

## UPDate

# HOME FOR THE HOLIDAY/S

Support a transplant family's journey this holiday season

LUCY AND ANTHONY

Anthony Rojas was born a healthy child in Long Island, New York.

Around the age of 3 he unfortunately developed Bronchiolitis obliterans, a severe lung disease, after contracting two different viruses.

As his symptoms worsened he was transferred to a nursing facility in New York. His doctors suggested he see a pulmonologist at The Children's Hospital of Philadelphia (CHOP) and his family began traveling to Philadelphia for his primary care.

He was listed for a lung transplant at 4½ years old but was removed from the list after a year when his health stabilized. Despite this, he continued to get sick often and required constant hospital stays, once even traveling by helicopter to Philadelphia for emergency care.

"We basically lived in the hospitals," his mom, Lucy, said.

Anthony remained at the nursing facility until he was 8 years old. In July of 2022 he was relisted for a transplant after his lung function declined. After two years of waiting, Anthony received his life-saving lung transplant in June of this year.

### **EASING** THEIR STRESS —

Anthony's mom Lucy learned about Gift of Life Howie's House when he was first listed for a lung transplant. When Lucy arrived, she was alone and unsure of what to expect.

"You walk in not knowing anyone or what to expect. On top of that you're thinking about the transplant, recovery and appointments ...

but as soon as you arrive, everyone greets you, welcomes you and makes you feel comfortable," Lucy explains.

Before discovering the House, the family would leave New York early in the morning to make Anthony's appointments in Philadelphia and drive back the same day. If Anthony had to stay overnight, they would need to find a hotel, which would add to their emotional and financial stress

Because of the House, Lucy and her family had an affordable, comfortable place to call home surrounded by people who understood their journey.

"It was a huge relief... seeing others with a common problem and who have been through something similar makes you feel safer and more protected," Lucy says.

### - A SECOND CHANCE AT LIFE —

After spending more than half of his life in the hospital, 10-year-old Anthony finally returned home this past August. Although he remained positive throughout his journey, Anthony is excited to enjoy normal kid activities without the burden of his oxygen.



Upon arriving home Anthony jumped into playing soccer and other games with his younger brother, Dylan. He also enjoys playing the piano which helped him through the most difficult times in the hospital. Lucy says that watching his growth and strength throughout his journey has been inspiring.

"If he is strong it means I have to be stronger," she emphasizes.

Lucy is also looking forward to the holidays. This will be the first time in years her family can celebrate without worrying about Anthony's oxygen needs. Most importantly she expresses her gratitude to the House and its staff for helping her family throughout their journey.

"I am thankful that I was introduced to the House. It's a wonderful, peaceful and welcoming environment, and has been a great help," she says.

### BEGINNING THEIR JOURNEY-

**Sarita has lived with COPD** (Chronic Obstructive Pulmonary Disease), a lung disease that limits airflow and causes breathing difficulties, for most of her life. Despite her diagnosis, she did not let it hold her back. From moving up the corporate ladder and starting her own business to traveling extensively with her husband, Mark, Sarita has led an exciting and active life.

For years she managed her disease and kept up with her treatments, allowing her to maintain her active lifestyle. That all changed in January of 2024 when her breathing suddenly stopped. Sarita was rushed to the hospital and intubated for almost 24 hours. The crisis triggered a severe decline in her lung function, and her pulmonologist informed her she would need a lung transplant to survive.

Sarita was listed for a lung transplant 6 months later in Philadelphia. She and Mark stayed at Gift of Life Howie's House during her evaluation and remained here while she waited for a transplant. After two months of waiting, Sarita received her life-saving new lung from an organ donor hero.

### — A PLACE TO **CONNECT**—

Sarita and Mark travel often, with home bases in New York and South Carolina. Having never heard of a facility like the House, they were uncertain of what to expect. Sarita immediately felt she was in the right place when she arrived.

"The warmth, the welcome and the immediate feeling of family from the staff and guests was amazing and palpable," Sarita recalls.



Both Sarita and Mark quickly formed relationships with other guests. They found the communal nature of the House to be one of the most uplifting parts of their journey.

"The social interactions and environment that allow you to connect with others who are going through a similar journey have been the best," says Mark.

Knowing that Mark had a safe place to stay and connect with other families while she was in the hospital helped ease Sarita's stress. The couple also appreciated the support from other guests, ranging from dinner invitations to offering an oxygen tank when needed. "The trust and generosity of people here is amazing," Sarita says.

### - LOOKING AHEAD -

Although Sarita faces a long recovery, she and Mark say that the community at the House has helped them immensely during

their transplant journey. As a Jewish couple they have experienced multiple inspiring moments of sharing prayer and providing support with people of different faiths.

"It's a common theme here to pray for, support, and listen to one another," Sarita explains. Mark adds, "We all have the commonality that we are all here waiting for a miracle."

Looking ahead, Sarita is excited for the holidays. After years of not being able to light actual candles due to safety concerns regarding her medical equipment, she eagerly anticipates lighting a Hanukkah menorah celebrating the festival of lights for the first time in a long time.

Sarita and Mark are also looking forward to spending more time with their 29-year-old daughter, Jodette, and getting back to traveling together. They express a deep gratitude to those who donate to the House for providing them support and comfort.



SARITA, JODETTE AND MARK

### Support a transplant family's journey with a gift today

This year numerous families will stay at the House over the holidays, and we need your help to ensure they are provided with affordable lodging, meals and important services during the transplant journey.

Every gift regardless of its size will mean the world to these families. Knowing they have a community of support behind them will bring much-needed hope during their darkest times. Your gift today will help keep the fees low by bridging the gap between the modest nightly fee of \$40 and the actual cost of providing services, which now exceeds \$200.

For families like Anthony's and Sarita's, the House is an essential part of their path back home. Help continue to support their journey and many others by making a gift today.

As Sarita says, "Through the kindness and generosity of financial donors, a very magical place exists."

If you can offer a special gift of \$250 or more, you'll also become a cherished member of the Family Circle.

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

### **MARK YOUR CALENDAR NOW**

## FOR #GIWINGTUESDAY

**DECEMBER 3RD** and participate in an opportunity to **DOUBLE** your impact this holiday season.

### **SPECIAL ANNOUCEMENT:**

Thanks to a matching gift from our partners at the Foxwynd Foundation, made possible through their Donor Advised Fund (DAF), your gift on Giving Tuesday to support Gift of Life Howie's House DOUBLES up to \$40,000.

On this national day of giving back, Gift of Life Howie's House is launching a matching gift fundraising challenge – an opportunity for caring people like you to put your compassion into action and help support transplant families!

For some families, even our low \$40 nightly fee is out of reach, that's why every gift during the Giving Tuesday fundraiser benefits

our Adopt-A-Family Program, which keep the nightly fees low and helps families who can't pay.

Every \$40 you help raise will be doubled and provides them with nights 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 an entire community of caring people.

This #GIVINGTUESDAY,
every \$1 you give will become
\$2 to support
Gift of Life Howie's House.

For questions about the Giving Tuesday Matching Gift Challenge, call us at 267-546-9812.

**SAVE THE DATE** for Gift of Life Howie's House

Strokes of KINDNESS

CALLING ALL ARTISTS! You're invited to express your creativity and care by submitting your own masterpiece for the theme "A Feeling of Home"

### **SUBMISSION DEADLINE:** February 28, 2025

### **VOTING PERIOD:**

March 3 - April 30, 2025

PLEASE JOIN THE HOUSE IN RAISING FUNDS for the mission through an art medium of your choice. You will have the chance to see your art displayed online during the voting period. All proceeds will benefit the Adopt-A-Family Program to continue providing

transplant families with an affordable home away from home during their transplant journey.

Artists who submit pieces are encouraged to request votes from their community to support the fundraiser. \$5 = 1 Vote. The artist with the most votes will win the contest. No limit on votes. The Art Contest winner will receive a \$200 gift card.

NOT PARTICULARLY CRAFTY? NO PROBLEM! You can still participate by voting for your favorite pieces during the voting period.

FOR MORE INFORMATION AND TO SIGN UP, please visit **GiftofLifeHowiesHouse.org** 



# Spotlight

by Talia Giordano, LCSW
Family Services
and Caregiver Lifeline Program Manager

### **Managing** Transplant Caregiver Guilt

After working with transplant caregivers and families for over 13 years, one theme continues to emerge: transplant caregivers consistently reveal feelings of guilt. Caregivers can often experience guilt from maintaining ones own physical and emotional health, communicating openly with loved ones, and allowing oneself to experience happiness and joy. Such feelings of guilt can weigh heavily, inhibit positive coping mechanisms, and strain relationships.

As one transplant caregiver explained, "I occasionally feel guilt or resentment, not against anyone in particular but against the circumstances. I mourn the loss of what we had planned for the rest of our lives together and the fact that it has been replaced by our new normal. Still, I am grateful that we have the time that we have been given."

Another caregiver stated, "The pressures of being a caregiver are often overwhelming. Caring for a loved one brings me mental and physical stress and worry of losing them. I have constant thoughts whether I am doing the right things for them. This significantly impacts doing essential things for myself and brings on additional concerns that someday I too will be in the same situation as the person I care for."

Another type of guilt transplant caregivers may experience is centered around feeling that they should have done things differently. A third caregiver recalls, "I went through a night of guilt last night, feeling upset and questioning why I didn't do more. I imagine that if I had made different choices at the beginning, the outcome might have been different."

Feelings of guilt cannot simply be "turned off" when one is told, "You shouldn't feel that way." Emotions such as guilt, sadness, or happiness can be supported and managed through positive coping tools. Instead of discouraging feelings of guilt in caregivers, these feelings should be normalized and validated, helping caregivers feel valued and maintain a sense of self-worth.

Self-care is imperative to managing stress and the burdens associated with caring for a loved one. Schedule self-care into your daily routine, like an appointment to help you feel more accountable. Self-care does not need to be an activity that lasts for hours; it could be a 15-minute walk outside, a 15-minute chair meditation, or a creative art or craft activity. Focus on activities that help you feel replenished – even if it is just for a few minutes.

Receiving support from others in similar situations can also be beneficial for caregivers. By participating in support groups with those who have similar experiences you can feel validated and appreciated for the feelings you are experiencing. You may also learn new tips and tools for navigating the caregiving and transplant process. The Caregiver Lifeline Program offers a virtual transplant caregiver support group twice a month that caregivers can join from anywhere in the world!

Finally, sometimes feelings of guilt, depression, and anxiety may be too overwhelming and cause a negative impact on daily functioning. If this is the case, speaking to a mental health professional is recommended. A mental health professional can work with transplant caregivers in developing and maintaining positive coping tools and long-term emotional wellness.

One transplant caregiver suggests, "...my advice to anyone in the process of receiving a donation [transplant] is make sure the patient and caregiver have counseling/psychiatric support before and after."

To talk with a social worker about resources and support around caregiver guilt, emotional wellness, or support groups, please reach out to Talia Giordano, LCSW at

caregiverlifeline@giftoflifefamilyhouse.org.

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



4



**20TH ANNUAL** 

## KIDNEY OPEN

OUTING GIFT of LIFE

Gift of Life Howie's House thanks those who joined the 20th Annual Kidney Open Golf Outing!

Beautiful weather, great friends and teeing off to support transplant families all made for a very special day.

The House is grateful to the generous sponsors as well as all the golfers and volunteers who were able to make it out to the event. Because of their support over \$151,000 was raised for Gift of Life Howie's House!





### **THANK YOU TO THE 2024 SPONSORS**

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[GIFTS of \$250+] to support the annual fund

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ITALIC = upgraded member BOLD = renewed member

We apologize for any errors or omissions and ask that you contac us at 267-546-9819 to report any

Processing times for check donations may vary. For faster payment processing, please consider making your gift online at Giftofl ifeHowiesHouse.org



### **HEART MEMBERS** Recognizing monthly contributors

who donate \$21 or more per month

**NEW Member** Ryan Ihlenfeldt

### 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

Now you can support Gift of Life Howie's House by

### DONATING YOUR UNWANTED VEHICLE, RV, BOAT, OR MORE!

Arrange a free pick-up then all the paperwork will be handled for you – and you may even qualify for a tax-deduction. It's an easy way to support the mission and make a difference in the lives of transplant families.



Scan the QR code or visit **GiftofLifeHowiesHouse.org** to begin the donation process.





### Legacy Society.

"If you care enough about a cause to support it, I think it's important to continue supporting even **after you're gone."** —Sean Rhoads, liver transplant recipient

Over 17 years ago, Sean Rhoads made the generous decision to become a living liver donor to his close friend who was suffering from Cystic Fibrosis, thus saving her life. However, rare complications from his surgery left him in desperate need of a transplant himself. Just two weeks later, Sean received a life-saving transplant thanks to an organ donor hero.

Gift of Life Howie's House was not in existence when Sean received his transplant, so his parents stayed at a nearby hotel for nearly 3 months during his hospitalization. He knows they would have benefited greatly from the services the House provides. Sean eventually recovered from his surgery and currently resides in Canada with his wife. Keri.

Wanting to help other families like his, Sean has been supporting the mission of the House annually since 2012. Recently, Sean and



Keri decided to make a planned gift and joined the Gift of Life Howie's House Legacy Society.

"It's good to be able to donate every year, but when you're gone, those donations stop. If you care enough about a cause to support it, I think it's important to continue supporting even after you're gone," says Sean.

"Organ donation is an important part of my life and my personal history, and I wanted to give back in a way that would help other people... It's good to know that something I'm doing is going to last longer than me."

Please join Sean Rhoads as a member of the Legacy Society for Planned Giving. To learn more about making a planned gift to the House, please visit GiftofLifeHowiesHouse.org or call 267-546-9812.

We also invite those who have already included the House in their will or otherwise made a planned gift to inform us so we can celebrate your commitment. The story behind your generosity may also inspire others to take action.