

UPDate

Ashley and Bobby Adams

One Year Later and Much to Celebrate at the 5th Annual Gift of Life Family House President's Reception

"We are indescribably grateful for the Family House and how positively it has affected the outcome of our situation. Without the Family House, it would have been very difficult for Ash to be with me every single day, both financially and logistically. Without her unyielding emotional support and care, I wouldn't be as well off as I am today. Guaranteed. And without the support and the positive environment of the Family House, Ash wouldn't have been as available and emotionally present for me. The Family House truly is a 'home away from home'!"

- Bobby Adams





LEFT: On March 20, 2015, Bobby and Ashley Adams were married in the ICU; later that same day, Bobby received his double lung transplant.

ABOVE: Bobby and Ashley Adams attending the 5th Annual Gift of Life Family House President's Reception on March 16. 2016.

On March 20, 2015, Bobby and Ashley Adams of Bordentown, NJ were newly married and Bobby had just received his precious gift of life, a double lung transplant. Yet there were many events that led to these miraculous events.

Bobby Adams grew up with the privilege of enjoying a healthy, care-free lifestyle. He had always enjoyed doing things outdoors, such as camping, hiking, snowboarding, and mountain biking. In January of 2015, that came to an abrupt and unexpected halt. Bobby started feeling very sick and, with symptoms only worsening, Ashley took him to the local emergency room. Neither of them had any idea that Bobby would be hospitalized for the next three and a half months – the majority of which were in critical condition.

When Bobby was first admitted to the hospital, he was quickly intubated and placed on a ventilator for life support. His lungs were failing, fast. The cause of his lung failure was unexpected.

After being diagnosed with Acute Interstitial Pneumonia and ARDS, Bobby was placed on ECMO, an additional type of life support, which oxygenates the blood. He was then placed into a drug-induced coma while doctors worked around the clock to try to save his life. While in this coma, doctors broke the news to Ashley that Bobby's only chance at survival would be to receive a double lung transplant.

Ashley felt like she was living a nightmare. Nothing felt real. Within a few days of being informed about the need for Bobby

to receive a transplant, a social worker at the hospital told her about Gift of Life Family House. She didn't know much about the Family House at the time, but she knew she was grateful to not have to pay thousands of dollars for a hotel room in the city with her mom, or sleep on a friend's couch anymore. The Family House was a very affordable alternative. What she quickly learned, however, is that besides not having to worry about the expense of lodging, the Family House also provided her with hot meals, cooked by people who really wanted to help, rides to and from the hospital, and the opportunity to meet some amazing people

LEGACY SOCIETY

Gift of Life Family House is proud to spotlight members of the Legacy Society who have made planned gifts to support the future of the Family House.

Jean and Sam Jones are passionate supporters of the Family House.

Jean Jones vividly remembers what it was like spending an entire summer living in a hotel in Washington, D.C. after her son's organ transplant in 2006, because there was no transplant house. "There were a lot of people that we got to know – some from Philadelphia – who really didn't have any place to stay," says Jean, who is from New Jersey. "It was very difficult for them."

After her son's successful transplant, Jean learned about our plans for the Family House and the rest, as they say, is history. "When I heard about the Family House, I thought, 'Oh my gosh, that is just wonderful.' So I got involved and then I signed up to be a volunteer." In addition to Jean's role as a volunteer, she and her husband, Sam, are generous supporters and great friends of the Family House. They also recently joined our Legacy Society.

Having experienced first-hand the plight of transplant families, Jean is especially interested in helping the Family House fill the need for affordable lodging and services. "It is just wonderful that families are able to stay a night, or as many nights as they need to, have transportation to the hospital, have meals, and help



from a social worker – anything they need. That's so much better than just being on your own in a big city and trying to find a place to stay – and having no one to talk to or help you." Jean explains that making provisions to include Gift of Life Family House in their will is their way of continuing to help long after they are gone. "When you put it in your will, you know it's going to go where you want it to go, to what you are passionate about."

"It takes a lot to keep the Family House running, and to be able to provide rooms for people who otherwise wouldn't be able to have a place to stay. I think it's very important that this continue."

— Jean Jones

Jean and Sam support a number of charitable organizations, especially those that directly serve people. We are very grateful that the Family House is among them. "It takes a lot to keep the Family House running, and to be able to provide rooms for people who otherwise wouldn't be able to have a place to stay. I think it's very important that this continue. The more I can help them to do that, the better."

who understood the frightening reality of what Ashley was dealing with; including House guests, volunteers, and staff.

The 2015 Gift of Life Family House President's Reception took place the same day that Bobby was listed for a lung transplant. At that time, Ashley and her mom were in attendance at the reception as Family House guests. For this year's President's Reception – honoring the Founders' Circle and 2015 Family Circle members – Ashley and Bobby were invited back to the house – not only to share their incredible story with event attendees, but also to celebrate their one year wedding anniversary and Bobby's first 'Transplant-a-versary'. They were honored to be there with some of the most generous supporters of the Family House and to share the miraculous conclusion of their incredible transplant journey.

Just two days after being listed for a transplant, Ashley and Bobby decided to get married right then and there, bedside in the hospital

ICU. Moments before their wedding ceremony, doctors came in to the room to give them the incredible news: they had a prospective donor for Bobby! After everything that had happened in the months leading up to this point, for two such miraculous things to happen in one day seemed to Ashley a sign that everything would be okay after all.

Ashley and Bobby couldn't have been happier on that particular day in March of 2015. Within a few days, Bobby had a new bride, new lungs, a new life. Bobby is now back to work, grateful for a little more normalcy and enjoying many of the things he still loves to do. All the while, the newlyweds are incredibly grateful for Bobby's donor and his family for making the selfless decision to choose organ donation, which allowed for Bobby's life-saving transplant. And the couple is also indescribably grateful for the Family House and how it positively affected the outcome of their situation – and which is only made possible by all of its wonderful supporters, especially its generous Founders' and Family Circle members.

2016 President's Reception

More than 100 Founders' Circle and 2016 Family Circle members were in attendance – it was a fabulous evening!

Jan Weinstock Esq., Vice President, **Administration & General Counsel** for Gift of Life, shared a special message with the audience: "Thank you for your unwavering support of this House and our mission. It is a joy to hear the sounds of music and laughter tonight – it feels like a family reunion each year, doesn't it? And it is equally important that this House be a sanctuary and provide comfort for families facing life's challenges; that it be a Home. You have stood side by side with us for years to make sure the Family House remains a true 'home away from home' for our families."

At the reception's conclusion, five former guests of the Family House joined Howard Nathan, President and CEO, on stage for a special announcement: "On behalf of our staff and the thousands of families served by our mission, it is with great pleasure and excitement to announce a new milestone that was only made possible because of your support. This March, we will have provided 30,000 room nights to transplant patients and their families! This represents over 1,200 families that received support over the past 4 ½ years! Thank you!"

Broad Street Beat, a semiprofessional contemporary a cappella group based in Philadelphia, entertained the audience with two beautiful performances.





From the White House to the Family House, the year's keynote speaker was former White House Chef John Moeller. During his speech, he gave an exclusive insider look at the famous White House and recanted some of his most memorable moments serving formal State Dinners and dining in the First Family's residence. He also shared his experiences plating up fantastic dishes across three White House Administrations – including Presidents George H.W. Bush, Bill Clinton, and George W. Bush.

If you are interested in becoming a Founders' or Family Circle member and attending our next President's Reception, please visit www.GiftofLifeFamilyHouse.org/support.

Gift of Life Family House invites you to join Sam and Jean Jones in supporting the future of Family House by becoming a member of the Legacy Society.

Joining the Legacy Society is easy. Simply include the language below in your will directing a charitable gift to the Family House and then let the Family House know about it. Such a bequest can take many forms including cash, stocks, or other gifts of value. A future gift made through a bequest may provide tax advantages that benefit you, your estate and your beneficiaries.

When you become a Legacy Society member, your gift will be acknowledged right away and you will be enrolled in various recognition activities, including an invitation to the yearly President's Appreciation Reception. Your name will also be published in the Family House's quarterly newsletter and on its website and, for members who make bequests of \$10,000 or more, your name will also be added to a special Legacy Society Wall being built in the Family House living room.

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 support for years to come. And, you will have the satisfaction of knowing that your deeply held values will live on through the loving care the Family House provides.

Sample language for making a bequest:

"I give, devise, and bequeath to Gift of Life Family House, a non-profit 501(c)(3) charitable organization located at 401 Callowhill Street, Philadelphia, PA 19123, EIN 26-0585694, or its successor-in-interest, [insert dollar amount or percentage] for its unrestricted use and purposes."

For more information about the Family House and planned giving options or to download a Legacy Society Membership form, visit www.GiftofLifeFamilyHouse.org

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.

Are You Getting Married this Fall?



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

– OR –

Personalized Table Signs

to display on each wedding table

You can also order a complimentary supply of green Donate Life bracelets and informational literature outlining 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

YOU'RE INVITED!



The 12th Annual Kidney Open Golf Outing is just around the corner.

Join us on Monday, August 29, 2016 for an exciting day of golf, networking and great food at the exclusive DuPont Country Club in Wilmington, Delaware. All proceeds will support the Adopt-A-Family Program at Gift of Life Family House!

Sponsorship packages and golf spots are now available and registration is open!

For more information visit www.GiftofLifeFamilyHouse.org

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!



Caregiver *Life*line Spotlight

by Carlene N. Bowen, RD, LDN, CNSC, registered dietitian, Jefferson Transplant Institute

CAN I EAT THAT NOW? NUTRITION TIPS AFTER ORGANTRANSPLANT

Malnutrition prior to transplant is common amongst most end-stage organ diseases. Prior to transplant, most patients have to follow dietary restrictions due to the limitation of their organs. Having a transplant will alleviate some of those dietary restrictions and bring improved quality of life. Contrary to some medical advice, a transplant patient cannot "eat whatever they want."

The immunosuppressant medication that is taken to protect the new organ may cause some nutrition-related complications, which may require new or additional dietary restrictions. Some of these complications include diabetes or NODAT (new onset of diabetes after transplant), excessive weight gain, hypertension (high blood pressure) and hyperlipidemia. The cause of NODAT is multifactorial, which can include, but is not limited to, factors such as the post-transplant medication regimen, age, weight status and family history. The onset of NODAT can be delayed or prevented by practicing a few healthy habits. Monitoring your blood glucose level is a critical step in knowing your risk for DM; this should be done with each post-transplant doctor visit. Your doctor can check a hemoglobin A1C level; this test gives a three month average of your blood sugar. A number greater than or equal to 6.5% indicates a diagnosis of NODAT.

Take control of your diet by limiting foods that contain added sugars such as sweets, desserts, and sugar-sweetened beverages. Instead, choose foods that contain whole grains and that are lower in calories and fat. By making these healthy food choices and exercising on a regular basis, you can maintain a healthy weight and assist in delaying diabetes.

Excessive weight gain is common in the transplant population; this can be caused when dietary restrictions are eliminated thus liberalizing the diets. Also, some medication can cause an increase in appetite, which leads to over-eating of not so healthy foods. Choose foods that are fresh and minimally processed, which include whole grains, lean meats, low-fat dairy products, fruits and vegetables. Ongoing nutrition education and regular physical activity are two key components in preventing excessive weight gain. Weight management programs such as Weight Watchers can help a patient to lose weight and to maintain a healthy diet.

Hypertension is a common side effect of immunosuppressant medications. A diet that is low to moderate in sodium (2,000 - 3,000 milligrams/day), along with weight management and exercise may help in the management of high blood pressure. Medication may be required if the blood pressure remains elevated, despite having a healthy lifestyle. Choose foods that are made from scratch and limit use of pre-made or boxed foods. If you use canned foods, choose those that are labeled as "no added salt" or "low sodium."

Hyperlipidemia is also a common side effect from some of the immunosuppressant medications that are prescribed. Limiting fats in your diet can help to lower your risk of heart disease. Choose lean meats, poultry, and fish or beans, peas, nuts, or seeds. Cook using low-fat methods like baking, broiling, or steaming. It is also necessary that you reduce the amount of fat and oil you use, as well as use healthier oils like canola or olive oil.

In addition to following a healthy diet, it is important for post-transplant patients to use precaution to avoid foodborne illness by selecting, cooking and storing your food. Some of the basic rules include avoiding undercooked meats, poultry, eggs, raw fish – such as sushi or sashimi – and raw milk or unpasteurized dairy products. Avoid herbal supplements and any over-the-counter medications that were not prescribed by your transplant team.

The registered dietitian (RD) at your transplant program is a great resource for food safety and nutrition information after transplant. If your program doesn't have a RD, you can find one using the Academy of Nutrition and Dietetics (AND) website www.eatright.org under the section "Find an Expert."

Resource: "Nutrition Following a kidney transplant" Renal Dietitian Practice Group 2015

For more resources and nutritional tips post-transplant, please visit our Caregiver *Life*line Program webpage at www.GiftofLifeFamilyHouse.org.



facebook.com/GiftofLifeFamilyHouse

Facebook is where you can find it all: Family House news, guest stories, blog posts, motivational and educational tips, photos, videos, and special events. Get all the latest Family House happenings in one user-friendly place. Friend us on Facebook today — helping us spread the word is just a 'share' away!



@Family_House

Twitter is the place for real-time snippets of the latest news and updates – along with additional guest quotes, event photos, Caregiver Lifeline news, and volunteer updates. Perfect for a quick glimpse into Family House happenings.



@GiftofLifeFamilyHouse

Instagram is the ideal app if you prefer a visual story – follow the Family House for exclusive images from inside the House, for inspirational Motivational Monday posts, and for lovely photos highlighting the empowering stories of our transplant families.



youtube.com/familyhouse1

Gift of Life Family House also has its own YouTube channel! For access to all Family House videos – past and present – in one user-friendly place, subscribe to our YouTube channel today.



pinterest.com/giftoflifefh/

If Pinterest is where you prefer to scroll for inspiration, be sure to follow the Gift of Life Family House Pinterest page for PIN-spiration on caregiving, general wellness and motivational support.

Morgan Stanley





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HOME' COOK HEROES



Environetics

The Home Cook Heroes program continues to offer volunteers a fun and creative way to support the Family House, while engaging collaboratively and cooperatively with your family, friends, coworkers or classmates. Groups of up to 10 people can prepare meals, on or off site, and serve them to our guests.

Bring your volunteer group and the food, and we will provide everything else in our modern, fully-equipped kitchen. For more information about the Home Cook Heroes program or to sign up, visit www.GiftofLifeFamilyHouse.org



Temple University's Business English Lingua Franca

Synergy Medical Education

It is a pleasure to recognize Home Cook Hero groups from February - April 2016

3 NE Thomas Jefferson University **Hospital Abington Hospital - MICU Allison Tran** Alpha Delta Mu, Social Work **Honor Society Arcadia for a Better Community AtlantiCare - Clinical Informatics Beneficial Bank** Brandywhine Valley Ski Association Cadette Troop 21099 **Carly Calhoun Chestnut Hill Hospital Christ Lutheran Church Comcast Cares Country Day School of the Sacred Heart Crozer Kidney Transplant** David's Parrot Party **Delmonte/Weiss Family Donors are Heroes** DWM, Fellowship Christian Church **Einstein SICU** Elizabethtown College -Philadelphia Alumni Chapter **Ellen Gottlieb and Friends** Environetics **Episcopal Academy Episcopal Academy Parents** Association **Ey Family**

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OF THE Family House

Meet Russell and Cindi Westendorf

"I think one of my biggest reliefs was finding the Family House, to be honest with you. That is when my heart felt better because I knew my wife was going to be okay."

-Russell Westendorf, lung transplant recipient

It was 33 years ago when Cindi and Russell Westendorf met at the Hospital of the University of Pennsylvania (HUP), purely by coincidence. Now, happily married with 3 grown children, they found themselves back at the same hospital, but this time for Russell to receive a life-saving lung transplant.

Prior to Russell and Cindi meeting, Cindi was a graduate student in Philadelphia studying counseling and creative arts therapy. Russell had gotten into a very serious motorcycle accident and was transferred to HUP, a hospital close by where Cindi was studying, to receive bone grafts. He stayed there for many months during his recovery. Cindi's family, who knew Russell's family, recommended she stop by his hospital room for a visit as she was already in the area – and they have been together ever since.

After they were married, Cindi and Russell settled in Colts Neck, NJ and had three sons. Russell worked as a stone and tile setter. Russell loved his job, especially the fact that his hours allowed him to be home with his children and his wife. However, it took a toll on his physical health and Russell developed a serious lung disease. Surrounded constantly by dust, insulation, and other hazardous materials, "it physically beat me up. Lung disease was part of what I did. It took some getting used to, but slowly my health got worse until suddenly I'm using 17 percent of my lung capacity, and started to have to use the oxygen."

Because of his illness, Russell was listed for a lung transplant in 2014. All too familiar with caregiving and support, Cindi, an art and trauma therapist, has been right by his side throughout his entire transplant journey. Russell could not be more grateful for their partnership, "She is my rock and probably the most giving person I've ever met in my life."

After two years on the transplant list, the couple was getting into bed one night about a week before Christmas when they received the call that donor lungs were available. They rushed to Philadelphia, over 70 miles from their home, at 2:30 in the morning and, upon arrival, Russell went right into surgery.

He awoke on December 19th with his gift of life – a new pair of lungs – thanks to someone's selfless decision to say yes to donation.

After the transplant surgery, Cindi was able to stay at Gift of Life Family House while her husband was in recovery. As Russell noted, "I think one of my biggest reliefs was finding the Family House, to be honest with you. That is when my heart felt better because I knew my wife was going to be okay."

On Christmas morning, a few days after the surgery, the doctors moved Russell back into the ICU due to a complication. Cindi, who

was staying at Family House, got a call from the hospital explaining the situation. "I got up, so startled. I didn't even think about it being Christmas but I woke up, got dressed, got myself together and opened the door and there were all these gifts [from the staff]. It was really special; it's just a little thing like that, that made me feel like we were in the right place at the right time."

Russell recovered from the complication and was released from the hospital a few weeks later. He was then transferred to the Family House to

continue his recovery. After hearing so many wonderful things about the Family House from his wife, he had high expectations upon arriving: "When I got here, I was totally blown away. Everybody here is just wonderful, very supportive. The thoughtfulness that went into planning this place and the relief of having meals is unbelievable. And I love the fact that you can sit around and share experiences with other transplant patients."

Russell especially enjoyed the Home Cook Heroes program, and the variety of nutritious meals that were served. "It's all been fabulous—the whole concept that people do this for us is so nice. It has really helped me open up my pallet and try different things that I normally wouldn't," said Russell. "I wouldn't even eat salad at home and now I am trying new things, like guacamole. It's given me a new lease on life – healthy eating is important for my recovery."

Russell and Cindi are thrilled to have a place where their sons can come for visits, a place where they can meet new families and volunteers and continue trying new foods. But above all, they are relieved to have a place where they can relax and work on getting Russell's physical health back to normal. Russell says, now more than ever, they will both continue to live by their personal motto: "Be Positive—that's my blood type."

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

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