who you were before the transplant and how your life has changed.
- Offer yourself grace for yourself, your partner, your body, and your whole experience. You will have good days and bad days, and it is completely normal as you adjust.
- Redefine yourself and your identity. Think about who you are now and how you contribute to your life as well as the lives of others.
- Remind yourself that your illness/transplant is only one piece of you.
- Utilize self-compassion and recognize your strengths. Allow yourself to step back and recall what you have gone through and the strengths you've gained from your journey.
- Be open and transparent with your loved ones and practice patience.
- Join a transplant support group to meet others who might understand what you are experiencing.

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



Golfers Teed Off at the 18th Annual Kidney Open

to Benefit Gift of Life Howie's House

Thank you to all the sponsors, golfers, volunteers and attendees who helped make the Kidney Open a huge success, raising more than \$134,000!

The Kidney Open started when Dan Sinnott, President of Sinnott Executive Consulting was diagnosed with a tumor on his kidney. Yearning to play one last round of golf, he called his friends and organized a golf outing to take place the day before he underwent surgery. His surgery was a success, and with that life-changing experience he developed a profound empathy for hospital patients. A year after his surgery, the same friends who attended his presurgery game decided to make their golf outing an annual event.





For the past 18 years, Dan has collaborated with current Transplant Foundation Executive Director, Howard Nathan, to use the outing to help support Gift of Life Howie's House.

All proceeds from the event benefit the Adopt-A-Family Program which helps subsidize the costs for families staying at the House to keep the room fees low. The program also covers the cost for families who cannot afford the nightly fee, ensuring that no family is ever turned away due to an inability to pay.

LEFT: Bill Soloway, House Advisory Board member and volunteer, Dan Sinnott, Golf Outing Founder and Bob Baur, House volunteer and donor father.

MIDDLE: Abdi Geleta, TIC Clinical Night Supervisor, *Gift of Life Donor Program* and Patrick Wysocki.

RIGHT: Dale Tennett and Lauren Warner, donor family.

Golf Carts Bridge to Life Double Eag

Double Eagle

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The LASTING LOVE and DEDICATION of Betsy and Bob

"In 2014 my Robert peacefully passed away, but our dedication and love

for the House will continue.."

Robert and Betsy Horen became involved with Gift of Life after Robert received a kidney transplant in 2006.

When the House opened in 2011, they enjoyed attending events and visiting on special occasions. After witnessing the outstanding care provided to the transplant families, the volunteers donating their time and the comradery among families, they became avid supporters of the mission.

A few years later Robert passed away. In celebration of their shared advocacy Betsy remained dedicated to the House. She even made the decision to join the Legacy Society for Planned Giving to support the future of the House, while ensuring that Robert's legacy lives on.

"In 2014 my Robert peacefully passed away, but our dedication and love for the House will continue," says Betsy.

For more information on making a planned gift to the House please visit GiftofLifeHowiesHouse.org or call 267-546-9812. If you have already provided for the House in your will, or by another planned gift, please let us know so we can celebrate your generosity now!



As with any tax-deductible gift, you should consult with your tax advisor to determine the degree to which your gift may result in tax advantages to you, your estate, and your beneficiaries.

SPONSOR-A-ROOM PROGRAM

It's not too late to secure your sponsorship for 2023



With the sponsorship of a guest room or common room at the 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 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 GiftofLifeHowiesHouse.org or call 267-546-9812. It's not too late to secure your sponsorship for 2023. Deadline for 2023 sponsorship is December 31, 2022.

The family of Brooklyn Krohe at Gift of Life Howie's House in front of the guest room they sponsored in memory of Brooklyn aka "B Nasty", their beloved daughter, sister, granddaughter, niece and cousin. Brooklyn was only 23 years old when she became an organ donor in 2020 and on the one-year anniversary of her passing, her family wanted to do something special in her memory. The family hosted a virtual fundraiser in Brooklyn's memory and raised over \$6,000 for the House! Thank you to Brooklyn's family and their generous community for raising funds to support the mission and for dedicating a few special places in the House in her name

for supporting families during their transplant journey.

Contributions of \$250 or more received between JUNE – AUGUST 2022

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

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

Anetta Good

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

Anonymous Chris and Lynn Fallon Friends & Family of Michael Bacher Sam and Jean Jones

2022 Family Circle

[GIFTS of \$250+] to support the annual fund HONOR IN PLATINUM [\$5,000+]

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Global Transplant Solutions, INC.

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Grand Lodge Independent Order of Odd Fellows of New Jersey

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Jan L. Weinstock, Esq.

Vaughn and Cynthia Whisker ITALIC = upgraded member **BOLD** = renewed member

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

Wish List Drives

Kelly L. Albright Boy Scouts of America coordinated by Matthew Marcinkowski The Children's Hospital

of Philadelphia Division of Nephrology

Ellie Eisenhofer Janine Fortuna Geoff Hillary

Heidi Krenitsky Rvan's Shamrocks coordinated by Carol McCloud Matthew Moore Marianna Samero Allison Sarver

Tyler Streib William Penn Senior High (STEM)

Fundraising Events

14th Annual No Shower Happy Hour hosted by David Nelson Jr.

18th Annual Kidney Open Golf Outing hosted by Dan Sinnott and Howard M. Nathan

16th Annual Bensalem Township Charity Challenge in memory of George Flocco hosted by BEDC

Celebration of Life in memory of Amy Corona Rossi Memorial Golf Tournament hosted by Anthony J. Rossi



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

NEW Members Scott Kennedy

Cindi and Vincent Pasceri

To make a contribution to Gift of Life Howie's House, please visit GiftofLifeHowiesHouse.org or use the enclosed envelope.

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

