



# Air Ways

## SERVICE THROUGH EDUCATION AND SUPPORT

### My Transplant Story

Carole Gibson Morton

Volume 23 Number 4 Sept-Oct 2014

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I have Alpha-1 Antitrypsin Deficiency Disorder. In other words, genetic emphysema. If I hadn't smoked, I probably would never have known I had it since I have no liver issues (it's a liver disorder that affects the lungs and/or liver). As a lot of teenagers in the '70s did, I started smoking. By the time I was in my late 20s I noticed strange 'episodes' that felt like my chest was caving in. It would almost always happen with strenuous activity. It almost always occurred when I would load or unload groceries. It would stop me in my tracks but I would wait a minute or two, pretend to tie my shoe so as to not draw attention to myself, and then go about what I was doing. I knew something was wrong but denial is a strong coping mechanism so I ignored it and continued on, chalking it up to being almost 30 years old or needing to lose five pounds, etc.

By the time I was in my late 30s those episodes were a lot more frequent and my main concern was lung cancer. I continued to smoke but I was always, always quitting, buying only one pack at a time instead of a carton. When I was 39 I requested a chest x-ray from my primary care physician who had been my family doctor my entire life. It showed COPD. I didn't know what COPD was nor was I told. The nurse told me to quit smoking. At the age of 42 I finally kicked the habit entirely and immediately came down with pneumonia. After visiting with a new doctor due to a change in insurance coverage, I was brutally honest and told her how I had quit smoking, but my breathing seemed to be getting worse. As a new patient, I probably would have been put through all the testing anyway, but she seemed to be putting me through the mill. By March of '99 I was diagnosed with Alpha-1. She saved my life.



I immediately went to a pulmonologist, supposedly the best in the city, and he told me to get my affairs in order. He gave me maybe five years to live. I was 45 years old, single, owned a home, and had just bought a new car. Instead of going back to work, I went to my elderly parents' home and told them that they were going to lose yet another child (two brothers died in childhood). I was beyond shocked. The next day at work I was called into my supervisor's boss's office who told me his family's story of being told to go home and die. He strongly advised me to forget that pulmonologist and find another one. He just might have helped save my life as well.

I found a pulmonologist in Indianapolis who listened patiently to my story and he gave me an assignment to return with two pages of questions about Alpha-1 and set an appointment for a few weeks later. I walked out of his office with all the confidence in the world and a whole new perspective. For the first time I heard the word "transplant". He was going

*(Please see My Transplant Story continued on page 3)*

#### EDITOR'S NOTE

We are looking for articles and photographs from lung transplant patients, caregivers, & lung transplant professionals. Personal experiences and clinical or treatment subjects are welcome.

To submit corrections, letters to the editor, photographs, and articles, send an e-mail to: [schumann10.ss@gmail.com](mailto:schumann10.ss@gmail.com)

Thank you!  
The Editor

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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.

#### 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.

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## President's Notes

Cheryl A. Keeler, President  
Second Wind Lung Transplant Association, Inc.

**H**appy Thanksgiving!!! I hope that all of you enjoyed this wonderful holiday that is uniquely American, in which we give thanks for the many blessings in our lives. Thanksgiving originated in 1621 when the Pilgrims gave thanks for a bountiful harvest after a year of sickness and hunger. Among the many blessings I gave thanks for are all of the members of Second Wind. Your continued support of Second Wind is a blessing and a reason to give thanks. I'd like to bring you up-to-date on the activities of the Board since the last edition of *AirWays*.



### AirWays

One of the things that makes *AirWays* special is that it is written for lung transplant patients as well as for health care professionals, and includes articles written by both lung transplant patients and professionals. Each of us has an individual story to tell. If you are willing to tell your transplant story, please

contact our Editor and fellow Board Member Steve Schumann at [schumann10.ss@gmail.com](mailto:schumann10.ss@gmail.com)

### Website Redesign

The Board of Directors has selected Weblinx, Inc., located in the Chicago area in Oswego, IL to redesign our current website. Weblinx presented a proposal that incorporated all of the updated aspects the Board wants to integrate into a new website. Our goal is to update the look and functionality of our website. We want the site to be modern, uplifting, and easy to navigate. Currently, the Redesign Committee is working with the designers updating information and creating a site map.

### Transplant News

#### • COPD Awareness Month

November is Chronic Obstructive Pulmonary Disease Awareness Month. According to the American Lung Association, COPD is the third leading cause of death in the United States. Also, eleven million Americans have been diagnosed with COPD and as many as 13 million people may have COPD and not even know it. Smoking contributes to the development of COPD, but it may also be caused by pollution and lung irritants such as fumes and dust. Shortness of breath is a clear warning signal of the disease. For additional information on COPD, see our website, under Transplantation - Diseases, or the American Lung Association at [www.Lung.org/copd](http://www.Lung.org/copd).

(Please see *President's Notes* continued on page 3)

- **UCSF Adult Lung Transplant Program Ranked Highest for Patient Survival.**

The University of California at San Francisco Medical Center has the highest one year survival rate in the nation, among institutions performing more than twenty adult lung transplants each year, according to data from the Scientific Registry of Transplant Recipients (SRTR), a national database of transplant statistics. Based on 104 adult lung transplants from July 2010 through December 2012, 96% of patients treated at UCSF Medical Center were still alive one year after surgery. The expected national rate is 84%.

- **Breathing Life into Lung Transplant Research**

The Lung Transplant Foundation has awarded its first grant of \$25,000 to a researcher studying bronchiolitis obliterans syndrome (BOS), or chronic rejection, which is the condition that represents the leading cause of late death among lung transplant recipients. Dr. Scott Palmer, scientific director of the Lung Transplant Program at Duke University Medical Center received \$25,000 for his approach to a new animal model replicating BOS. Dr. Palmer is attempting to understand the critical pathways that lead to the development of BOS and block that development through the use of existing pharmacological agents. Congratulations Dr. Palmer and good luck with your research!

- **UNOS Board Activity**

The UNOS Board of Directors approved a series of policy revisions and new policies to help minimize the risk of transmitting blood-borne infectious disease through transplantation. The new and updated requirements apply to both deceased and living donors and address a variety of topics including:

- ✓ Laboratory testing of potential donors and recipients, including new requirements related to nucleic acid testing
- ✓ Collection, storage, tracking and reporting of donor and recipient specimens
- ✓ Informed consent of potential recipients
- ✓ Donor risk assessment and screening

The Second Wind Board of Directors wishes you all a Merry Christmas and Happy New Year. May you and your family have a blessed and peaceful holiday season.

to make sure my life was saved. At the time of diagnosis my lung function (FEV-1) was down to 27% of predicted and 40% was the number that qualifies for disability. I continued to work another six months, hauling an oxygen tank with me, but when my 16 year old nephew had serious issues with his parents (my sister and her husband), I invited him to live with me and then I went on disability. We saved each other over the next four years.

I bought my first home computer the week I went on disability. I knew there was an Alpha-1 online presence with websites and a chatroom and I just needed to learn how to find them. I had already had some contact with a fellow Alpha via emails and she and I remain friends today. I found websites and an email list, but most importantly I found a chatroom. I couldn't wait until 8:00pm every evening to get into that chatroom to learn as much as I could. I met people who had actually had lung transplants. Until then, I pretty much dismissed the idea of a transplant because it just sounded way too far out there for me. They convinced me otherwise and I made one very good friend who helped get me through the entire process. I also met a guy in that chatroom with the same sense of humor as me and we started a cyberspace flirtation that would last a lifetime.

I wish chatrooms were still popular today. I realize Facebook has taken over but I doubt Facebook connections would have had the impact on me that the chatroom did. There's something about talking in real time to 10 or more people at once. Some nights we didn't even talk about our illness. As years passed, we all got to know each other well and I met most of them in person eventually.

By 2001 I was ready to think about transplant. I called a family meeting to get their support. My parents mostly sat there and listened. This was all too strange for them to comprehend and people of that generation didn't question doctors but accepted any fate they were handed. My brother, sister and their spouses were on board so I had my support system in place. Over time my parents learned more about transplant and accepted the path I had chosen.

Living with low lung function is sad and lonely. I had a good group of friends but they were busy working and having a social life. Even though we talked on the phone and would visit back and forth, I wasn't able to participate in the night life or shopping sprees or weekend trips. I always put on a happy face but I felt very left out which breeds resentment and depression. My emotions were all over the place in those years before transplant. I had a dog, two cats and a teenage nephew who came and went in a flash, rarely staying long enough for a meal. The house was mostly quiet and it was starting to get exhausting just constantly letting the dog outside and back in again. I always swore that dog was trying to kill me or save

*(Please see My Transplant Story continued on page 5)*



### PATIENTS WITH RARE LUNG DISEASE FACE AGONIZING TREATMENT DILEMMA

#### *Sirolimus Slows Progression of LAM, But Could Complicate Lung Transplant*

MAYWOOD, IL. – Doctors who treat patients with a severe and progressive respiratory disease called lymphangioleiomyomatosis (LAM) can face an agonizing treatment decision. The drug sirolimus can slow progression of the disease and help relieve shortness of breath. But some patients eventually may need lung transplants, and sirolimus can cause potentially fatal complications following transplantation.

“It’s a terrible situation,” said pulmonologist Dr. Daniel Dilling, medical director of Loyola University Medical Center’s LAM Clinic and Lung Transplantation program. The Food and Drug Administration has issued a “Black Box” warning about the use of sirolimus in lung transplant patients, at least when started at the time of transplantation. Many physicians therefore do not use the drug in LAM patients once they go on the transplant waiting list, since it is uncertain when the operation will occur.



“It’s a terrible situation,” said pulmonologist Dr. Daniel Dilling, medical director of Loyola University Medical Center’s LAM Clinic and Lung Transplantation program. The Food and Drug Administration has issued a “Black Box” warning about the use of sirolimus in lung transplant patients, at least when started at the time of transplantation. Many physicians therefore do not use the drug in LAM patients once they go on the transplant waiting list, since it is uncertain when the operation will occur.

But information about the drug’s metabolism, an animal model and an informal physician survey suggest that a drug similar to sirolimus may be an option for LAM patients, according to a presentation Dilling made during the 34<sup>th</sup> Annual Meeting and Scientific Sessions of the International Society for Heart and Lung Transplantation in San Diego. Dilling earlier presented at the 2013 International Lymphangioleiomyomatosis Research and Patient Educational Conference sponsored by the LAM Foundation

LAM occurs almost exclusively in women. An abnormal growth of muscle cells invades the lungs, eventually causing airways to become obstructed. Symptoms include shortness of breath, chest pain, chronic cough and pneumothoraces (lung collapses). As the disease progresses, many patients will need

to go on oxygen, and some will require lung transplants. LAM is uncommon, but not as rare as once thought. As many as 30,000 to 50,000 women worldwide may have the disease, according to the LAM Foundation.

Sirolimus belongs to the rapamycin class of drugs that also includes everolimus. According to a 2011 study published in the *New England Journal of Medicine*, sirolimus in selected patients slowed the progression of the disease and was associated with a reduction in symptoms and improved quality of life. Sirolimus sometimes is given to lung transplant patients to prevent rejection. But two studies found that sirolimus caused a serious and sometimes fatal complication called anastomotic dehiscence, which impairs wound healing if the drug is given around the time of the operation. Consequently the connections where the donor’s lungs are sutured into the recipient break apart.

Sirolimus (trade name, Rapamune®) has a relatively long half-life, meaning it stays in the body even after a patient stops taking it. Consequently, many physicians do not prescribe sirolimus in patients who are waiting for lung transplants.

However, some LAM physicians have begun prescribing everolimus (Zortress®), which has a shorter half-life. Once a patient undergoes a lung transplant, the patient is immediately taken off the drug. In an informal survey, Dilling found that physicians who have used this strategy report no dehiscence problems. Moreover, a recent animal study at the University of Cincinnati found that if sirolimus treatment ceased immediately, wound healing was not impaired. And an earlier study of pulmonary fibrosis patients who took everolimus found that among 11 patients who had lung transplants, there was no increased incidence of wound-healing/anastomosis problems.

Historically, Loyola physicians have not prescribed rapamycin-class drugs to LAM patients who are on the waiting list for lung transplants. “However, in light of recent evidence and experience, we are reconsidering this policy,” Dilling said.

Laura Lentz, chair of the board of directors of the LAM Foundation, said that in raising the topic, Dilling “is providing a service that is going to make a big difference for women who have LAM.” Lentz agrees with Dilling that more research is needed on rapamycin-class drugs in LAM patients. “One of the frustrations of having a rare disease is that there has not

*(Please see LAM continued on page 7)*

my life; I never decided which.

Back “in the day” when I was on the transplant waiting list at IU/Methodist in Indianapolis, the rules were so relaxed. There was no mandatory pulmonary rehab and I just went for a six month spirometry and chit-chat with the doctor. It was fairly easy and stress-free. It was also before the LAS (Lung Allocation System) was in place and the system of that era consisted primarily of time served on the waiting list. When I reached my 24 month waiting time, my coordinator informed me I was number 4 on the list but the first three were waiting for small lungs; in other words, children.

Panic set in. That day I moved in with my parents to wait for “The Call”. My dog came with me. That first night I realized I had felt a heaviness in my chest all day long. I tried chalking it up to stress and activity but it wouldn’t go away. Paramedics were called and I was taken to the hospital, admitted, and had a “cardiac event” while on the heart monitor. The next day the cardiologist performed a heart catheterization during which he hit a pool of blood. So, now not only have I had a “cardiac event”, but I’ve also had a slight stroke. The cardiologist told me right after the cath that my heart wasn’t strong enough for a transplant. When they wheeled me out of the surgery room, there stood my sister and my parents crying like babies; he had told them the same thing. Unfortunately, I couldn’t speak clearly for two days but I was eventually able to tell my mom that this guy didn’t call the shots and that the only person who would determine my eligibility was the transplant doctor, which gave her some comfort

My heart needed a lot of mending and I was put on hold status for transplant. My transplant doctor called me himself, at my parents’ home, to let me know that hold status meant I was on the list forever but just wouldn’t get called until my heart ejection fraction (whatever that is!) reached 40% to be considered strong enough for transplant surgery. It took seven months, and by the time I got the call my ejection fraction reached 65% and my lung function was down to the 10-12% range.

After three months of living with my parents, I wanted to go home. I still hadn’t been put on active status and was trying hard to accept the fact that I might not ever get a transplant. I missed my cats, told my nephew he didn’t need to witness my possible, impending death so he moved back with his parents, I left my dog with my parents, and moved back home. Through the local Council on Aging I got light housekeeping help three times a week at no charge. The caregiver and I got along great and I looked forward to her two-hour visits three times a week. It also gave my parents and sister time off from checking on me constantly.

Every three months I got an echocardiogram to check my heart’s progress. In June the technician let me know that what

she was seeing looked great and not only was my ejection rate normal, but it was above normal. I looked at my sister and we both knew what this news meant – I was going to get a transplant after all. That was a great day. Sure enough, a few days later my transplant coordinator called and asked if I was ready to be put back on active status. I will never forget her exact words after I said yes; she said “You are now number one on the list”.

That night I had the worst-ever panic attack. Over all these years, I was prone to panic attacks, or as I call them, temporary respiratory failures. That might not be the correct terminology, but when you lose your breath it can turn into what feels like panic. My sister was my go-to person to sit with me during these attacks as she lived about 10 minutes away. I didn’t need or want any help but I always wanted someone in the house with me when they occurred. My sister was an RN at the time so she was the perfect person to call. This night the attack lasted four hours with no relief. It was so horrendous, I prayed for death to get me out of my misery.

The next day, fully recovered and with my brain thinking clearly, I realized my panic was due to having no plan in place for “the call”. That evening all my family came over and we got it all squared away. My sister-in-law, who has a phobia about anything medical and didn’t want to get involved with the actual surgery process, was selected to be the stay-at-home person, keeping everyone updated via the internet. She was also the only person I would call when I got ‘The Call’. She put everyone’s phone number in her cellphone that night. The plan was I was to make only one call – to her – and she would then call my mom, my sister and my best friend. Their instructions were to come directly to my house with their already-packed bags and not waste time calling each other.

At 11:00pm (why is it always at night???) on August 19, 2003, my phone rang. Though I didn’t have caller ID., I knew who it was. My coordinator asked if I was interested in a pair of lungs – her exact words. I was tempted to crack a joke but in a split second decided to respect this process as it was far too serious to make light of. She didn’t tell me I had to rush so I didn’t. I made that one phone call to my sister-in-law, posted on the Alpha-1 email list that I had been called, turned off the computer, and sat there congratulating myself on my calmness. I then decided to pop some Valium because I didn’t really trust the calm feeling to last and it’s a 3½ hour drive to Indianapolis.

My mom, my sister and my best friend all arrived separately but within minutes of each other. I got in the car with my best friend and my sister drove Mom back to her house to drop off her car so they were about 30 minutes behind us. My best friend has a lead foot and it didn’t take nearly 3-1/2 hours to get there. The whole time I remained calm (thank you, Valium) and we talked about how our happiness meant

*(Please see My Transplant Story continued on page 7)*



*Transplant Anniversaries*  
**SEPTEMBER 2014**

<u>Name</u>	<u>Transplant Date</u>	<u>Yrs</u>
Elena Khan	9-1-2011	3
John McNamara	9-1-2006	8
Dennis Gentry	9-5-2011	3
David W. Courtney	9-8-2008	6
Tom Archer	9-11-2006	8
Cynthia Whie	9-11-2012	2
Marilyn Sundt	9-15-2011	3
Cheree Peirce	9-16-2012	2

**OCTOBER 2014**

<u>Name</u>	<u>Transplant Date</u>	<u>Yrs</u>
Alan Schwenk	10-6-2009	5
<b>Joe Kelley</b>	<b>10-7-2004</b>	<b>10</b>
Diane T. Young	10-10-2010	4
Philip Tabasso	10-17-2006	8
<b>Patrick K. Dooley</b>	<b>10-18-2000</b>	<b>14</b>
<b>Damian Neuberger</b>	<b>10-19-1997</b>	<b>17</b>
Lynn Shirley	10-19-09	5
<b>Beth Davenport</b>	<b>10-20-1995</b>	<b>19</b>

*Congratulations to all who celebrate another milestone!*

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.

**Vitamin D Deficiency Shown to Increase Rejection Rates in Lung Transplant Patients**

Pauline Camacho MD

Director Loyola University Osteoporosis and Metabolic Bone Disease Center, Loyola University Health System (LUHS)

*(Reprinted with permission from Loyola University Health System, released 4/24/2012)*

Newswise — Vitamin D deficiency is associated with an increase in lung transplant rejection and infections, according to research conducted at Loyola University Health System (LUHS). Researchers also found that recipients who remained deficient for one year following the transplant had a higher mortality rate than those who had normal vitamin D levels. These data were published in the latest issue of The Journal of Heart and Lung Transplantation.

“Patients who undergo lung transplants are at risk for rejecting the organ, and two-thirds of these patients are vitamin D deficient,” said Erin Lowery, MD, first author, assistant professor, Department of Pulmonary and Critical Care Medicine, Loyola University Chicago Stritch School of Medicine (SSOM). “Given the high prevalence of vitamin D deficiency in lung transplant patients and the growing evidence that this supplement helps the immune system tolerate the organ, optimal levels of vitamin D are critical for positive outcomes in these patients.”

The study evaluated 102 patients who underwent a lung transplant and had vitamin D levels evaluated within 100 days prior to or following surgery. Twenty-one patients had normal vitamin D levels and 81 were deficient. The rejection rate in the deficient group was more than double that of the nondeficient group. Infections also were more frequent in the deficient group than in the nondeficient group (mean 4.01 versus 2.71). In addition, the mortality rate of vitamin D deficient patients one year after transplant was nearly five times higher than those who were not deficient.

Prior to lung transplant, 52 percent of patients received a vitamin D supplement. An additional evaluation was performed one year after transplant to determine if levels were normal or deficient. Seventy-five patients had normal vitamin D levels and 27 were deficient. In the year after the lung transplant, all patients received a vitamin D supplement.

The health benefits of vitamin D are widespread and range from warding off cancer, osteoporosis, heart disease, diabetes and depression. Until now, researchers could only speculate that vitamin D also improves the health of lung transplant patients.

*(Please see Vitamin D Deficiency continued on page 7)*

# Did You Know...?

Julie Martin

Director Second Wind Lung Transplant Association, Inc.

**I**t's the time of year when shopping becomes a full contact sport which moves many of us to the web. It's also the time of year for giving, and now you can combine them while benefiting Second Wind.

There are two ways to help, both with no costs, no obligations, nor any hidden fees, and you don't need to enter any codes. It's all automatic!

1. Sign up with iGive.com, which is an online mall with over 1500 participating stores, many of them high-end retailers. They donate a percentage of your purchases to Second Wind, and now they will also donate an additional \$5.00 for each new member that selects Second Wind as their designated charity. Please go to [www.igive.com](http://www.igive.com) for complete information about their program.
2. Amazon.com will donate 0.5% of the price of your purchases when you shop at AmazonSmile ([smile.amazon.com](http://smile.amazon.com)). Please go to this Amazon website for complete information about the program: [www.smile.amazon.com/about](http://www.smile.amazon.com/about)

There are other organizations that have Second Wind in their name, so please choose: **Second Wind Lung Transplant Association Escondido, CA** to ensure that your support is credited to us.

Happy Holidays,

Julie



*(LAM continued from page 5)*

been a lot of work in this area," Lentz said. "There are more unknowns than if this were a common disease."

The LAM Foundation seeks safe and effective treatments, and ultimately a cure, for LAM through advocacy and the funding of promising research. The foundation serves the scientific, medical and patient communities by offering information, resources and a worldwide network of hope and support. Loyola has been designated a Center of Excellence by the LAM Foundation since 2010. Dilling cares for 50 LAM patients, one of the largest groups of LAM patients at a single center in the world.

*(Reprinted with kind permission of Loyola University Medical Center, Maywood, IL. For further information please contact Jim Ritter, Media Relations, [jritter@lumc.edu](mailto:jritter@lumc.edu), (708)216-2445*



*(My Transplant Story continued from page 5)*

someone else's worst nightmare. We were silent most of the trip.

The plan was for my brother to drive Dad up to Indy but not until they got word that is was a "go". I was taken to surgery about eight hours after arriving at the hospital. It's unusual for that first call to be the only call so I knew I was lucky; I just didn't know my luck would continue way beyond expectations.

*To be continued...?*



*(Vitamin D Deficiency continued from page 5)*

"This was the first study to explore the impact of vitamin D deficiency in lung transplant patients," said Pauline Camacho, MD. "We have determined that there are multiple benefits to maintaining normal vitamin D levels in lung transplant patients."

Other investigators were: Bradford Bemiss, MD, chief resident, Department of Medicine, SSOM; Thomas Cascino, fourth-year medical student, SSOM; Ramon Durazo-Arvizu, PhD, assistant professor, Department of Preventive Medicine & Epidemiology, SSOM; Sean M. Forsythe, MD, associate professor of medicine, Department of Pulmonary & Critical Care Medicine, SSOM; Charles Alex, MD, FCCP, program director for lung transplant, LUHS; Franco Laghi, MD, professor of medicine, Department of Pulmonary & Critical Care Medicine; and Robert B. Love, MD, lung transplant surgeon and professor, Departments of Thoracic & Cardiovascular Surgery and Microbiology & Immunology, SSOM.

## Support Groups & Events Calendar

*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.*

### ***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

#### **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**

Third Tuesday every month, 7:00 PM  
EMS Building Rm 3284, 2160 S. First Ave.  
Maywood, IL 60153

Pre-, post-transplant patients, & support person(s)  
Caregivers only support group, first Wednesday every month.  
Combined Transplant Support Group, first Thursday every month. This meeting and Caregivers at same address.

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

*(Please see Events Calendar continued on page 9)*

## WE REMEMBER

Ruth L. Heath

Ironia, NJ,

Date of Birth: January 30, 1939

Single Lung Transplant, June 4, 2003

University of Pennsylvania

Date of Death: August 19, 2014

John McHale

Bridgewater, NJ

Date of Birth: February 22, 1962

Bilateral Lung Transplant, May 26, 2008

University of Pennsylvania

Date of Death: June 18, 2014

Chuck Karlan

Littleton, CO

Date of Birth: April 12, 1947

Single Lung Transplant, November 30, 2008

University of Colorado

Date of Death: October 10, 2014

Ken Nottestad

Fenton, MO

Date of Birth: January 31, 1936

Bilateral Lung Transplant, June 12, 1999

Barnes Jewish Hospital

Date of Death: October 13, 2014

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



*In Honor Of*

*Ken Nottestad*

*by*

*2nd Wind Board of Directors*

*St. Louis Chapter of Second Wind*

*Both Ken and his wife Linda have been members of Second Wind since June, 2006. They both have been very active members, with Linda serving as a Board Member numerous times in national's St. Louis Chapter of Second Wind. Linda has expressed the joy they both experienced during Ken's fifteen plus years post-transplant. Our deepest sympathies go out to Linda and their family. Ken will be missed by all who knew him. May he rest in peace.*



## New Members and Membership Renewals September 2014 — October 2014

### NEW MEMBERS

Terri Beatty	Sharon Brettschneider
Kelly Connelly	Joseph Heugly
Chris House	Susan Lewis
Michael Ofchus	Virginia Watkins

### RENEWALS

Nikki Addison	Patricia Ashbridge
Carolyn Aspegren	Grace Bachman
Tom Barbour	MarthaBecker
Henk Berends	Jan Chicoine
Robert Courtney	Patrick Dooley
Debra Guthrie	Donald Gwynne
Mary Hardy	Elena Khan
Jane Kurz	George Landrum
Carrol Litwin	Maria Loss
Julie Martin	William McAuley
Rory McCue	Judy & Damian Neuberger
Garry Nichols	Irene Overton
Brian Puhalsky	Starla Sage
Mark H. Swartz	Fred Walker
NormaWatson	Cynthia White
Paul Woods	

We also welcome all our new and renewed members who wish to remain anonymous.



## 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

George Landrum	Patrick Dooley
Cathy Cuenin	Henk Berends

### Donations for Financial Assistance Fund

Peg Matthews

### Donations for Membership Fund\*

Peg Matthews

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

We also express our sincere thanks to all our donors who wish to remain anonymous.

*Events Calendar continued from page 8)*

### University of Chicago Medical Center

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

Center for Care and Discoveru (CCD), 7th Floor Conf.Rm.  
7710 5700 S. Drexel Ave., Chicago, IL 60637

Contact: Kaitlin Ray, LCSW

kaitlin.ray@uchospitals.edu or call 773-702-4608

Pager 6720

### University of California San Francisco

Lung Transplant Support Group, Third Thursday of every month, 1-3 pm, Room 1015.

A505 Parnassus Ave., San Francisco, CA 94143

Contact: Avry Todd, MSW, 415 353-1098

Apryl.Todd@ucsfmedctr.org

### 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)

*(Please see Events Calendar continued on page 10)*



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Second Wind Lung Transplant Association, Inc.  
1020 Gull Court  
Palatine, IL 60067

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*(Events Calendar continued from page 9)*

## Support Groups & Events Calendar

**University of Washington Medical Center** Seattle, WA  
Meetings for 2015

### *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.uwltsg.org](http://www.uwltsg.org)

### **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](mailto:laskowskiedward@att.net) or call 414-231-3013

### **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](mailto:Kathy.Lam@DignityHealth.org) Phone: 602-406-7009

