

UPDATE

SMOOTHING the path to care **FOR NEARLY A DECADE**

We've been helping make the journey to world-class care more accessible for transplant families

It's a great relief to have a comfortable, affordable and supportive place to stay while a loved one receives care at one of our city's exceptional transplant centers. For nearly a decade, Gift of Life Family House has been providing all of this along with much needed stability to transplant families and patients during their sometimes unpredictable transplant journeys.

In 2011, not long after we opened, Lindsey and Bill Schwartz came to stay with us with their 10-month-old son, Stephen, who needed a kidney transplant. At the time, he was our youngest guest.

We've been their oasis of comfort ever since the Schwartz family walked through our doors that day over nine years ago.

The **MIRACLE** kid

Now 10 years old, Stephen Schwartz likes to move fast. Whether he's riding his bike, the new electric scooter that he got for Christmas, or racing electric go-karts at an indoor track with his dad, Bill, Stephen likes to stay in motion. And he loves cars, both old and new: visiting car museums, reading car magazines and playing video games about car racing.

It's hard to believe that when Stephen was still in his mom Lindsey's womb, he was gravely ill. Stephen was diagnosed with Autosomal Recessive Polycystic Kidney Disease (ARPKD), or infantile PKD,

Stephen Schwartz and his dad, Bill. The Schwartzes are now one of our longest-returning guests.

continued on Family House page 2

a rare genetic disorder that affects 1 out of every 20,000 children. The disease causes poor kidney function and breathing problems that can hinder an infant's survival. Throughout her pregnancy, Lindsey and Bill Schwartz were determined to learn everything they could about the diagnosis, find the best care, and manage their own expectations for what was an uncertain outcome.

Stephen beat the odds. On January 4, 2011, Stephen's loud cries in the delivery room were sounds of pure joy to his parents and doctors. To aid his breathing, both of his kidneys were removed when he was just six days old. He remained on dialysis for two years until he grew big enough to receive a kidney transplant. Unfortunately, neither Lindsey nor Bill were a match to Stephen's blood type, so they were unable to be his kidney donor.



2013 Taking a bath at the Family House post-transplant.

"The affordability of the Family House gave us the ability to get Stephen the best healthcare."

Just as the Schwartz family received their first miracle at Stephen's birth, their second miracle occurred when a family friend offered to get tested to be his kidney donor and was a perfect match. On May 9, 2013, two-year-old Stephen Schwartz received his precious gift of life.

Each year, on May 9th, the Schwartz family spends the day celebrating Stephen's kidney transplant anniversary with cake, balloons, and a family outing. After transplant, they were able to start celebrating milestones: "We had our first vacation, we took our first plane ride, Stephen started elementary school and took the school bus," says Lindsey. **All these things and much more were made possible because of the selflessness of Stephen's kidney donor.**

Smoothing the path to CARE

The road to Stephen's kidney transplant was filled with many challenges. Dialysis treatments, tube feedings, infections and complications all took their toll.

The Schwartzes desperately wanted Stephen's kidney transplant and aftercare to happen in Philadelphia, a 3½ hour drive from their home in Virginia. Explains Lindsey, "There are not many places

in the country where you can get pediatric nephrology care, especially for this type of disease and pediatric kidney transplant." **Lindsey calls the Family House an integral part of making Stephen's care in Philadelphia possible.**

"At the time, the financial aspect of traveling to Philadelphia would have prevented us from keeping Stephen's care there after transplant. The affordability of the Family House gave us the ability to make that decision and get Stephen the best healthcare."



2013 Watching Television in a guest room at the Family House

"The few times we had to stay in a hotel in Philadelphia it was incredibly expensive. That's not financially feasible to do four times a year on top of huge medical bills. And then you add in the cost of getting to Philadelphia for regular visits plus any other times the doctors say, 'Stephen's labs aren't looking good, you need to come.' That happened quite a lot."

The Schwartzes are now one of our longest-returning families as they continue to come to Philadelphia for Stephen's follow-up care.

The COMFORT of knowing what to expect

Though Stephen's healthcare and transplant journeys have been filled with great successes interspersed with major hurdles, **Lindsey, Bill and Stephen have learned to roll with the punches and focus on the many ways they have been blessed.** One part of their journey that Lindsey says is never a surprise is the Family House.



2014 Playing foosball in the Activity Center at the Family House

"The Family House has everything you need to have a relaxing, easy place to stay."

"We know what to expect every time we go. It's comfortable. It's clean. There's food and coffee. What I need to bring and what I don't need to bring is always the same. **Everybody is kind and welcoming. The predictability of it and knowing I can afford it is just so wonderful.**"

In the beginning, when they needed a refrigerator in their room to store Stephen's medications and tube feedings, the Family House gladly provided it. "The Family House has everything you need to have a relaxing, easy place to stay."

Lindsey enjoys the meals provided by our Home Cook Heroes and marvels at the variety and convenience of our pantry. "The pantry



L: The Schwartz family: Lindsey, Bill and Stephen; R: Stephen ready to go indoor go-kart racing.

is awesome. We'll always get a snack there and will grab some cereal to eat in the car on the way to the hospital in the morning."

The Activity Center at the Family House has been a favorite of Stephen's since he was little. Whether he's playing video games, foosball, or doing arts and crafts, there's always something fun for him to enjoy when he visits.

HELP US PROVIDE A "welcome home"

As spring arrives, the Schwartz family is looking forward to many good things happening. Stephen will finish fourth grade. He'll get to run outside with his new puppy, Maverick, a Bernese-Poodle mix. And he'll be able to golf with his dad, Bill, using his own set of clubs. He'll continue to race in his junior go-kart league and maybe even win a prize.

We're proud to be there throughout Stephen's journey and hope that you will be there for the many transplant families like the Schwartzes who depend on the comfort and stability that the Family House provides.

This spring, we ask that you consider making a monthly recurring gift in support of families in our care 365 days a year, 24 hours a day. Here are some of the ways your monthly gift can be put to good use:

- \$10** Supports the cost of a ride to and from the hospital
- \$21** Helps provide a family use of our full-service kitchen for one week
- \$40** Covers the fee for one night of lodging and supportive services to one family
- \$100** Helps cover the cost of running a support group

When you make a recurring monthly gift, you will become a member of our Welcome Home Club. Contributors of \$21 or more will be recognized as Heart Members and will be invited to a special contributor's event as well as have their names listed on our contributor's wall, our website and in our publications.

Gifts of all sizes—both monthly and one-time gifts—are appreciated and help us continue the vital work of providing transplant families with affordable lodging, supportive services, and, most importantly, a place to call home when they are far from their own homes.

To make a recurring monthly gift, please visit our secure online donation page:

<https://support.giftoflifefamilyhouse.org/WelcomeHomeClub>

To make another type of gift, please use the enclosed envelope or visit our website:

GiftOfLifeFamilyHouse.org

Become a Welcome Home Club member now!

Scan this QR code to sign up!



20 SUCCESSES OF 2020

THANKS TO YOU!

Thank you to everyone who helped provide hope, healing and the comforts of home to our guests and the broader transplant community in 2020. Some special accomplishments from last year include:

1



Remained open during the pandemic and made numerous changes to safely continue providing affordable lodging, meals and supportive services for transplant patients and their families

2

Provided 4,396 lodging nights of care to families



3

Installed new ovens in the kitchen for guests and volunteers to use

4

Expanded our dining area into our former living room and installed new flooring to allow for socially distanced meals

5

Began updating and refreshing the guest rooms by installing new carpets, window treatments, custom tv mounts, light fixtures, and bed coverings

6

Created a new webinar series to provide the transplant community with health and wellness information during the pandemic which was attended by over 1,300 participants

7

336 dinners and 46 brunches provided by Home Cook Hero volunteer groups



8

Served 15,038 meals to transplant families at the Family House

9

New milestone reached in April: served the 250,000th meal since opening in 2011



10

Celebrated the Family House's 9th birthday with a special appearance by Bobby Rydell

11

Received 132 yummy baked goods drop-offs



12

45 wish list collections coordinated by volunteers

13

Provided 158 hours of counseling to guests through the Caregiver Lifeline Program



14

Over 140 birthday fundraisers were created on Facebook to help raise funds for the Family House

15

Launched Sponsor-A-Room Program and 8 new guest rooms were sponsored by generous contributors



16

Over \$119,000 raised at the 16th annual Kidney Open Golf Outing

17

New milestone reached in October: provided 70,000 room nights to transplant families since opening



18

12 new Legacy pavers were dedicated with special inscriptions to be placed in the Legacy Garden



19

Over \$40,000 was raised through the 40 Hours for the Family House fundraiser on Giving Tuesday

20

52 total Welcome Home Club members who give monthly to support the Family House

FACES

Nicole's Journey

Past guest Nicole Kohr is about to reach a major milestone and will be celebrating her second lung transplant anniversary this June! Nicole, 28, was diagnosed with Cystic Fibrosis at a young age and was given a low chance of surviving past age 10. Nicole describes her personality as a "bull" and says that "if someone tells me I can't do something, then I'm going to fight very hard and go do it." Nicole beat the odds, and it wasn't until the age of 21 when her doctors told her that she would need to start looking into transplant surgery. A few years later, Nicole was added to the lung transplant waiting list. And in June of 2019, just two weeks after getting married, Nicole received the best wedding gift one could ask for, a life-saving lung transplant!



Nicole and her mom, Patti, stayed at the Family House for a little over two months during Nicole's transplant and recovery journey. She says that although her recovery was hard, "knowing that you're coming back to a place that's peaceful and understanding is priceless." Nicole and her mom particularly enjoyed interacting with the Home Cook Hero volunteers and the delicious meals they provided every night. "It was so comforting to come home from a long day of physical therapy and have spaghetti waiting for you." Nicole says she is thankful for the people at the Family House that make the journey for transplant patients doable, and explains, "when you're experiencing so much trauma on a regular basis, you really just need some love at the end of the day, and I felt like I got that at the Family House."

Growing up, Nicole's passion and escape was always the theatre. She started participating in theatre groups from a young age and continued to star in and write for shows all the way into college.

of the Family House



When her condition started to worsen, however, she could no longer participate in shows the way she wanted to. That is when she began to write a musical about her journey and experiences as a Cystic Fibrosis patient, and soon enough she had finished writing the lyrics to her full-length musical, *Fall Risk*. Today, Nicole is in great health leading up to the two-year anniversary of her lung transplant and is now putting all her efforts into producing and bringing her musical to life!

LEFT: Nicole with her mother, Patti and husband Jared. RIGHT, TOP TO BOTTOM: Nicole at the Family House celebrating one year liver transplant; Nicole with her husband Jared on the Family House patio; Nicole with her friend on the Family House patio.

2021 Transplant Webinar Series

Through our Caregiver Lifeline Program, complimentary webinars will be available throughout 2021 for transplant patients, families, and professionals. We will be partnering with various organizations and content experts to deliver these important educational sessions.

Upcoming Topics:

- **Understanding the Organ and Tissue Donation Process and How Organs are Allocated**
- **Post-Transplant Skin Cancer**
- **Changes in Cognitive Functioning in Transplant Patients**
- **Coping with Grief and Loss During Transplant**
- **Navigating Transplant Survivor's Guilt**
- **COVID-19 and Transplant Update**
- **Post-Transplant Nutrition and Cooking Demo**
- **Financial Implications of Transplant**

Thank you to our 2021 Transplant Webinar sponsors: CSL Behring, CryoLife, Inc., COTA - Children's Organ Transplant Association and Veloxis Pharmaceuticals.

Transplant and Caregiver Support Groups

We will continue to offer support groups for transplant patients and families virtually throughout 2021 via Zoom.

- **Central PA Transplant Support Group:** The third Tuesday of every month from 6pm-7pm
- **Transplant Caregiver Support Group:** The last Tuesday of every month from 4pm-5pm
- **Support Group for Past and Current Family House Guests:** The first and third Monday of every month from 4pm-5pm

If you are interested in receiving information and registering for any of our upcoming webinars or support groups, please visit our website at GiftofLifeFamilyHouse.org

THANK YOU to all the volunteers last year who sponsored a meal by dropping off dinner, arranging for catering or making a donation to cover the cost of a meal.

Recognizing Home Cook Hero Meal Sponsors October–December 2020

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BOLD = Home Cook Hero All Star
All-Stars are committed volunteer groups who provide a meal to Family House guests through the Home Cook Heroes program at least 12 times in a calendar year.



Home2 Suites by Hilton

We miss all of our Home Cook Hero volunteers and hope to welcome them back to the Family House kitchen soon!

Thank You

for supporting families during their transplant journey.

Contributions of \$250 or more received between OCTOBER – DECEMBER 2020

Founders' Circle

[GIFTS OF \$10,000+]

New members who have made gifts of \$10,000 or more
James and Paula Duva

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

Connelly Foundation
Gervato Family Foundation
The Gitlin Foundation
The Gordon Charter Foundation
Betsy Horen
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2020 Family Circle

[GIFTS OF \$250+]

to support the annual fund

HONOR IN PLATINUM [\$5,000+]

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ITALIC = upgraded member

BOLD = renewed member

Sponsor-A-Room Program

New 2021 Guest Room Sponsors

AmeriHealth Caritas
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The Hampton Foundation
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Sam's Spirit
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The Legacy Garden Paver Program

Thank you to those who dedicated an engraved paver

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in memory of Keith Fidati

Penny Girls Foundation

in honor of Nicholas Reger, Elizabeth Reger Sutter and Matthew Sutter

Lindsey Schwartz
in honor of Stephen Schwartz and Kristin Freeman



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

NEW Members

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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.