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### EDITOR'S NOTE

This issue of the *AirWays* newsletter has been delayed going to the printer due to a change in the Editor position. Sadly, as you may have read in last years May-July 2017 newsletter, we, and I, lost a good friend in Steve Schumann to whom I passed the position of *AirWays* newsletter editor some years ago. So it has taken a bit of time to get back up to speed and understanding the new process of putting out *AirWays*. Timeliness will improve with the next newsletter.

We are always looking for articles and photographs from lung transplant patients, caregivers, and lung transplant professionals. Personal experiences, and clinical or treatment subjects are welcome. To submit corrections, letters to the editor, photographs and articles, please send an e-mail to:  
neuberger1234@comcast.net

Thank you,

Damian Neuberger, Ph.D.  
*AirWays* Newsletter Editor  
Bilateral Lung Transplant 10/19/97 Loyola Univ.  
Med. Center  
Kidney Transplant 10/19/11 Univ. Wisconsin  
Hospital & Clinics

## The History of Lung Transplantation

Ramsey Hachem, M.D.  
Washington University of St. Louis

Dr. James Hardy performed the first human lung transplant in 1963 in Jackson Mississippi. Before proceeding with human lung transplantation, Dr. Hardy and his team had performed approximately 400 transplant experiments on dogs. However, while the transplanted lung seemed to function reasonably well early after transplantation, the dogs ultimately rejected the lungs within a month despite various immunosuppressants available at the time. Nonetheless, the team believed that "cautious clinical application of the procedure" in humans was acceptable, but decided that the initial recipient must have a fatal underlying disease to justify undertaking the unknown risks. After evaluating many candidates over a year, the team identified a patient who met their selection criteria. The patient was a 58-year old man who had lung cancer involving the left main airway and obstructing distal airways resulting in lung collapse and recurrent pneumonia. While the patient was serving a life sentence in prison, Dr. Hardy outlined the potential complications and risks with him in detail and he agreed to proceed.



The eventual donor had been brought to the emergency department because of a massive heart attack resulting in heart failure and shock. Shortly after arrival, he arrested and when it became apparent that successful resuscitation was not possible, his family consented to organ donation. The donor was taken to the operating room for retrieval, and the recipient was prepared for transplantation in an adjacent operating room almost simultaneously. Both operations were remarkably uncomplicated and the recipient began breathing spontaneously. Indeed, the arterial oxygen saturation improved from 87% before to 98% immediately after the transplant. Chest x-rays and an angiogram confirmed that the transplanted lung was well ventilated and perfused. The immunosuppressive regimen consisted of azathioprine, prednisone, and cobalt radiation to the mediastinum and thymus. Notably, cyclosporine and tacrolimus, which are the cornerstones of immunosuppression in modern transplantation, had not yet been discovered.

After the initial success, the patient developed progressive kidney failure and became increasingly malnourished. He was started on peritoneal dialysis but died eighteen days after the transplant. An autopsy showed no evidence of rejection. Despite the ultimate outcome, this case encouraged the field of lung transplantation by demonstrating that the transplanted lung could function physiologically and rejection could be averted with the available immunosuppressants, at least for a short time. However, over the next ten years only 36 lung transplants were performed worldwide and the majority of recipients died within a few days; two recipients survived more

(Please see *History* continued on page 3)

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### *AirWays*

*AirWays* is published six times per year (if enough material of interest is submitted or found) by Second Wind Lung Transplant Association, Inc. by and for lung transplant candidates, recipients, caregivers, and transplant professionals worldwide.

We welcome all contributions to the newsletter; however, we reserve the right to edit submissions. Articles printed in *AirWays* are the property of Second Wind Lung Transplant Association, Inc. and may not be reprinted without permission from the Board Executive Committee.

We appreciate our members' help in obtaining donations to support Second Wind Lung Transplant Association.

### General Information

Membership in Second Wind includes a subscription to *AirWays*. To join or change your address please contact Second Wind via postcard, toll free phone, or e-mail listed below.

Cheryl Keeler, 2781 Chateau Circle, Columbus OH 43221  
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### A Word of Caution

Every attempt is made to print accurate technical/medical information from reliable sources. We would not knowingly present erroneous information but because of time and technical constraints it is not possible to check all submitted information.

Articles printed in this newsletter are for general information only and not meant to be taken as professional medical advice. Each individual's situation is different and information in the newsletter may or may not apply to you or your circumstance. It is your responsibility to discuss any information herein with your physician to determine whether it is beneficial or deleterious to your health.

To submit an article for publication in *AirWays*, send an MS Word document as an attachment to: neuberger1234@comcast.net

Send hardcopy submissions to the editor:

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## President's Notes

Cheryl A. Keeler

Second Wind Lung Transplant Association, Inc.

The Board of Second Wind hopes all of you survived the winter months and are looking forward to the future.



### Board of Directors

We are pleased to announce that we have four new Board Members who began on January 9, 2018. They are Tim Adams, Patrick Henry, Damian Neuberger and Amanda St. Lawrence. Later in this edition and the next, these new members will introduce themselves to all of you.

### *AirWays*

The edition of *AirWays* covering December 2017, through March 2018 is being completed and will go to the printer. This edition includes articles from two of our Board Members sharing their transplant experience. As we have stated before, we strive to provide support, advocacy, education, information and guidance. Your help is needed to fulfill this effort. We would like to publish more articles about personal transplant journeys. Your individual stories give hope and information to those awaiting a lung transplant. If you are willing to share your transplant experience, please write your story and email a copy, along with your picture, to our new Editor, Damian Neuberger at neuberger1234@comcast.net.

### Financial Assistance Program

During the months of December 2017, January 2018, and February 2018 we granted a total amount of \$2,154.70. We would like to tell you a little about these grants and not just a total amount. One of the grants was awarded to a young woman in New York City. She is on the waiting list for a lung transplant at one of the major transplant centers in her area. She is here in the US on visa permit and is living with her sister. She has also started the process of becoming a US citizen. She applied to Second Wind for help in paying the rent. The small apartment she shared with her sister cost \$950.00 per month. When I spoke with the applicant on the phone, she was dispirited, fearing they might be evicted.

(Please see **President** continued on page 4)



(History continued from page 1)

than a month. The leading cause of death, and the primary obstacle to better outcomes was poor healing of the airway anastomosis, which sometimes eroded into adjacent vessels and led to massive bleeding into the lung.

In 1981, Dr. Norman Shumway and his colleagues at Stanford University performed three heart-lung transplants. Two of the three transplants were successful and the recipients were still alive when the team reported their results in 1982; one recipient died four days after the operation because of multi-organ failure. Dr. Shumway attributed the success to refining surgical techniques through primate experimentation and the advent of cyclosporine, which reduced the necessary steroid doses thus mitigating their negative impact on anastomotic site healing.

In 1983, the Toronto Lung Transplant Group performed the first successful lung transplant. The recipient was a 58-year old man with pulmonary fibrosis. The operation and early post-operative course was fairly uncomplicated. He was treated with cyclosporine and azathioprine for immunosuppression and initially did not receive steroids to minimize the risk of airway anastomotic dehiscence. However, in the first two weeks he developed two episodes of rejection that resulted in respiratory failure and required steroids and lymphocyte depletion. The recipient ultimately recovered and was discharged home. When the group reported their experience in 1986, he was alive and leading a normal lifestyle. This success was remarkably encouraging for pulmonary physicians and patients with lung disease, but the early rejection was an ominous prediction of future obstacles and limitations.

Over the ensuing decade, the number of lung transplants performed worldwide increased rapidly. In 1987, approximately 45 transplants were performed, and by 1990, over 400 were performed worldwide. Activity continued to increase rapidly until the mid 1990's when the number of annual transplants plateaued at approximately 1400. In recent years, the number of transplants has increased to approximately 2200 per year. Over the years, outcomes have improved, as surgical techniques, donor and recipient selection, and medical therapy have been refined. In fact, the median survival of patients transplanted between 2000 and 2006 was 5.5 years compared to 4 years for those transplanted between 1988 and 1994. However, outcomes in the modern era remain far from ideal, as chronic rejection has emerged as the leading obstacle to better long-term survival. Likewise, the shortage of suitable donor organs remains the primary limitation to the more widespread use of lung transplantation. Nonetheless, as we look to the future and consider the challenges ahead, reflecting on the history of our field provides insight and hope.

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## GRATITUDE FOR THE LIFE SO GENEROUSLY GIFTED

by

Brian Puhalsky

Bilateral Lung Transplant Recipient

Cleveland Clinic

January 30, 2017

**Editors Note:** This is the first of what is hoped to be many articles written by transplant recipients or those waiting to receive the gift and hope for renewed life that have been posted on the Second Wind Email Support Group. No posted messages will be included in **AirWays** without prior written or phone approval provided to the editor.

**W**ell, here it is, my one-year anniversary. I am humbled to think about the life-changing gift I was given, and the life I have been so generously gifted.

I'm not sure if any of you remember my journey, but if I may, I'd like to recap. Around May 2010, I was told by my pulmonologist that there was nothing more he could do for me and I should get my affairs in order. Having a 35-year-old wife and 2 children, ages 9 and 5 at the time, all I could think about

(Please see **Gratitude** continued on page 4)

We paid \$500 toward her rent and her sister came up with the rest of the money.

We told you in the last edition of AirWays about a young girl who is waiting on a lung transplant. Her entire family had to relocate to another state so their youngest sister could be placed on the waiting list. Originally, the family asked for help with the cost of food. There are five children in this family. The Mother wanted to wait until December to ask for the remainder of their grant. She wanted the money so she could prepare a wonderful Christmas dinner and bake some cookies for the children. Through your generous donations, we were able to grant them a \$250.00 gift card from Kroger and hopefully they will receive their young daughter's call soon.

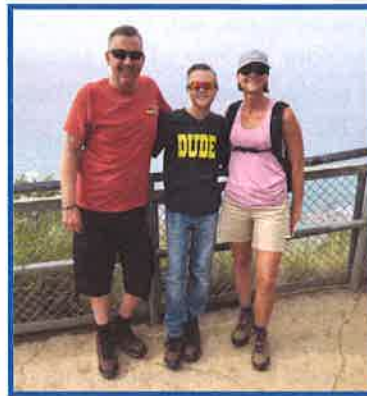
The remainder of grants we were able to process during this period consisted of grants for gasoline to help with the cost of going to their transplant center and help with temporary lodging while they are at their transplant center. There was one application for help with the costs of medication. He was only 6 months post-transplant. The family was shocked at the cost of some of their medication. He applied to us for any kind of help we could provide. He was paying for his medication with a credit card. That should be your last resort when it comes to medication. We were able to help with \$500 and some help with the medication providers. Some of the drugs we are required to take have programs to help if you can't afford the medication. Your Social Worker at your center can help in contacting the pharmaceutical manufacturers who have such plans. To those of you who have generously donated to this program, thank you very much. I know that your donations have made a difference in many people's lives. Thank you!

## **Transplant News**

### **Pulmonary Fibrosis Foundation**

The Pulmonary Fibrosis Foundation (PFF) announced a new tool that helps in finding clinical trials you may be eligible to join. The PFF Clinical Trial Finder will help you navigate more than 100 clinical research opportunities that will advance the treatment for pulmonary fibrosis including idiopathic pulmonary fibrosis. You can try the finder at: [trials.pulmonaryfibrosis.org](http://trials.pulmonaryfibrosis.org). The PFF Clinical Trial Finder is intended to help raise awareness of and increase

*(Please see President continued on page 8)*



Brian Puhalsky and his family on their recent Hawaiian vacation "It was so incredible on so many different levels. I climbed to the top of Diamond Head on Easter Sunday. It was a pretty emotional day as well as hot and humid but I was so glad to be there."

was how I was going to tell them.

On my drive home, I began to think that this was not going to be an option, and I had to fight. I got home and immediately started surfing the Web. I started finding different forums on lung disease and transplant. I kept this all to my self for a few days and contacted the Cleveland Clinic. Sure enough, after hours of testing, I was told I was a transplant candidate having 18% lung function at the time.

So the journey began, that is until 6 months later. Nov. 5, 2010, our family would once again be rocked. My youngest, 6 at the time, was diagnosed with Leukemia. I decided at that point that I would put my transplant into second priority over his and we then began a 3 1/2 year battle against childhood cancer. It was at this point that I learned what strength was. In the time we spent going through chemo, pancreatitis, hospital stays that would equal years of time, nausea, wheel chairs, baldness, and mouth sores to name a few; my son never complained once. Literally, not once did he complain! His only question was when he would be able to play basketball again.

After the 3 1/2 year treatment program that he was enrolled in, mercifully we were given back a healthy 10-year old. Then my journey started again. I started pursuing my listing again, and was at about 15% FEV1 at that time. I was well within the parameters of a transplant, except for my ability to function. I was still too high functioning according to my 6 minute walk test. So I waited. As my son got healthier, I became sicker and really was unable to function as a dad; throwing balls, going swimming, hiking, sledding, etc.

We did however play a lot of Wii and could go to Cavalier games, thanks to the handicap program they have in place at the arena. Not to long after though, I was listed. So, I figured it was time to get ready. Wrong! I stayed on the list for another 2 1/2 years while a match was found.

Side note: At this point it had been 7 1/2 years since the journey began. In that time, my youngest had never known what it was to have a functioning dad. A physical dad yes, but functioning? No! In those years, as he became healthier, I became sicker to the point that in the last year, I was basically homebound. Moreover, bedroom bound. It was too strenuous to shower any more, and because of my breathing, I could not sit and take a bath. My wife began showering me and would just get in with me because it was just easier for her (well, that's what she says anyway 😊). I was unable to walk more than about 100 feet and was on 15 liters O2. It was at this point

*(Please see Gratitude continued on page 6)*



# Qualifying for Social Security Disability Benefits With COPD

Bryan MacMurray  
Director of Outreach  
Disability Benefits Help

If you suffer from advanced chronic emphysema or bronchitis that doctors refer to as Chronic Obstructive Pulmonary Disease (COPD), you might be unable to work because of how the condition impacts your daily life. If COPD has rendered you unable to work, you might qualify for Social Security Disability benefits. COPD can be very serious, and affect your daily functions. The Social Security Administration (SSA) oversees two kinds of disability benefits, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

The SSDI program is a credit-based disability program that is based on work history. In order to receive SSDI benefits, you must have worked enough to earn sufficient credits. That means you have to have paid in adequate taxes to the SSA. Usually, that means that you have to have worked the equivalent of about five years full-time out of the last 10 years. Your medical condition must meet the SSA criteria to be considered permanently and fully disabled. The SSA uses a medical guide, which is called the Blue Book, to determine this.

COPD is a listing level disease, which means that it is included in the Blue Book. If your condition meets the Blue Book requirements, you will be approved for benefits and the SSA will not have to evaluate you using your functional capacity and your restrictions. COPD can be a serious and life-threatening condition. COPD can impact your daily activities as well as your ability to work. COPD is a chronic condition that requires extensive ongoing medical treatment, so it is expensive to treat. The treatments can have side effects and impact the ability to function as well.

## The Medical Requirements for Disability Approval

The Blue Book is the medical guide used by the SSA to determine whether or not an individual is legally and permanently disabled. To qualify for disability benefits based on the Blue Book listing, you must have a confirmed diagnosis of COPD. A lung functioning test will be conducted by a consulting doctor hired by the SSA. The test has to show that you suffer from restricted or limited airflow because of your condition. Your medical testing will include a spirometry test that shows your FEV1 values, which reveals how much volume you can forcefully expel within one second. The expected amount does vary based on your height when not wearing shoes.

For example, someone who is as tall as five feet should exhale about 1.05 liters. People who are at least six feet tall or taller should be able to exhale 1.65 liters. There is a chart that has specified FEV amounts and heights. The chart is used by the SSA to determine whether or not someone with COPD is disabled. If your problem isn't the air circulating in and out of your lungs, COPD might cause you difficulty with oxygenating your blood. You could be eligible for disability benefits because of the poor diffusing capacity of carbon monoxide of the lungs. Another way you can medically qualify for benefits is ABG, which is the arterial blood gas values of carbon dioxide and oxygen. There are values listed for each of these tests in the Blue Book.

## Meeting The Criteria For Disability Approval Using The Medical-Vocational Allowance

If your condition doesn't meet the requirements for approval for disability benefits by the Blue Book guidelines, you can still qualify for benefits using a medical-vocational allowance. This process involves using a residual functioning capacity (RFC) that shows you have limited abilities. If you can prove that COPD limits your breathing capacity so severely that there is no work you are able to do or no jobs you can perform based on your age and experience, health conditions, work history and experience, and educational background then you may qualify for benefits.

To have success with the RFC, you must show that your ability to exert yourself and your breathing capacity is too low for you to be able to work. Your physician will have to complete the RFC to indicate his or her medical opinions regarding your ability to function and activities that you can or cannot do because of your COPD. For example, you are unable to lift more than 5 pounds, you cannot be exposed to any fumes or dust, you are unable to stand for more than an hour at a time, and you are unable to walk more than 500 feet before resting. The SSA will then go over all the information and give you an RFC assessment based on the work that you can perform based on your physician's restrictions and the results of your breathing tests. If you are unable to perform any kind of work because of your education, health, age, and experience, you will be awarded disability benefits.

You can apply for disability benefits online at [www.ssa.gov](http://www.ssa.gov), by visiting your local Social Security office, or by calling 800-772-1213. The process can be time-consuming, so make sure you provide all the available documentation to support your claim.

For more information about this article, the best person to contact by email is [drp@ssd-help.org](mailto:drp@ssd-help.org)

I actually did begin to get my affairs in order. I began buying final gifts, making sure all bills that could be taken care of were. I started buying things and putting them away that I thought my wife would need, and with the help of a dear friend was in the process of making a final video for the family to keep. I was pretty sick.

Then, January 29, 2017 at 8 PM, my cell phone rang. Before I even picked up the phone I knew what it was. Sure enough a calm voice on the other end said, "Brian? this is Matt, we have located lungs for you." My wife could hear the conversation and came to the doorway. Once she realized she wasn't hearing things, she began to cry and gathered the kids.

I was told that the lungs were questionable and were coming from a heroin overdose. It didn't take long to accept them though, after all, I didn't know how much longer I had and wasn't sure if I would make it till the next call. I was told I didn't have to be at the clinic till 8 AM. The next morning we woke early and found the worst snowstorm of the season had arrived. The drive that generally takes 40 minutes to make took 2 1/2 hours that morning. STRESS!!!!!! Never the less, we got there in time and hours later I went into the Operating Room with 15 liters of O2. Five hours later I came out on 2 liters of O2, and 18 hours later, I was on room air saturating a 100%.

Which brings me to today. 1 year later. I have lived a lifetime in the last year. We make use of every moment now. I play basketball with my son, we go to the YMCA every day (except Sunday) and when we want to do something, we go. We go right then.

In two months we will be going to Hawaii for 2 weeks. A vacation we have planned for 8 years. We started saving air miles back then and swore that if we ever made it through the ordeal, we would take the vacation of a lifetime. My wife and I never got to take a honeymoon, and this is where we wanted to go. We are definitely not rich people so this is a huge thing for us. But even bigger is having the health to do it.

I am so thankful for my donor, this gift, and the sunrise every morning. I am so thankful for my wife who, in all of this has had it harder than any of us. She, day after day, had to lay her head down at night wondering if she would have her husband and son the next day. Had we passed away, our suffering would have ended, but hers would have began.

I am just so thankful for the extra time I have been given!

So in conclusion, for those of you who are starting your journey, or are in the middle, or for those of you that think you are too tired, continue to fight. Everyday find one thing to fight for and fight as hard as you can for every breath. In my first year, there are things I have had to give up, and I have had minor bumps, and I take a truckload of pills every day. But I thank God for every bit of it and it is sooooo worth it. You don't realize how beautiful life is, until you get it back.

## TIM ADAMS – DIRECTOR



Tim is almost 9 months “and counting” from his single lung transplant in June of 2017. He went swimming 2 years ago in a fresh-water lake in New Jersey and almost did not come home. The local pulmonologist told him he had only one year to live. Diagnosed with Idiopathic Pulmonary Fibrosis, it was recommended that Tim go to UPenn for treatment and he did. Tim moved to Temple University Hospital in 2017 and, as Tim says it, “Temple and Dr. Criner’s team saved my life.” He praises God, and prays for the donor and his family. Tim also asks blessing on the doctors and nurses in his lung transplant team. Tim is very excited with his “new life” and is determined to help other patients.

He enjoys “giving back” by being involved in helping other transplant patients. Tim is writing an article for Temple on the personal transplant experience for Temple’s entry program. Tim notes that it is strictly the view from the patient, not the doctor. He is also writing a paper that defines the patient role in the causes and results of complacency-instigated complications. Complacency plays a significant role in the longevity (life expectancy) of transplant patients. Tim has also joined a “patient-to-doctor” panel at Temple and sits on the Board of the Second Wind Lung Transplant Association.

Tim mentors patients and helps them with the process before and after lung transplant. Patients ask him questions that they want to hear answers from another patient. Temple Hospital wrote an article on Tim for their “Temple Talk” magazine and website. Several patients have contacted Tim after reading the article.

Tim received his BSE Electrical Engineering Degree from University of Michigan and business Post Graduate Studies at U of M. He has 40 years of marketing experience introducing new products, positioning new products and companies, and developing programs/projects for his clients. He worked both staff and line positions on the “client side” of Fortune 100 companies and moved to the consultant side as a partner at a large strategy/advertising firm. Tim then worked for several marketing consultant firms and formed his own consultancy practice and a marketing institute helping companies develop marketing strategies. Tim’s company provided services and programs to top Fortune companies including GE, Westinghouse, Danaher, Aetna, US Surgical, United Technologies, Pilot Pen, Cannondale Bicycles, Loctite, and more.

He is married and has 2 adult children.



# A Walk in the Park

by Michael Vitez

Director of Narrative Medicine

Lewis Katz School of Medicine at Temple University.



The other day, just after lunch, a man in a wheelchair was pushed out the main entrance to Temple University Hospital and rolled into the sunshine. He had a mask on his face, and an oxygen cannula leading into his nose. People all around were bustling in and out of the hospital through the sliding doors. But they were extras on his stage. He stood, something he had worked on and was quite proud of, lifted his chin to the sky, and exulted: “I’m outside!!!!” He literally

breathed in the moment – inhaling fresh air for the first time into his new right lung. Holding firmly onto a walker now with one arm, he raised the other arm in triumph, a half-Rocky.

The man, Tim Adams, 69, was not alone, but the locomotive on his own train. As he pushed the walker, slowly, his physical therapist, Casey Gillick, a former gymnast, held his arm. Walking behind, pushing the empty wheelchair with oxygen tank, was Isais Rosario. “I’m his chauffeur,” said Rosario, a member of the rehabilitation team. The patient’s wife, Donnamarie Adams, in most ways first, followed last.

The July sun on this afternoon was rejuvenating, not punishing, and the temperature a glorious 87 degrees. Doctors and nurses and civilians sat on shady benches eating their lunches, talking on phones, laughing. A summer day! He looked about him. There were flowerbeds and birds, cars dropping people off. A horn blared on Broad Street. Life!

Slowly, steadily, he moved across the hospital’s brick apron, passing the traffic circle in front, toward the sidewalk and street. “I’m going to try and escape,” the patient quipped. “We’ve got security and cameras,” confided Rosario, playing along. “He can’t go anywhere.” The patient stopped. “I just want to rest for a second.”

Tim Adams had been days from death. That’s no exaggeration. “Dr. Criner took a look at me one Friday after I failed a breathing test. ‘You’re checking in.’ Three days later I had a lung.” Gerard Criner is head of Temple’s Lung Center. The transplant was on June 19. Not five weeks ago. “I’m so happy,” the patient said. “It’s like my first shower a couple days ago. Oh, joy!”

Gillick, his physical therapist, had been in the next room, working with another patient, and heard him through the walls and closed doors, crooning, giving that new lung a workout.

Adams was in marketing all his life, a creative type. He made up a song. “I’m in the shower I’m free. I’m in the shower, just me!”



This singing didn’t surprise anyone. In the physical therapy room, on the 8th floor, he browbeats the staff to play James Brown, and he sings along with the Godfather of Soul to “Get on up,” which, in this setting, could be considered a motivational song. On his first trip outside, he wore t-shirt, gym shorts and running shoes. “They told me to dress for success,” he said.

Enough rest. Gillick wanted him to walk over to some steps. He walked and gushed. “You should know this hospital saved my life and there are literally angels all over. They held my hand. Stayed with me night and day. This is the best place in the world.” The therapist helped the patient up and down the steps. Now she wanted him to stand on his tiptoes 10 times. He did. “You did so well. How about another five?” “Liar. Liar. Pants on fire,” he said. Then he explained: “I say this because they’re always pushing me beyond, harder, more, another five, another ten, which is why I’m here.”

He was quite astonished at all that he’d learned: How to stand again. How to walk again. How to breathe – and recited his new mantra: “Breathe in the flowers, blow out the candles.” He kept moving, a lap around the entrance area. Two women in hijabs were on a bench, eating lunch. “Can I have a bite of that sandwich?” he asked playfully, but also longingly. “Is that a Philly cheesesteak?” “I wish,” she replied. “It’s a bootleg one from a truck.” A pizza man was getting out of his car in front of the hospital with three steaming boxes. “807! 807!” shouted Adams. His room number. Rosario the chauffeur shook his head. “It’s fruits and vegetables for him.”

Donnamarie Adams marveled at her husband, and kept taking photos of him to chronicle the occasion. “He’s come a long way,” she said. “You’re in the hospital five weeks, it feels like five months.” She has stayed at the Gift of Life house in Center City as he has convalesced, and they will stay there together for another week after he is discharged from the hospital before going home to Ventnor.

Tim had one last exercise—kicking a soccer ball back and forth with Rosario. The patient held onto his walker, lifted his leg slightly, and kicked the ball, alternating right foot and left. In the spirit of the moment, he raised a hand in triumph after one kick and shouted just like the announcers on Telemundo, “Gooooooooal!” “You’re going to sleep this afternoon,” said his wife.

# Transplant Anniversaries

## DECEMBER 2017

Name	Transplant Date	Yrs
Eric Harned	12-22-14	4 years

## JANUARY 2018

Name	Transplant Date	Yrs
<b>Karen Couture</b>	<b>1-21-96</b>	<b>22 years</b>
<b>Holly Hahn-Baker</b>	<b>1-3-98</b>	<b>20 years</b>
Stephen Hamilton	1-6-11	7 years
Anne B. Lovett	1-1-16	2 years
<b>Paula Moscariello</b>	<b>1-1-94</b>	<b>24 years</b>
Laura Roix	1-7-17	1 year
Leanne Storch	1-15-14	4 years
Michael E. Thomas	1-16-12	6 years

## FEBRUARY 2018

Name	Transplant Date	Yrs
<b>Sandra M. Anderson</b>	<b>2-3-01</b>	<b>17 years</b>
Re-transplanted	12-5-08	
Chathia Brown	2-20-17	1 year
Karen Ettinger	2-1-12	6 years
<b>Everett Johnson</b>	<b>2-14-06</b>	<b>12 years</b>
<b>Cheryl Keeler</b>	<b>2-3-05</b>	<b>13 years</b>
Maria Loss	2-1-08	10 years
Peg Matthews	2-16-10	8 years
<b>Jack Norton</b>	<b>2-14-02</b>	<b>16 years</b>
Mark Steitz	2-16-16	2 years

## MARCH 2018

Name	Transplant Date	Yrs
James D. Fanoni	3-5-17	1 year
<b>Kathryn M. Flynn</b>	<b>3-25-96</b>	<b>22 years</b>
<b>Paula Huffman</b>	<b>3-19-99</b>	<b>19 years</b>
John Jordan	3-22-10	8 years
Joseph Matheis	3-25-17	1 year
Kim McElhaney	3-6-16	2 years
Jesse Richardson	3-25-14	4 years
Reana Woods	3-9-10	8 years

In the above list of lung transplant anniversaries for the months December 2017 through March 2018, there are 4 individuals who are now eligible to be honorary members based on their survival for 20 years or more. Congratulations! See article on Policy for Honorary Membership later in the newsletter.

**There were numerous anniversaries from members whose information is marked as confidential, so therefore we cannot list anything about their membership in AirWays.**

(President continued from page 4)

participation in clinical trials, thereby accelerating the development of new treatment options for patients.

### American Lung Association

Northwest suffered many fires. The smoke from these fires, along with stagnant weather conditions, created widespread unhealthy air-quality. The ALA also points out that the ash left from the fires is also unhealthy. For those residents with respiratory problems such as asthma, COPD, and those with chronic heart diseases should take extra precautions. The ALA offered some tips on how to deal with the wild fires, for example by keeping fireplace dampers closed and using the recirculation setting on your home air conditioner and cars.

### UNOS/UNOS

UNOS contacted Second Wind on February 28th regarding proposed changes that our members and we might find to be of interest. The first proposal of interest is "Modifications to the Distribution of Deceased Donor lungs". This proposal basically changes where deceased lungs will be available for transplant. It eliminates the Donation Service Area (DSA) and deceased donor lungs will now be available to the individual with the highest LAS score residing in a 250 nautical mile radius from the donor hospital. When we think about this change, I believe the "regions" previously established by UNOS would make no difference. If a donor lung becomes available in Philadelphia, you would have to make a circle around Philadelphia that represents 250 miles from the donor hospital. Without looking at a map, this would take in several lung transplant hospitals in New York, Pennsylvania, and probably Maryland, and perhaps Virginia. This circle would represent the first zone of distribution for lungs procured from donors at least 18 years old.

UNOS believes this proposal makes lung allocation policy more consistent with the requirements of OPTN (Organ Procurement Transportation Network) Final Rule. It removes the DSA, an inconsistently shaped geographic area, as a unit of distribution for lung allocation and replaces it with a consistently applied circle.

The second proposed change deals with a form utilized by transplant centers.

We hope all of you enjoy these Spring days and please remember to tell just one person today how much you love them and how much they mean to you.



# Medicare Part D Plans Can Deny Coverage for Immunosuppressant Medications?!



Lisa Potter, PharmD, BCPS  
Transplant Pharmacist  
University of Chicago Medicine  
Chicago, IL 60637

and

Jennifer McDermott, PharmD,  
BCPS



Transplant Pharmacist  
Spectrum Health  
Grand Rapids, MI 49503

An alarming pattern has emerged where some lung transplant recipients have encountered challenges with immunosuppressant drug coverage under their Medicare plan. This problem does not affect patients who had Medicare prior to the transplant and have immunosuppressant drug coverage under Medicare Part B. This problem is specific to patients who convert from some other insurance to Medicare after their transplant and therefore rely on Medicare Part D for immunosuppressant drug coverage.

Companies who offer Medicare Part D plans must follow the rules set forth in the Medicare Prescription Drug Benefit Manual.<sup>1</sup> Although the Manual mandates that all immunosuppressant drugs are on plan formularies, it does not mandate they actually cover these medications for all their beneficiaries. Part D plans are only obligated to cover immunosuppressant drugs when used for indications approved by the Food and Drug Administration (FDA) or for off-label indications supported by the Centers for Medicare & Medicaid Services (CMS)-approved compendia. These CMS-approved compendia include Drugdex® and AHFS Drug Information®.

No immunosuppressant drug is FDA-approved for use in lung transplantation. The CMS-approved compendia only support off-label use for tacrolimus and cyclosporine in lung transplantation. The compendia include generic language supporting off-label use for leflunomide in “organ transplantation.” This means that mycophenolate mofetil, mycophenolic acid, azathioprine, everolimus, and sirolimus are vulnerable to denial by Medicare Part D plans when used for lung transplant recipients. This vulnerability to denial baffles transplant providers and recipients alike, because these additional drugs are needed to construct a well-rounded and effective immunosuppressive regimen for a lung transplant recipient.

Clinical trials evaluating the efficacy of all these immunosuppressive drug therapies have been conducted in lung transplant recipients. Lung transplant providers are able to construct immunosuppressive drug regimens by utilizing results from lung transplant studies conducted to date as well as by extrapolating study results from other types of organ transplants into the lung transplant population. However, the lung transplant studies conducted to date do not meet the strict criteria needed to obtain FDA approval. The CMS-approved compendia determine, utilizing their own internal set of criteria, whether the available literature is robust enough to receive their endorsement for off-label use.

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## ***Patient Story: Phillip J. Tetsworth***

On September 3, 2016, I was given the blessing of a lifetime and had a single lung transplant at Spectrum Health in Grand Rapids, Michigan. I was 64 years old and suffered from pulmonary fibrosis (a lung disease which, under normal circumstances, has an approximate life expectancy of 3 years; once diagnosed). Prior to this transplant, as one can imagine, my wife and I thoroughly reviewed with our insurance company what would be covered pertaining to procedures, doctors, transplantation, hospital stays and, of course, medications. Although I had co-pays, deductibles and co-insurance, the medications required for my transplant were covered. My transplant occurred and all was well and, with the exception of co-pays, all my medications were covered, including CellCept (mycophenolate mofetil).

In February of 2017, I turned 65 and became eligible for Medicare. We thoroughly reviewed all options available to us. Again, we reviewed prescription coverage and we were told my medication coverage would not change. Based on those reviews and conversations, we decided to stay with my existing insurance company and chose a Medicare Advantage Plan. However, we quickly learned that the Medicare Part D component of the plan would not cover CellCept (mycophenolate mofetil), an immunosuppressive drug that prevents organ rejection after transplant, which I needed.

On March 2, 2017, I received a letter from the insurance company stating that under section 1860D-2 (e)(1) of the Social Security Act, CellCept is one of the drugs that is not a covered Part D drug by law for use in lung transplant, and it would not be covered. It IS covered for other transplants- just NOT lung transplants! I had been receiving this drug since September 2016, and, prior to being on Medicare, the insurance covered it less my co-pay amount. Since the cost of this drug is extremely expensive monthly, we asked our transplant team to help

*(Please see Medicare continued on page 10)*

us. Dr. Reda Girgis, Medical Director of Lung Transplantation for Spectrum Health, Grand Rapids, and Dr. Jennifer McDermott, Transplant Pharmacist were happy to help us appeal to Medicare. It was turned down. Dr. Girgis then requested an Expedited Appeal of our case to an Administrative Law Judge arguing that I had been on this drug since my transplant, and an interruption in coverage waiting for a decision could potentially be life-threatening. Again, the appeal was denied.

This, I simply do not understand. I was covered before I was 65, but because I turned a year older, it is not covered now? It is interesting to me that it is recognized as an immunosuppressive drug that prevents organ rejection after transplants for some transplants; but not for lungs? It appears that the trials for this drug have been completed for other organs but not lungs. I may be over-simplifying, but to me, it seems a drug that is needed (and approved for) after transplant of other organs should be accepted as a drug needed for after transplant of a lung.

In addition, I have been told the law reads that the insurance provider “may” choose to cover this drug and apparently, some Medicare Part D plans choose not to. For those of us who have gone through the process of having an organ transplant (which saves our lives, but changes them drastically), and who are on fixed incomes, the added stress of dealing with high medical costs, and the nuance of the law that allows an insurance company the option of covering a specific drug needed to maintain one’s life, is particularly frustrating.

I would strongly urge serious review of this “quirk” in the Social Security Act and Medicare law in this regard.

#### ***Patient Story: Leslie Allen***

My name is Leslie Allen and I am 62 years old. I was diagnosed with bronchiectasis in my early 30's. My disease progressed slowly until 2011 when I qualified for the transplant list for a bilateral lung transplant. In 2013, at age 58, I was called to The University of Chicago Hospital for my transplant. I was absolutely terrified and hopeful at the same time. After all the years of sickness, hospitals, forced retirement, missed family functions, IV's, and oxygen, I was given a new chance at life.

But, never in a million years did I think that I would

(Please see **Medicare** continued on page 12)

## MEMORIAL DONATIONS

*In Memory of Frank Carlson*  
by  
Elizabeth Carlson

*In Memory of Nikki Addison*  
by  
Tim Addison

*In Memory of Robert Metcalf*  
by  
Dr. Kristina Zivrev  
Elaine Snoble

*In Memory of Karen Nichols*  
by  
Boulos Ghaleb  
Diana Haverlack  
Martha Badila

*In Memory of Willaim McAuley*  
by  
Judy McAuley



**Be thankful for the  
bad things in life.**

**For they opened  
your eyes to  
the good things  
you weren't  
paying  
attention to  
before!**





# How a Double Lung Transplant at Loyola Saved the Life of a New Mom with Cystic Fibrosis

Jim Ritter  
Media Relations  
Loyola University Medical Center



Fanny Vlahos and her son

MAYWOOD, IL – Wednesday, September 20, 2017

**C**ystic Fibrosis patient Fanny Vlahos was nearing the end of the second trimester of her pregnancy when she caught pneumonia and her lung function declined drastically. By the time her son was four months old, Mrs. Vlahos was tethered to an oxygen tank and too weak to even bend over the crib and pick him up. But after undergoing a double lung transplant at Loyola University Medical Center, Mrs. Vlahos was able to breathe easily again.

"The magnitude of the gift of life is not lost on me," said Mrs. Vlahos, who lives in Downers Grove. "This donor gave me lungs, but gave my son his mother. That gift can never be repaid."

Cystic fibrosis is an inherited, progressive disease that causes thick fluid to form in the lungs and other organs, making it increasingly difficult to breathe. As the disease progresses, lung transplantation becomes an option, said Erin Lowery, MD, a Loyola Medicine pulmonologist and lung transplant specialist.

"Once they undergo a transplant, I really get to see a transformation in these patients as they heal and recover and move on with their lives," Dr. Lowery said.

Mrs. Vlahos has had some setbacks, but overall has done extremely well with her transplant. "I have a future, and I don't see that future dimming any time soon," she said.

Loyola Medicine provides comprehensive, multidisciplinary care for children and adult patients. Loyola's pulmonologists are leaders in their field, and work with surgeons, nurses, respiratory therapists, dietitians, genetic counselors, social workers and psychologists to provide the highest quality of care. The Cystic Fibrosis Foundation accredits Loyola's lung transplant program.

Loyola has performed more than 900 lung transplants, making it the largest program in Illinois. Loyola has performed more than twice as many lung transplants as all other programs in Illinois combined.



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have to beg for my rejection medications that keep me alive. No one that has gone through a life changing time like this should have to worry about whether they can afford to stay alive. No one in this country should have to worry about whether life-saving medications or procedures can be afforded.

I personally have 20 prescription drugs, and have to take 24 pills each day to stay healthy and alive. When you have that many medication copays every month, you reach Medicare's "coverage gap" very quickly. I have, at times, paid several hundred dollars a month out of pocket for my rejection drug, mycophenolate mofetil. I have also bought my prescription pill by pill because I couldn't afford to pay for it all at once. Having to worry about all this while fighting with insurance companies and Medicare is humiliating and shameful. I fought long enough to be able to breathe; I don't want to have to fight to be able to stay alive.

This situation undoubtedly causes a lot of stress for lung transplant recipients. The transplant community is aware of this issue and has begun work to remedy it. The American Society of Transplantation has taken a position. Their statement, available online, summarizes the problem and proposes solutions.<sup>2</sup> A paper was recently published in the American Journal of Transplantation outlining the potential scope of the problem, in the event that all Medicare Part D chose to deny off-label and off-compensia claims.<sup>3</sup> Despite acknowledgement of the problem, it has yet to be solved.'

If coverage for your immunosuppressant drug(s) have been denied for this off-label and off-compensia reason, and appeals of those decisions have also been denied, you will need to seek alternate sources of obtaining them. Options for alternate sources include discount programs like Rx Outreach® or GoodRx, or industry-sponsored assistance programs. NeedyMeds ([www.needymeds.com](http://www.needymeds.com)) is a web-based clearinghouse allowing you to search by drug, and connecting you with available assistance programs. Speak with providers from your transplant center; they will be able to help you.

If you have personally had one of your immunosuppressant drugs denied by your Medicare Part D plan for this off-label and off-compensia reason, please consider filing a complaint. Filing a complaint with your insurance plan will not get you far, since the plan is indeed acting within parameters allowed by the Medicare Prescription Drug Benefit Manual. Consider filing your complaint with Medicare itself ([www.medicare.gov/claims-and-appeals/file-a-complaint/complaint.html](http://www.medicare.gov/claims-and-appeals/file-a-complaint/complaint.html)) or with the Center for Medicare Advocacy ([www.medicareadvocacy.org](http://www.medicareadvocacy.org)). We are confident that this issue will find a solution. However, solutions to

government-based problems such as this take time. In the interim, keep in close contact with your transplant center to find alternate sources of medication. Going without medication is not an option!

1. Prescription Drug Benefit Manual. Centers for Medicare & Medicaid Services. Chapter 6: Part D Drugs and Formulary Requirements [www.cms.gov/medicare/prescriptiondrugcoverage/prescriptiondrugcovcontra/partdmanuals.html](http://www.cms.gov/medicare/prescriptiondrugcoverage/prescriptiondrugcovcontra/partdmanuals.html)
2. Immunosuppressant Drug Coverage Under Medicare Part D Benefit. American Society of Transplantation. Available online at [www.myast.org/public-policy/key-position-statements/immunosuppressant-drug-coverage-under-medicare-part-d-benefit](http://www.myast.org/public-policy/key-position-statements/immunosuppressant-drug-coverage-under-medicare-part-d-benefit).
3. Potter LM, Maldonado AQ, Lentine KL, et al. Transplant recipients are vulnerable under the Medicare Part D benefit. Am J Transplant 2018; Feb 15: Epub ahead of print.

## WE REMEMBER

Karen B. Nichols

Hometown: Chevy Chase, MD  
Single Lung Transplant: 2011  
Date of Death: 01-23-2018

Frank Carlson

Hometown: Tinley Park, IL  
Double Lung Transplant: 8-4-2016  
University of Chicago, IL  
Date of Death: 3-11-2017

Katherine Glasgow

Hometown: Hendersonville, TN  
Single Lung Transplant: 6-4-1997  
Vanderbilt Univ. Medical Ctr.  
Date of Death: 3-20-2017

Henk A. Berends

Hometown: Lynden, WA  
Transplant date: 11-29-2003  
Univ. of Washington Medical Center  
Date of death: 10-30-2017

*At the going down of the sun and in the morning  
We shall remember them!*



# Some Journeys Last A Little Longer

by  
Patrick Henry



All of us who seek a lung transplant hope and expect that the recovery will go well, and typically it does. But every case is different and in mine, things did not always go as planned.

If you are about to embark on this journey yourself it's important to realize that, while there may be pitfalls along the way, you can overcome them. I did, and now, more than two years out from my single lung transplant, I'm doing great. I've been given a second chance at life, able to do things now that would've seemed impossible not that long ago.

My trip on to the transplant list began many years ago. Thanks to a family predisposition to emphysema (both my mother and a sister suffered from it) and a smoking habit I picked up as a teenager, my fate had long been decided. And, although I quit smoking in my early 40s, twenty-five years later the disease finally caught up with me. I got to the point where I couldn't walk more than a few steps without having to stop to catch my breath.

On oxygen 24/7 and essentially housebound, I was listed for a single lung transplant at the Cleveland Clinic in April 2015. Imagine my shock when, a mere four months later, I got "The Call." Three hours later my wife and I were in Cleveland, and twelve hours after that I awoke to find a nurse a foot from my face shouting, "Congratulations, Mr. Henry. You have a new lung!"

Given my drugged state, her words didn't register right away, but finding my wife's hand in mine, seeing the smile of relief on her face, I began to understand the enormity of what the nurse had said. Thus began what we expected to be a four-six week recovery, but which turned into a five month long struggle to get back on my feet.

The first roadblock was a problem with my native lung. During the surgery it suffered more than one pneumothorax—holes in the lung wall through which air was escaping. The doctors tried various techniques to close them, but ultimately time was the only cure. In mid-October I was released to a local hotel with a chest tube still in place on that side, and (despite the care provided by the amazing nurses and aides on ward J-8-2) I was supremely happy to be out of the hospital.

That feeling didn't last long because soon I was struggling to breathe again. Seems a blood clot had formed in my leg, broken off and traveled to my new lung. It was small, but big enough to cause me to be readmitted. It would become another three months before I was well enough to be released again.

I ran into a series of setbacks, including a rejection episode and a trachea that didn't fit correctly (who knew they came in

different sizes?). It would continually slip out of place, making it difficult to get air in or out. Remaining bedridden for weeks on end left me so weak that I couldn't stand on my own, but by following the instructions of the physical therapists, I slowly regained my strength. I was quite the sight, shuffling up and down the halls attached to chest, feeding and oxygen tubes, but I did it and it paid off.

One of the more critical aspects of my recovery came from an unlikely source—a music therapist. I'd heard from a nurse about this young woman who roamed the halls pushing a cart full of guitars, keyboard, drums and tambourines, and who I was told would be happy to visit and play a song or two for me. I thought, what the hell, anything had to be better than daytime TV! It turned out to be so much more.

Laura, who played multiple instruments in most any style of music you could name, provided more than a brief diversion from the tedium of the hospital routine. She wasn't simply a musician who threw a little therapy in on the side. No, she was an experienced therapist who happened to use music as one of her tools. She had an uncanny ability to play a song with lyrics that spoke to my current state of mind, and to probe my reactions in a way that helped me understand my many complicated feelings—where they came from and how I could effectively deal with them. She helped me appreciate the base of strength I didn't realize was already there inside me, strength I needed in order to deal with the physical and emotional challenges that seemed never to end.

In the end, however, the most important person in my recovery was the woman who stayed by my bedside 14 – 16 hours a day for every one of those five months—my wife, Camille. In addition to the emotional support she provided, there were times when her vigilance literally kept me alive. Medical professionals are, after all, human, and mistakes are inevitable. Having someone to support and watch over you during your recovery is essential. Hopefully you will be lucky enough to have someone at your side as devoted as Camille was to me.

Looking back on the whole experience now, I learned two things that may be helpful to you on your journey.

First, your recovery will be a team effort. Everyone, from your support person to the doctors, nurses, aides, therapists, even down to the hospital's food service and housekeeping staff, are part of your team. Treat them with the patience and respect they deserve. You'll need every one of them to succeed.

Second, trust that if and when the time comes, you will find the inner strength necessary to deal with whatever challenges arise. You've made it this far, which means you've already dealt with much more than most people ever will, so have no doubt—you'll be up to finishing the job.

And, of course, if you happen to see someone walk by your hospital room pushing a cart piled high with musical instruments, invite them in. You'll be surprised how much it will help smooth the path ahead.

## NEW MEMBERS

Tim Adams	Velor Coe
Renee Crenshaw	Kim McElhaney
Stephen Hamilton	Joseph Matheis
Bisharad Mitchell	George O'Neal
Robert Purvis	Indira Ramochan
Robert Redfield	Timothy Robison
Jerome Rudd	Jerry Russell
Robert Wielgopolski	Marilyn Williams
Ronald Zimmer	Grace Zaegel
Holly Hahn-Baker	

During this time, we had 5 new members who asked to be coded as confidential. We would like for all of you to know that we do not share your information with anyone unless we have your written permission to so. By being "confidential" we can't list you as a new member, or when you renew your membership. We also can't list your transplant anniversary date.

## MEMBERSHIP RENEWALS

Advocate Christ Medical Center - Corporate Member

Oak Lawn, IL

Greg Briggs\* —

✓Kevin Gargan\*

✓Gwen Herron

✓Anne Lovett

Lydia Burton —

✓Peg Matthews

✓Timothy Monahan

✓Paula Moscariello\*

✓Katie Moyer

✓Nancy O'Mara

✓Cheree Peirce

✓Alan Schwenck

✓Lori Schilling

✓Michael E. Thomas

✓Amanda St. Lawrence

✓Anita Tracey

✓John Jordan

✓Cheryl Keeler

✓John Dorn

Cleveland Clinic - Corporate Membership

There were four (4) individuals up for renewal who wish to remain confidential.

\*Honorary Members are members of Second Wind who have reached 20 years post transplant, or who have been a member of Second Wind for 20+ years. In the above renewals, we have three members who are Honorary Members and no longer pay dues.

## POLICY FOR HONORARY MEMBERSHIPS

It is the Policy of Second Wind Lung Transplant Association, Inc. to recognize Members as Honorary Members in the following cases:

- Those Members who have been Members of the Association for more than 20 years; or,
- Those Members of the Association that are more than 20 years post-transplant, independent of the number of years such Member has been a Member of the Association.

Honorary Members will be recognized as such by publication of their status in AirWays, on the Email Support Group and on the Association's Facebook page. In addition, annual dues of the Association, if any, will be waived in perpetuity.

As of this newsletter covering the period up to March 2018, there are eight (8) members who qualify for honorary membership. Congratulations!

## Donations to Second Wind Lung Transplant Association

The Board of Directors expresses appreciation to the following people for their financial support of Second Wind. Thank you very much for your donations, they are most appreciated!

### General Fund

John Jordan	Robert W. Kramer
Peg Matthews	Katie Moyer
Alan P. Schwenck	Michael E. Thomas
Ronald C. Zimmer	Zimmer's Service Center, Inc.
Tiffany Coco	

### Membership Fund\*

Cheree L. Peirce	Chuck Schuele
William E. Lange	

\* Membership Fund provides for waiver or reduction in membership dues for those with limited financial resources.

### Financial Assistance Fund

Leslie Casey	Patrick Henry
Timothy Manahan	Anita A. Tracey

We also want to express our sincere thanks to those donors who want to remain anonymous.

Notice: It is the Policy of Second Wind Lung Transplant Association, Inc. to prohibit the posting of any email and/or message regarding the exchange of medications on any communication medium of the Association.

## Support Groups & Event Calendar Policy

*AirWays* posts coming events that are of interest to our readers. Please submit the name of the event, location, date(s), time(s), website link, contact person. and a short description of the event if needed. We are not able to include fundraisers.

*Closing dates are the end of the months of January, March, May, July, September, and December. Due to printing and mailing schedules, please submit items for publication at least two weeks before the closing date.*



# Support Groups & Events Calendar

## ***Lung Transplant Support Groups.***

### **Dover Campus, St. Clare's Health System**

400 West Blackwell Street, Dover (Morris County), NJ  
For information, call (732) 412-7330

### **Cincinnati Support Group**

Second Thursday of each month at 6:30pm, hosted at the home of Robert and Cynthia Lohstroh; 4120 Beamer Ct., Cincinnati, OH 45246. Phone: (513) 752-0451.

Covers Cincinnati, Dayton, and Northern Kentucky.

### **St. Louis Second Wind Lung Transplant Association**

Second Wind of St. Louis is now available on Facebook by searching that name.

Second Sunday of each month, 2pm, at Chris' Pancake and Dining. Contact person: Amanda Helderle, 314-225-6751  
may12usch@yahoo.com

### **Loyola University Medical Center**

Pre-transplant, post-transplant patients, & support person(s).

First Tuesday every month, 11 AM - 12:15 PM

Third Tuesday every month, 6:30 PM

All meetings: EMS building, 3rd floor, Rm 3284

2160 S. First Ave, Maywood, IL 60153

For information, contact Susan Long (708) 216-5454

slong@lumc.edu

### **Emory Lung Transplant Support**

First Monday of the month at 12 noon on the Emory Campus.

Location Changes. Contact Julia Bucksot at  
jsbucksot@gmail.com for more information

### **Shands Hospital Lung Transplant Support Group**

Shands Cancer Hospital, South Tower, 5th Floor

1515 SW Archer Rd., Gainesville, FL 32610

Contact: Micki Luck, nodurm@shands.ufl.edu

Phone: 352-519-7545

### **University of Washington Medical Center Seattle, WA**

Support group meets the second Tuesday of the month between 12:30 and 2:30 PM in a conference room off of the cafeteria.

Many people meet in the cafeteria to have lunch before the meeting. Contact person is Angela Wagner,  
email wagnera@uw.edu

### ***Pre- and post-transplant Support Group***

UWMC patients, their family and friends. Meetings are on the Second Tuesday of the month, 12:30-2:30.

### ***Caregivers Support Group Meetings***

Meetings on the 4th Wednesday 12:30pm to 2:00pm, January through October. Open to transplant families, friends, spouses & partners. No patients please. Both meetings are held in the Plaza Cafe Conference Rooms B/C. Contact: Angela Wagner, MSW at 206-598-2676;  
www.uwlts.org

### **University of California San Francisco**

Lung Transplant Support Group, Third Thursday of every month, 1-2:30 pm., 505 Parnassus Ave., Room 1015. Moffitt San Francisco, CA 94143-0307 Contact: Andrea Baird, LCSW  
Andrea.Baird@ucsf.edu / 415-353-138

### **St. Joseph's Hospital & Medical Center**

Lung Transplant Support Group

500 W. Thomas Rd. , Phoenix, AZ 85013

2nd Tuesday of every month, 11:45 am – 1:00pm

Mercy Conference Room Contact: Kathy Lam, LCSW

Kathy.Lam@DignityHealth.org Phone: 602-406-7009

### **University of Chicago Medical Center**

Lung Transplant Support Group for transplant recipients and those who are listed. Third Wednesday of every month, 5-6:30 pm.

Center for Care and Discovery (CCD),

7th Floor Conf.Rm. 7710

5700 S. Drexel Ave., Chicago, IL 60637

Contact: Fran Hammon, LCSW

frances.hammon@uchospitals.edu or call 773-702-4608

Pager 6720

### **St. John Medical Center**

A Second Chance Lung Transplantation Support Group

26908 Detroit Rd. Second Floor Conference Room

Westlake, Oh 44145

Second Tuesday of most months 6-8pm

Group Discussion: Recipients, Caregivers, & Families

Contact Kathy Lewis (kathy2lungs@yahoo.com)

### **University of Texas Southwestern Transplant Support Group**

St. Paule Auditorium, 5939 Harry Hines Blvd.,  
Dallas, TX 75390.

Pre-lung transplant patients and caregivers are also welcome.

Contact: Jodie C. Moore, MSN, RN, ACNP-BC

jodie.moore@utsouthwestern.edu Phone: 214-645-5505

### **Second Chance for Breath Lung Support Group**

#### **St. Lukes Medical Center**

2900 West Oklahoma Ave., Milwaukee, WI 53201

For pre & post lung transplant patients

Contact Person: Ed Laskowski

laskowskiedward@att.net or call 414-231-3013

### **Ohio State University Lung Transplant Support Group**

Comprehensive Transplant Center

770 Kinnear Road, Columbus, OH 43212

For directions assistance call: 614-293-8000

medicalcenter.osu.edu

Please call our office with any questions at 614-293-5822

Meeting last Tuesday of the Month 6:00 p.m. to 7:30 p.m.

### **UCLA Lung Transplant Support Group**

Ronald Regan UCLA Medical Center

757 Westwood Plaza Driv, Los Angeles, CA 90095

8-120 Conference Room

12:00 to 1:30 pm

Stephanie Aguirre, MSW, ACSW Phone: 310 267-9728

saguirre@mednet.ucla.edu



Please Share This Issue  
of AirWays With Friends,  
Family & Colleagues

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Second Wind Lung Transplant Association, Inc.  
2416 Covert Road  
Glenview, IL 60025  
**RETURN SERVICE REQUESTED**

19810-326010

